mPR:

Designing and evaluating an mHealth intervention to increase the reach of Pulmonary Rehabilitation in Aotearoa New Zealand

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Abstract

Introduction

Chronic respiratory diseases (CRD) are a highly prevalent public health issue with stark inequities and significant morbidity and mortality. Pulmonary Rehabilitation (PR) is an effective intervention which is proven to reduce the symptom burden for people living with a CRD. Uptake, attendance, and completion of PR worldwide are poor. New and novel ways of delivering PR are required to increase the reach of PR. This thesis aims to investigate a method of delivering PR that may increase the reach of PR services in Aotearoa New Zealand (NZ).

Methods

Prior to development of a new delivery method of PR in NZ, a survey of all PR services in NZ was completed. Simultaneously, a scoping review of the literature was undertaken to determine the factors that may influence engagement in and experiences with telerehabilitation, and their experiences of engaging in this form of PR. The information from these two studies led to the iterative process of developing the content for a mHealth PR programme (mPR) – the first of its type specifically for the NZ population. The mPR intervention was developed by a multidisciplinary team including public health physician, mHealth experts, behaviour change experts, physiotherapists, computer scientists, people living with a CRD, and engineers. Throughout the development process two further studies were undertaken, which further shaped the content of mPR. Furthermore, an evaluation of our mPR programme was undertaken with a preference-based trial and the patient experience was assessed through a mixed methods study which was nested in the preference-based trial.

Results

The national survey of PR services demonstrated that prior to the COVID-19 pandemic, PR services in NZ offered predominantly centre-based PR with only 5% of services offering any home-based options. No services offered telerehabilitation, and all services operated within normal working hours. The survey also found that during the

COVID pandemic many services pivoted their services to provide telerehabilitation options.

The scoping review identified device, data access, digital literacy, and concerns regarding lack of support from peers and clinicians were key barriers to participation in telerehabilitation. Studies reported the convenience and reduced burden of telerehabilitation were reported as positive factors for participants engaging in telerehabilitation.

A preference-based study was used to determine whether PR attendance and completion rates may be improved by offering the participants their choice of delivery model (centre-based or mPR). Whilst 64% of participants preferred centre-based PR, of the 36% that preferred mPR, they were more likely to be younger and employed. Whilst attendance and completion rates were higher in the centre-based group - high levels of satisfaction and perceived benefit were reported from the mPR programme.

Conclusions

Whilst centre-based PR remains the preferred option for many, the addition of mHealth delivered PR can increase the reach to those who might otherwise be unable to access PR services.

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Attestation of Authorship

I hereby declare that this submission is my own work and that, to the best of my knowledge and belief, it contains no material previously published or written by another person (except where explicitly defined in the acknowledgements), nor material which to a substantial extent has been submitted for the award of any other degree or diploma of a university or other institution of higher learning.

22 May 2023

Signature Date

Co-Authored Works

The original proposal for the development of an mPR programme was led by Professor Robyn Whittaker. The subsequent proposal was building on previous work in mHealth programmes and consultation with respiratory and PR clinicians which received funding in 2018 from the MedTEch CoRE. The proposal brought together a team of experts to lead the project from across academic institutions and health services. The candidate was not involved in the conceptualisation or initial consultation work of the project but became involved soon after consultation began in her capacity as a specialist PR clinician.

Co-Authorship

Chapter 2. Survey Candy, S., Reeve, J., Dobson, R., & Taylor, D. (2022). Characteristics of pulmonary rehabilitation programmes in New Zealand: A survey of practice prior to and during COVID-19. *The New Zealand Medical Journal (Online), 135*(1550), 13-25	**Candy** (80%) Conceived the study, registered and sough ethical approval, conducted surveys and data analysis, wrote the manuscript and responded to journal reviewer feedback. **Reeve** (10%) Conceived the study, provided supervision (oversight and leadership), assisted with survey question development, collaborated on data analysis and provided feedback on manuscript. **Dobson** (5%) Provided assistance with survey development and provided feedback on manuscript. **Taylor** (5%) Conceived the study, provided supervision (oversight and leadership), provided feedback on the manuscript.

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Chapter 6. The impact of patient preference on attendance and completion rates at centre-based and mHealth pulmonary rehabilitation: a pragmatic clinical trial. Sarah Candy, Julie Reeve, Rosie Dobson, Robyn Whittaker, Jeffrey Garrett, Jim Warren, Amanda Calder, Taria Tane, Trina Robertson, Usman Rashid, Denise Taylor	**Candy** (80%) Conceived the study, registered the study, wrote and submitted ethics and locality applications, conducted the investigation and data analysis, write the manuscript. **Reeve** (4%) Conceived the study, provided supervision (oversight and leadership), collaborated on data analysis, provided feedback on manuscript. **Dobson** (6%) Conceived the study, provided supervision (oversight and leadership), collaborated on data analysis, and provided feedback on manuscript. Whittaker (4%) Conceived the study, provided feedback on manuscript. **Rashid** (3%) Conducted statistical analysis, collaborated on data interpretation, provided feedback on manuscript drafts. **Taylor** (4%) Conceived the study, provided supervision, collaborated on data analysis, and provided feedback on manuscript.

Chapter 7. The participant experience of mobile technology delivered pulmonary rehabilitation Candy, S., Reeve, J., Dobson, R., Whittaker, R., Taylor, D.	**Candy** 80 Conceived the study, registered the study, wrote and submitted ethics and locality applications, conducted the investigation and data analysis, write the manuscript. **Reeve** (6%) Conceived the study, provided supervision, collaborated on data analysis, provided feedback on manuscript. **Dobson** (4%) Conceived the study, collaborated on data analysis, provided feedback on manuscript. **Whittaker** (4%) Conceived the study, provided feedback on manuscript. **Taylor** (6%) Conceived the study, provided supervision, collaborated on data analysis, provided feedback on manuscript.

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Publications and Presentations

Parts of the work presented in this thesis have been published and/or presented in the following forums:

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Candy S, Reeve J, Taylor D. Factors influencing participation in telerehabilitation for people with chronic respiratory disease. A scoping review of the literature. Under review with the *New Zealand Journal of Physiotherapy*.

MANUSCRIPTS TO BE SUBMITTED

Candy S, Reeve J, Dobson R, Whittaker R, Taylor D. The participant experience of pulmonary rehabilitation via mobile technology. Plan to submit to *Respiratory Care*

CONFERENCE PRESENTATIONS

Candy S, Reeve J, Dobson R, Taylor D. Pulmonary Rehabilitation Services in New Zealand. Cardiorespiratory Physiotherapy symposium with Prof Julie Redfern. Auckland, NZ, October 2019.

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AWARDS RELATED TO THIS WORK CONTAINED IN THIS THESIS

Candy S, 2023 Annual scientific meeting of the Thoracic Society of Australia and New Zealand, Respiratory nurses Special Interest Group, Best Oral Presentation.

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CO-AUTHORED PUBLICATIONS

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https://formative.jmir.org/2019/4/e15466/

Whittaker R, Dobson R, **Candy S**, Tane T, Burrows K, Reeve J, Tawhai M, Taylor D, Robertson T, Garrett J, Humphrey G. Mobile Pulmonary Rehabilitation: Feasibility of Delivery by a Mobile Phone-Based Program. *Frontiers in Computer Science*. 2021 Mar 23;3:9.

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Houchen-Wolloff L, Spitzer K A, **Candy S**. Access to service around the World. Editors Holland A, Dal Corso S, Spruit M. Pulmonary Rehabilitation. 258-272. European Respiratory Society. *ERS Monograph*

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	Amendment for Survey 2		21/08/2020
4	Content Development	HDEC 19/NTZ/74/AM04	12 January 2021.
6	Preference Study	HDEC 21/NTB/54	23/03/2021
		Amendment	10/11/2021
		AUTEC 21/113	11/05/2021

Abbreviations

AE	Adverse event
ANZCTR	Australian and New Zealand clinical trials registry
App	Smartphone application
CAT	COPD assessment test
COPD	Chronic obstructive pulmonary disease
CRD	Chronic respiratory disorder
DHB	District Health Board
EQ5D-3L	EuroQol – 3 level
HDEC	Health and disability ethics committee
HRQoL	Health related quality of life
ILD	Interstitial lung disease
mHealth	Mobile Health
mMRC	Modified medical research council
mPR	Mobile pulmonary rehabilitation
NI	North Island
NZ	New Zealand
PCT	Preference clinical trial
PHO	Primary health organisation
PR	Pulmonary rehabilitation
SBQ	Sedentary behaviour questionnaire
SI	South Island
SMS	Short messaging system
SPSS	Statistical package for social sciences
UK	United Kingdom
VAS	Visual analogue scale
VC	Video conferencing

Chapter 1 Introduction

1.1 Statement of the problem

Chronic respiratory diseases (CRD) are associated with a significant burden for patients, whānau, and health care systems. Pulmonary rehabilitation (PR) has proven efficacy to reduce the symptoms and morbidity of living with a CRD, but the uptake of PR is low (Levack et al., 2012; Steiner et al., 2015b). PR is traditionally delivered at a hospital outpatient centre and participants are normally required to attend the centre twice weekly for eight weeks (Alison et al., 2017). This model of PR has been demonstrated to be highly effective (McCarthy et al., 2015) but is associated with many patient-related and organisational barriers (Cox et al., 2017).

There is growing evidence for the use of mobile health (mHealth) to support management of chronic conditions such as cardiac disease (Rawstorn et al., 2016), diabetes (Dobson et al., 2018), Parkinson's disease (Tsiouris et al., 2017) and stroke rehabilitation (Signal et al., 2020).

1.1.1 Aims and Objectives

This thesis outlines the process undertaken to develop and test an mHealth application for PR**.** The overarching aim of the thesis was to investigate whether an mHealth programme designed for use in NZ might increase the reach of PR in NZ. The specific research objectives to be addressed in this thesis are:

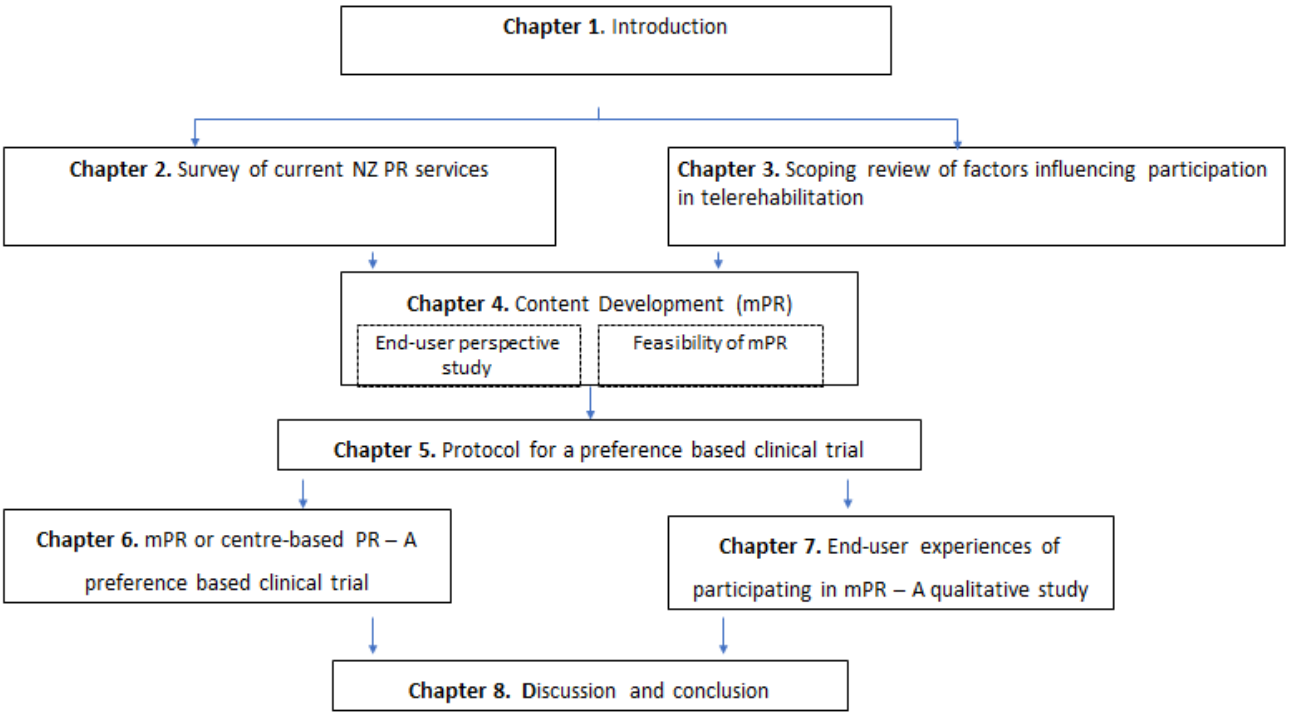
1. To develop an understanding of current PR practises in NZ and how these might impact uptake and completion
2. To identify factors which influence patient participation in telerehabilitation
3. To develop the content for a NZ based mHealth PR programme
4. To evaluate the content for a NZ based mHealth PR programme
5. To identify patient preference for delivery of PR via either centre-based or mHealth delivered PR, and ascertain if allowing participants to choose their delivery method improves the rate of attendance at PR
6. To evaluate end-user experiences of the NZ purpose designed mHealth intervention (mPR)

1.1.2 Structure of the thesis

The structure of the thesis involves gathering information to inform the content development of an mHealth intervention for PR, followed by studies which detail the design of the intervention, assess the patient preference and outcomes from centre-based and mHealth PR, and finally ascertain the patient experience of participation in our purpose designed mHealth PR programme. The thesis structure is shown in Figure 1.

Figure 1

Structure of the Thesis



1.1.3 Key terminology

Throughout this thesis, the terms telerehabilitation, mHealth and mPR are used extensively. *Telehealth* interventions are considered as those that provide healthcare services from a distance through the use of technology or telecommunications (World Health Organization, 2011). For the purpose of this thesis:

- Mobile health (*mHealth*) is a form of telehealth which uses mobile devices, (including mobile phones), to deliver health services and information (World Health Organization, 2011).

- *Telerehabilitation* is a domain of telehealth which uses information and communication technologies to provide clinical rehabilitation services remotely (Kairy et al., 2009). In this thesis, the term telerehabilitation is used to refer to PR remotely delivered into the patient's home using technology. This may include telephone (including text messaging), videoconferencing facilities and web-based applications.
- *mPR* refers to the NZ based PR intervention developed and tested in this work.

1.2 Background to the problem

1.2.1 Chronic respiratory disease

Prevalence

CRD including chronic obstructive pulmonary disease (COPD), asthma, bronchiectasis and interstitial lung disease (ILD), contribute to 7% of global burden of disease, and are thought to be the third leading cause of death worldwide (Maio et al., 2016). Estimated prevalence rates of COPD vary globally with Australia 5% (Australian Institute of Health and Welfare), USA 12% (Ford et al., 2013) and United Kingdom 4 – 10% (Garvey et al., 2013) In NZ, COPD is estimated to affect 14% of adults over 40 years of age (Telfar et al., 2015b). Indigenous groups (including Māori in NZ), ethnic minority groups and people from socioeconomically deprived areas are disproportionally affected by COPD, with higher prevalence and increased rates of hospitalisation and mortality (Telfar et al., 2015b).

Burden

Chronic respiratory diseases are associated with a significant burden on healthcare systems (Milne & Beasley, 2015). Additionally, there is a large symptom burden for people who are living with a CRD, who may experience shortness of breath, fatigue and exacerbations which lead to reduced exercise capacity, poor health related quality of life (HRQoL), increased dependency, repeated hospitalisation and increased levels of anxiety and depression (Felker et al., 2001). Whilst CRDs are not curable, treatment can relieve symptoms and improve patient's HRQoL. One non-pharmacological treatment which has shown to reduce the burden associated with CRDs and reduce hospitalisations is PR (McCarthy et al., 2015; Puhan et al., 2016).

1.2.2 Pulmonary Rehabilitation

PR is an evidence-based, multidisciplinary intervention which is a key component in the management of people with CRD (Mak et al., 2017). PR is a formalised, structured programme which includes exercise training, education, self-management, and behaviour change (Martijn A Spruit et al., 2013). PR is usually delivered in group sessions which occur twice per week over a six to eight week period (Alison et al., 2017) and is normally delivered and supervised by a team of healthcare professionals (Alison et al., 2017). Whilst PR programme were initially designed for people living with COPD, PR has been shown to be effective for other chronic respiratory conditions including ILD (Dowman et al., 2021) , bronchiectasis (Lee et al., 2021; Lee et al., 2017), asthma (Osadnik et al., 2022) and more recently in people recovering from COVID-19 (Spruit et al., 2020). A meta-analysis of 65 randomised control trials investigating PR clearly demonstrated it can reduce breathlessness, improve HRQoL and reduce hospital admissions for exacerbations of COPD (McCarthy et al., 2015). Clinical guidelines strongly recommend referral to PR for all patients with COPD (Yang et al., 2017), and this has been extended to people following hospital admissions with an exacerbation of COPD (Puhan et al., 2016).

Despite the compelling evidence regarding the effectiveness of PR, the reach of PR programmes is poor, with low referral, uptake and completion of PR (Rochester et al., 2015). The RE-AIM framework provides a useful tool to evaluate the impact and sustainability of health interventions by examining five dimensions (Kwan et al., 2019). Reach is the first dimension of the RE-AIM framework and can be defined as the number, percentage and representation of eligible patients who participate in the intervention (Forman et al., 2017). Reach can be broken down further to access, uptake and completion - these terms are often used interchangeably in the PR evidence and in the clinical environment - and are useful for consideration of different challenges when considering the reach of PR. Holland et al (2021) provides useful definitions for these terms in the context of PR, shown in Table 1, and these terms will be used throughout this thesis.

Table 1

Key concepts and definitions for pulmonary rehabilitation: access, uptake, and completion (Holland et al., 2021)

	Definition	Potential metrics
Access	Are eligible patients offered a PR programme?	Number of programme available per geographical area/population. Percentage of eligible patients who are referred.
Uptake	Do patients take up the offer of rehabilitation?	Percentage of referred patients who attend a PR assessment. Percentage of referred patients who attend at least one session
Completion	Do patients finish the rehabilitation programme?	Percentage of patients attending 70% of sessions. Percentage of patients attending a discharge assessment.

1.2.3 Barriers to Pulmonary Rehabilitation

Access to Pulmonary Rehabilitation

Data from international studies has shown patient referral rates and access to PR vary. A large UK national audit of asthma and COPD programmes explored rates of referral to PR and found that only 15% of those eligible were referred to PR (Steiner et al., 2015a). A 2015 survey in Canada, found rates of access to PR to be only 0.4% of the COPD population (Camp et al., 2015), and in the USA rates of between 2.6% - 3.7% of the COPD population have access to PR reportedly due to uneven distribution of PR programmes across the country (Moscovice et al., 2019). Similar to the US, in Australia, PR programmes are disproportionately distributed in large metropolitan areas (39%) and access to PR is estimated to be between 5 – 10% of the population with COPD (Johnston et al., 2011). A NZ survey in 2009 found that only 2% of the COPD population had access to PR (Levack et al., 2012), although it is thought this may vary across individual regions (Dummer et al., 2020).

Uptake and completion

The rate of uptake and completion of PR both nationally and internationally has shown between 30–50% of those who are referred do not complete PR (Yohannes & Connolly,

2004). UK audit data has revealed an uptake rate of 59% (Steiner et al., 2015a), and likewise a NZ centre reported uptake rate of 63% of those referred to PR (Candy et al., 2020a). The same NZ study reported 38% of referred participants went on to complete PR (Candy et al., 2020a). The reasons for low uptake and completion are complex and can be linked to patient related factors or organisational and system factors.

Patient related factors

Transport and travel

A common barrier to PR is patient access to transport and travel options. This barrier is multifactorial and potentially interrelated to other factors such as socio-economic status, geographical location and severity of disease, each of which may also limit access to PR. Distance and travel involved with attending PR have been investigated, and distances of greater than 36 miles (58kms) or 30 minutes travel time has been found to be related to non-completion (Fan et al., 2008).

The mode of transport available to patients may bring about different challenges for attending PR. A study investigating the reasons why people declined participation in PR research reported an inability to travel independently, an inability to manage public transport, or the inaccessibility of car parking to be influential factors (Taylor et al., 2007).

Many PR services are operated from large metropolitan centres and access to PR in remote and rural centres can be limited (Dummer et al., 2020; Moscovice et al., 2019), thus travel from rural or remote areas may impact upon the reach of PR. This is important as a higher prevalence and greater burden of COPD (Milne & Beasley, 2015; Terry et al., 2019) has been reported in rural areas (Ansari et al., 2007; Raju et al., 2019). Many challenges exist to setting up and delivering PR in remote settings. In remote and rural communities there are less specialist services and lower numbers of health care professionals making the challenge of establishing and maintaining provision of speciality services difficult. An international comparison of PR services in seven countries showed the majority of PR services were based at large metropolitan hospitals (Desveaux et al., 2015).

Ethnicity

Ethnicity has been shown to impact PR access and uptake in many countries. In the USA participants in PR programmes are more likely to be non-Hispanic white (Spitzer et al., 2019) and in the UK 82.5% of participants are "White British" (Steiner et al., 2015a). A NZ study found ethnicity was a predictor of completion of PR with Māori and Pacific people being less likely to complete (Candy et al., 2020a). It maybe that the type (cohort or block) and location of the PR programme impacts participation; one study compared the experiences of participants in a mainstream hospital outpatient service led by non-indigenous health care professionals, to a marae (Māori meeting house) based programme led by Māori, for Māori (Levack et al., 2016). Results showed while many of the same barriers exist to attending PR, regardless of ethnicity, for Māori, additional important cultural factors influenced their participation in PR.

Additional patient related factors

Other patient factors related to lower access, uptake and completion of PR included socio-economic status; one study showed those from more deprived areas have significantly reduced odds of participating in PR (OR 0.42-0.59) (Spitzer et al., 2019). Living situation and marital status has also been reported to impact attendance and completion of PR with people who are married being 7.3 times more likely to attend than those who are widowed or divorced (Keating et al., 2011), and people living alone being less likely to complete than those with social support (Young et al., 1999). Likewise people who are current smokers (OR 0.3, 95% CI 0.1-0.9) or suffering depression are less likely to complete PR (OR for completion 0.55, 95% CI 0.34 – 0.87) (Keating et al., 2011).

Organisation factors

Several organisational factors have been found to be associated with PR uptake and completion. The structure of the programme has been shown to impact completion with cohort programmes, (all participants starting and finishing at the same time) having better completion rates than rolling programmes, which is attributed to the social connections and support of peers (Steiner et al., 2015b). Conversely, cohort programmes may mean longer wait times before commencement of PR, and longer wait times have been found to be associated with lower completion rates (Steiner et al., 2015b). This suggests services should consider the needs of their population when

designing their PR services. Other organisational factors impacting the reach of PR, include the inclusion criteria of PR programmes and the hours of operations, with many services only operating during work hours, restricting options for people who are working (Candy et al., 2022; Johnston et al., 2011).

1.3 Emerging models for PR

To address the poor reach of PR, the American Thoracic Society (ATS) and European Respiratory Society (ERS) published a Policy Statement in 2015 on 'Enhancing Implementation, Use and Delivery of Pulmonary Rehabilitation'. This statement called for novel pulmonary rehabilitation program models that make PR more accessible and acceptable to patients and those who refer to, or pay for, services. This, in conjunction with the recent COVID-19 pandemic has seen the rapid development of new models of PR and in particular the introduction of technology to deliver PR. Telerehabilitation , the delivery of rehabilitation services using information and communication technology (Kairy et al., 2009), has the potential to overcome some of the barriers identified to uptake and completion of PR and studies investigating telerehabilitation have become more frequent over the last ten years. To date, telerehabilitation programmes have been delivered using telephone calls, videoconferencing (VC) facilities and mobile and web-based applications (apps) or a combination of these. For this thesis the different models for telerehabilitation delivered in the home will be defined as found in Table 2. In practise there is often overlap between the models with more than one model being utilised (e.g, web-based models using text messaging and/or telephone calls).

Table 2

Emerging models of telerehabilitation in PR

	Model	Description
	Telephone	PR delivered through the telephone, including telephone calls and text messaging.
	Video conferencing	Supervised individual or group PR delivered in the home using videoconferencing facilities
	Web-based models	Computer or phone-based interventions (mobile and web-based applications) offering unsupervised, asynchronous PR

Note. PR = Pulmonary Rehabilitation

Cox et al. (2021) recently completed a systematic review which showed telerehabilitation can achieve equivalent clinical outcomes to centre-based PR with no additional safety concerns (Cox et al. 2021). The authors acknowledge a low number of studies in the review, with heterogeneous programme models, making the conclusions somewhat guarded.

1.3.1 mHealth as a potential solution to improve the reach of PR

Mobile health (mHealth) is the delivery of health information or interventions through a mobile device, such as a phone or tablet. Mobile phones are becoming increasingly ubiquitous. Reports suggest there are more mobile phone connections than people in New Zealand, with 121 active mobile connections per 100 population (Commerce Commission, 2018) A range of delivery modalities for PR can be utilized through a mobile device such as text messaging, video messaging, mobile internet, apps and wearable sensors. mHealth is a developing field which has been shown to enhance the management of other chronic health conditions through providing support, monitoring, and self-management strategies (Dobson et al., 2018; Pfaeffli Dale et al., 2016; Whittaker et al., 2016). mHealth may offer opportunities to increase the reach of PR without compromising safety or clinical efficacy and may allow current barriers to centre-based PR to be overcome, providing access to individually tailored PR almost anywhere, anytime, with on-going support and motivation.

The use of mHealth in the management of CRD has been explored with programmes for monitoring symptoms (Cruz et al., 2014), providing self-management support (Free et al., 2013; Korpershoek et al., 2018) and promoting physical activity (Demeyer et al., 2017; Liu et al., 2008; Tabak et al., 2014). Three studies have tested and evaluated a PR programme delivered via mHealth, with two using a mobile app (Bourne et al., 2017; Park et al., 2020b) and the other a web-based app (Chaplin et al., 2017). Two of these mHealth PR programmes delivered all the essential components of PR (Chaplin et al., 2017; Park et al., 2020b). These studies only included people living with COPD and those who had access and competency with internet and mobile phone apps, therefore did not represent all the population who may benefit from PR. All studies used exercise capacity or HRQoL as primary outcome measures and reported clinical improvements which were equivalent with centre-based PR. However, adherence and completion of mHealth delivered PR reported a gradual decline in usage from logging into the programme 3.9 times in week one to 2.5 times in week six (Bourne et al.,

2017; Chaplin et al., 2017), and a large number of participants failing to complete (Chaplin et al., 2017). This non-completion was attributed to the time commitment, technology difficulties, and exacerbation of illness or comorbidities.

To date, it appears that whilst centre-based PR is effective, the reach of these programmes appears sub-optimal. Telerehabilitation provides a potential solution which has been shown to be safe and likely as effective (Cox, McDonald, Hill, et al., 2018) as centre-based PR, however, not much is known about the uptake of telerehabilitation in the clinical setting or implementation of these models, particularly in NZ. Thus, in order to attempt to improve the uptake and completion of PR in NZ, we aim to develop an mHealth PR programme. The key steps required involve:

1. Understanding the current PR service organisation and structure in NZ to identify how we can extend and develop this to improve the reach of PR,
2. Understanding the end-users needs and preferences is essential to developing a patient-centred intervention,
3. Reviewing the literature in conjunction with formative research into end-user's perspectives of mHealth delivered PR to inform the content of the intervention.
4. Develop and test a NZ specific mHealth application for PR.

To investigate if an mHealth intervention can increase uptake and completion of PR in NZ, a preference-based research methodology has been used. Adherence and completion of PR may be influenced by group allocation in a randomised controlled trial, with some participants not physically able to access a centre-based programme or not having the skills or interest in mHealth. In the real-world clinical setting participants would choose (in consultation with health care professional) which delivery method (mHealth or centre-based) to best meet their needs and testing the mPR intervention using this design allows important information on patient preferences, uptake, completion, and ultimately, if providing mHealth as an alternative delivery method to centre-based to improve the reach of PR.

Chapter 2 Characteristics of pulmonary rehabilitation programmes in New Zealand. A survey of practise prior to and during COVID-19

2.1 Prelude to manuscript

Developing an understanding of how PR programmes were being delivered across NZ was important as the background work prior to developing any other delivery methods for application in the NZ context. The following chapter is designed to address Objective 1 of the thesis:

> *To develop an understanding of current PR practises in NZ and how these might impact uptake and completion.*

2.1.1 Why was the study needed?

The information gathered from this research helped to form an understanding of the baseline of PR services in NZ and inform the development of alternative PR delivery options. Developing an understanding of the current services provided information on factors influencing the reach of PR in addition to how we could build on current service structure to improve access and completion of PR in New Zealand.

The aim of this study was to describe the characteristics of PR services in NZ, including the distribution of services across NZ, the programme structure and organisation, and the programme content.

2.1.2 What was undertaken?

Two consecutive surveys of PR services across NZ were undertaken. The first survey was conducted in 2019 to establish a baseline of what PR services were provided across the country. The survey was administered as an online survey using REDCap software. Shortly after data collection was complete, NZ went into a national lockdown in response to COVID-19 restrictions which lent the opportunity for a second survey (undertaken in 2020 with the same population) to determine how services had responded to the pandemic and how service provision had changed.

2.1.3 Publication citation

Candy, S., Reeve, J., Dobson, R., & Taylor, D. (2022). Characteristics of pulmonary rehabilitation programmes in New Zealand: A survey of practice prior to and during COVID-19. *The New Zealand Medical Journal (Online), 135*(1550), 13-25. Retrieved

https://journal.nzma.org.nz/journal-articles/characteristics-of-pulmonary-rehabilitation-programmes-in-new-zealand-a-survey-of-practice-prior-to-and-during-covid-19-open-access

2.1.4 Contribution by the candidate

The candidate led the design of the study and the development of the survey tools, with guidance from her supervisors. The candidate obtained ethics approval, complete the data collection and data analysis. The candidate wrote the manuscript with input and feedback from her supervisors and co-authors.

2.1.5 Supporting Documents

Supporting documents associated with this chapter can be found in Appendices and include ethical approval for each survey, participant information and consent forms, copy of advertisements and survey questions.

2.2 Abstract

Background:

Pulmonary rehabilitation (PR) is a core component in the management of symptoms for people living with chronic lung disease. Access to PR is a barrier for many people resulting in low uptake and completion. Differences exist in the structure, organisation, and content of PR services both nationally and internationally. Developing an understanding of service provision in Aotearoa, New Zealand (NZ) is important for future developments which aim to reduce barriers to access.

Aim:

The primary aim of this survey was to develop an understanding of current pulmonary rehabilitation practices in NZ. The onset of a COVID-19 lockdown in NZ in March 2020, shortly after completion of the initial survey, enabled a follow-up survey to determine how services had adapted in response to the global pandemic.

Methods:

A cross-sectional observational design using two sequential purpose designed online surveys administered before (Survey 1) and after COVID-19 lockdowns (Survey 2) in NZ.

Results:

Survey 1 was completed by 36 PR services across NZ and showed homogeneity in the content and structure of services provided. PR was primarily funded by District Health Boards (DHBs), run by a multi-disciplinary team of health professionals, and included participants with a range of chronic respiratory conditions. All programmes completed pre and post PR assessments, were a minimum of eight weeks in duration, and included exercise and education. Survey 2 showed that during level 4 and level 3 COVID-19 restrictions in NZ, 11 (40.7%) of services paused PR programmes, with 16 (59%) adapting the service to provide home-based rehabilitation via telephone or teleconference facilities.

Conclusion: PR programmes in NZ report following Australian and New Zealand PR best practice guidelines and are homogenous in content and structure, but COVID-19 restrictions highlighted the need for services to provide more diverse options for service delivery. Future service development should focus on providing a range of

delivery options allowing increased access to PR, tailoring therapy to meet individual needs, and ensuring services are engaging for all participants to optimise participation.

Pulmonary rehabilitation (PR) is an evidence-based, multidisciplinary intervention which is a key component in the management of people living with a chronic respiratory disease, including COPD (Alison et al., 2017). PR is a formalised, highly structured programme which includes exercise, self-management, education, and behaviour change support with health professional supervision. PR has been clearly demonstrated to improve breathlessness; health related quality of life (HRQoL) and reduces hospital admissions for exacerbations of COPD (Laviolette et al., 2008; McCarthy et al., 2015). Clinical guidelines strongly recommend the uptake of PR by all people with COPD, particularly following hospital admissions (Alison et al., 2017). Despite this, the uptake of, and sustained engagement with PR programmes in NZ is poor, with estimates of less than 1% of all people with COPD participating in PR, and only 38% of participants referred to PR completing the programme (Candy et al., 2020a; Levack et al., 2012). Reasons for low attendance and adherence include transportation difficulties, lack of perceived benefit, depression, and the interruption to the patient's daily routines (Candy et al., 2020a; Guo & Bruce, 2014; Harrison et al., 2015; Keating et al., 2011).

The structure and organisation of PR services has been shown to influence attendance and completion rates (Stone et al., 2021). Several international PR programme surveys have been published in recent years (Camp et al., 2015; Johnston et al., 2011; O'Neill et al., 2008; Sundh et al., 2017) which have shown variability in the organisation, structure, and content of programmes both within and across different countries.

The primary aim of this study was to develop an understanding of what PR service provision looks like across NZ, and how this complied with best practice guidelines. The initial survey (Survey 1) sought to describe the characteristics, organisation, structure, and content of PR programmes across NZ. In March and August 2020, the global COVID-19 pandemic prompted significant changes in the way healthcare was being delivered in NZ resulting in PR services needing to adapt in order to meet the needs of their population. Therefore, a second survey (Survey 2) was conducted following the Level 4 and Level 3 COVID-19 restrictions in NZ, to: (1) Determine the impact of COVID-

19 restrictions on PR services in NZ; and (2) Assess differences in pre and post COVID-19 PR programme delivery and content in NZ. Furthermore, both Survey 1 and 2 aimed to identify any gaps in PR service provision and areas for development to enhance accessibility and uptake of PR for people living with a chronic respiratory condition in NZ.

2.3 Methods

2.3.1 Study design

A cross-sectional observational design, including two sequential purpose designed surveys administered online, was utilised. Ethics approval was granted from Auckland University of Technology Ethics Committee (AUTEC) on 21/5/2019, and an amendment was granted for Survey 2 on 21/08/2020. Data for Survey 1 was collected from July to September 2019 and for Survey 2 between August and September 2020.

Inclusion criteria:

Programmes met the inclusion criteria if their service was consistent with the American Thoracic Society (ATS) (2016) definition for PR – see Figure 2.

Figure 2

PR Services must include the following:

1. Programme delivered by exercise physiologist or physiotherapist
2. Minimum six weeks duration
3. Include functional assessment (e.g., 6MWT)
4. Include a measure of health related quality of life

For Survey 1, programmes were required to have had a PR programme operating within the last six months.

Only services which responded to Survey 1 were invited to participate in Survey 2.

Respiratory support groups or maintenance groups were excluded.

2.3.2 Survey Tool

The two surveys used a purposefully designed instrument developed by SC, JR, RD, and DT. The survey was uploaded to REDCap software for administration. The survey was

designed to represent the NZ context. Questions were developed based on other PR surveys conducted internationally (Camp et al., 2015; Johnston et al., 2011; O'Neill et al., 2008; Spruit et al., 2014) and adapted to the NZ context, which included questions specific to the NZ structure of district health boards, the health care professionals delivering PR in NZ and the different cultural groups seen in NZ. Secondly, taking knowledge already known about PR programmes in NZ from previous studies (Levack et al., 2012) and updating and extending this knowledge. Both surveys were piloted with two clinicians working in PR to enhance content validity; neither was included in the final administration of the study however their PR services were included. Feedback from pilot was minor and the survey was modified to improve readability. Survey 1 consisted of 72 questions over five sections, taking approximately 30 minutes to complete. Survey 2 involved 25 questions over three sections and took ten minutes to complete.

2.3.3 Procedures

Potential PR programmes throughout NZ were identified through:

1. Invitations posted in physiotherapy respiratory special interest group newsletters.
2. Contacting physiotherapy professional leads at each District Health Board (DHB) throughout NZ, requesting forwarding the survey invitation to clinicians coordinating the PR programme.
3. Internet searches for PR programmes in NZ.
4. Utilising professional networks.

Only one respondent per service was invited to take part in the survey.

All identified PR programme co-ordinators were sent an email invitation to participate, outlining the aims of the survey along with a participant information sheet. Interested participants were asked to return a written consent form via email prior to being sent the online survey link via the REDCap. One automatic reminder email and survey link was sent to all participants who did not respond within 14 days.

The second survey was administered by contacting all participants who completed the first survey by email and inviting them to complete the Survey 2.

2.3.4 Data Analysis

All data provided was de-identified and analysed by aggregation. A simple descriptive statistical analysis was completed. The qualitative data collated from open ended questions were analysed using a simple general inductive thematic approach to identify common themes and meanings from the data (Thomas, 2006).

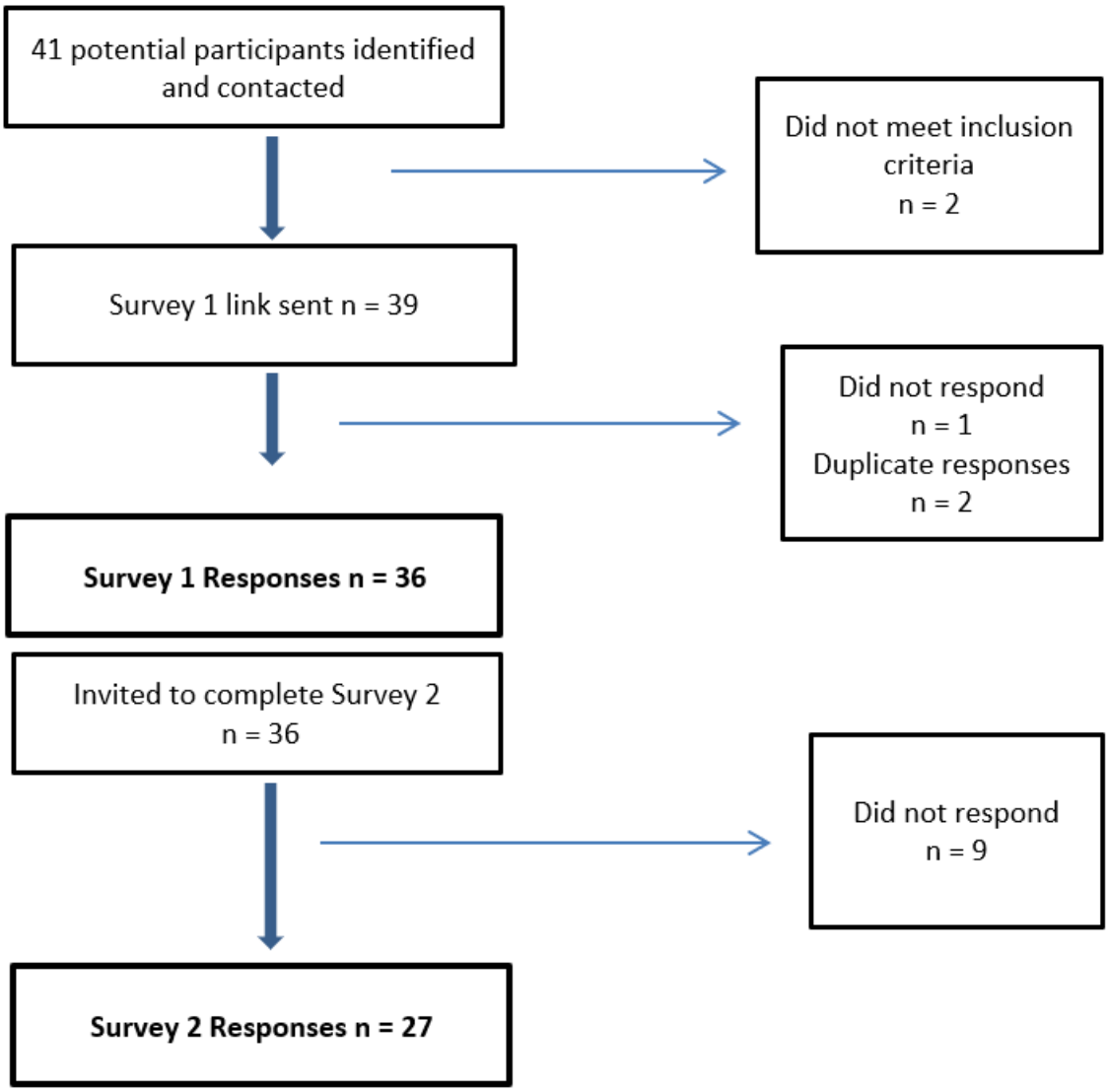
2.4 Results

2.4.1 Responses

Initial searches and advertisements identified 41 potential participants for Survey 1 who were sent participant information sheets. Two respondents did not meet the inclusion criteria. Thirty-nine survey links were sent out and 38 responses received. Two services duplicated their responses which were checked for inter-rater reliability before duplicates were removed. Responses were analysed from 36 (97.3%) programmes for Survey 1. Survey 2 was sent to all respondents of Survey 1 and 27/36 (75.0%) responded to Survey. Response rates can be seen in Figure 3. Respondents to Survey 1 were physiotherapists (n=27; 75.0%), nurses (n=7; 19.4%) and exercise physiologists (n=2; 5.5%).

Figure 3

Flow chart of participants through Survey 1 and Survey 2.



2.4.2 Geographical Distribution

NZ is currently divided into 16 regions for local government purposes, and 15 regions had a minimum of one respondent to Survey 1. Survey 1 was completed by 28 (77.7%) PR services in the North Island (NI), and 8 (22.2%) in the South Island (SI). Survey 2 was completed by; 19 (70.3%) PR services in NI, five (18.5%) SI, with three responses (11.1%) not stipulating their region.

2.4.3 Programme setting

The majority of respondents provided PR at one site only (n=23; 63.9%) with 13 (36.1%) offering programmes across multiple sites. The setting of the programmes

surveyed can be seen in Table 3. Of note, four services (10.8%) offered home based rehabilitation prior to COVID-19 restrictions in Survey 1.

Table 3

Pulmonary Rehabilitation Programme setting (n=36)

Setting	n	(%)
Hospital Outpatient	19	(52.7)
Community venue	15	(41.6)
Home based	4	(11.1)
Hospital inpatient	1	(2.7)
Church	3	(8.3)
Private facilities	3	(8.3)
Marae	2	(5.5)
Water based programme	1	(2.7)
Telerehabilitation	0	(0.0)

Note. n= sample size

2.4.4 Programme organisation

The programmes surveyed reported delivery by a multi-disciplinary team with 27 (75.0%) programmes reporting utilising four or more different health care professionals directly in the delivery of the programme. The disciplines reported to be involved are listed in Table 4. The majority of programmes were funded by the public health services; 26 (72.2%) by DHBs, 4 (11.1%) by Primary Healthcare Organisations (PHOs) and 4 (11.1%) by combined DHB/PHO funding. Two (5.5%) programmes were reported to be self-funded by participants and one service (2.8%) was funded by a combination of self-funding/insurance. Referrals to the PR services came from a variety of health care professionals (HCP) (see Table 5). Sixteen services (44.4%) undertook an annual service audit of the programme. A further four services (11.1%) reported having undertaken service audits, but not on a regular basis. A service audit had never been completed by n=16 (44.4%) of respondents.

Table 4

Disciplines directly involved in the delivery of PR

Health Care Profession	n	(%)
Physiotherapist	32	(88.8)
Nurse	29	(80.5)
Dietician	21	(58.3)
Occupational Therapist	15	(41.7)
Health Care Assistant	15	(41.7)
Health psychologist	10	(27.8)
Peer Support / volunteer	7	(19.4)
Social worker	7	(19.4)
Pharmacist	6	(16.6)
Exercise Physiologist	5	(13.8)
Doctor (primary or secondary care)	5	(13.8)
Other *	3	(8.3)

Note. *Other included smoke free specialists and green prescription providers

2.4.5 Programme structure

PR programmes were mostly eight weeks in duration and predominantly utilised group-based exercise and education classes. Respondents were asked about the format of their PR programme and the majority (69.4%) used a block/cohort programme. Block programmes require that all participants start PR on the same day, whereas a rolling programme allows participants to enrol at any time. An individual (1:1) programme was reported to be offered by one (2.7%) respondent. Twenty-four (66.7%) respondents reported having a waitlist to start the programme, with eight (22.2%) reporting the wait time for PR to be up to six months, the majority of which followed a block format programme (n=6; 75.0%). Only two services (5.5%) offered PR outside of normal working hours, with the remainder of services provided only within 9am to 5pm Monday to Friday.

2.4.6 Programme Content

The inclusion of a pre and post programme assessment was reported by all respondents with further follow up assessment (> 3 months post completion) included by 10 programmes (27.7%). All services included measures of exercise capacity and health related quality of life with the different measures used shown in Table 5. Programmes included patients with a range of chronic respiratory conditions, see Table 5. Only one programme (2.7%) offered multi-morbidity rehabilitation

programme (i.e., included participants living with multi-morbid long-term health conditions).

Table 5

Structure and content of NZ PR programmes (n=36).

	n	(%)
Programme format:		
Block programme	25	(69.4)
Rolling programme	10	(27.8)
Other (mixed n=1, individualised n = 1)	1	(2.8)
Programme Component		
Exercise, group education	33	(91.6)
Exercise, individual education	2	(5.5)
Other	1	(2.7)
Referrals from:		
Respiratory physician	34	(94.4)
General Practitioner (GP)	33	(91.6)
Physiotherapist	31	(86.1)
Nurse	31	(86.1)
Other physician	23	(63.8)
Other health care professional	18	(50.0)
Self-referral	12	(33.3)
Other	1	(2.7)
Participant diagnosis:		
COPD	36	(100)
Interstitial lung disease	34	(94.4)
Bronchiectasis	33	(91.6)
Asthma	26	(72.2)
Post thoracic surgery	23	(63.8)
Lung cancer	19	(52.7)
Prehabilitation	18	(50.0)
Obstructive sleep apnoea	14	(28.8)
Cystic fibrosis	1	(2.8)
Breathing pattern disorders	1	(2.8)
Programme length:		
< 8 weeks	1	(2.8)
8 weeks	25	(69.4)
> 8 weeks	10	(27.8

	n	(%)
Exercise test:		
6MWT	30	(83.3)
1 min STS	8	(22.2)
5 rep STS	6	(16.6)
ISWT	3	(8.3)
Other (30 sec sit to stand, 2-minute step test, CPET)	3	(8.3)
Health related quality of life measure:		
CAT	24	(66.6)
CRDQ	7	(19.4)
SGRQ	5	(13.8)
CCQ	3	(8.3)
SF36	2	(5.5)
Other (Leischer cough (2), LINQ (1), HADS (1), WHO QOL (1), EQ-5D (1))	7	(19.4)
None	1	(2.7)

Note. GP: General practitioner; 6MWT: six-minute walk test; 1min STS: one minute sit to stand; 5 rep STS: five repetition sit to stand; ISWT: incremental shuttle walk test; CAT: COPD Assessment Test; CRDQ: chronic respiratory disease questionnaire; SGRQ: St George questionnaire; CCQ: chronic COPD questionnaire; SF36: short form 36; LINQ: lung information needs questionnaire; HADS: hospital anxiety and depression index; WHO QOL: world health organisation quality of life;

Respondents were asked if they offered any adaptations to the programme for participants of different cultural backgrounds, with 22 (61.1%) reporting making adaptations to the service including: moving the location of PR to a marae (n=3; 8.3%), recruitment of health care professionals to reflect the different cultures in the classes (n=5; 13.8%), provision of an interpreting service (n=10; 27.7%), and provision of written material translated to different languages (n=6; 16.6%).

At the time of data collection for Survey 1, none of the services included a telerehabilitation component in their PR service. Respondents reported using digital technologies to assist in the delivery of centre-based programmes via appointment reminders through email (n=16; 44%) and/or text messaging (n=22; 61.6%). Technology was also used for delivering self-management education (n=13; 36.1%) in the form of videos and power point presentations.

2.4.7 Survey Two

Of the 27 who completed Survey 2 responses, 11 centres (40.7%) stopped their PR programmes completely during the COVID-19 associated lockdowns (NZ level 3 and 4

restrictions). In the programmes that continued to operate during COVID-19 restrictions, the telephone was the most frequent modality used for completing PR assessments, delivering exercise prescription, and self-management education. Some respondents utilised video conference facilities (n =7; 25.9%) and/or text messaging (n =2; 7.4%). The content of the programmes and modalities used during the COVID-19 lockdowns is shown in Table 6. Ten services (37.0%) reported that following COVID-19 restrictions being lifted, they planned to recommence services with the addition of telerehabilitation options for participants, whereas five services (18.5%) reporting likely resuming the same services as prior to COVID-19 lockdowns. Twelve services (44.4%) remained unsure of their future structure at the time of the survey.

Table 6

Delivery of Pulmonary Rehabilitation during COVID-19 restrictions (n=27).

Component of PR	Delivery modality	n	(%)
Assessment	Did not complete assessment during lockdown	16	(59.2)
	Telephone	9	(33.3)
	Video conference	1	(3.7)
Exercise Prescription + progression	Telephone	15	(55.5)
	Video Conference	7	(25.9)
	Paper	7	(25.9)
	Email	5	(18.5)
	Mobile Apps	2	(7.4)
	Home booklet	1	(3.7)
	Not described	1	(3.7)
Self-management education	Telephone	11	(40.7)
	Paper	8	(29.6)
	Video conference	6	(22.2)
	Email	6	(22.2)
	Text messaging	3	(11.1)
	Mobile Apps	3	(11.1)
	Other (web-based resources)	1	(3.7)

Respondents were asked to describe the most significant barrier when trying to deliver PR during COVID –19 restrictions. The most common themes included: not being able to assess participants in person (n=16; 59.2%), not being able to complete objective measures (n=15; 55.5%), a lack of digital access for participants (n= 15; 55.5%) and low digital literacy for participants and staff (n=13; 48.1%). Respondents also reported not

being prepared for the restrictions, and not having the time and resources to develop alternative methods for delivering PR.

Respondents were asked if access to national PR resources would have been helpful to the delivery of PR during COVID-19 restrictions. Twenty-one (77.8%) responded they would have liked access to resources, especially New Zealand specific exercise and self-management educational videos. Other resources respondents would have found helpful during COVID-19 restrictions are shown in Table 7.

Table 7

Resource's respondents reported would be helpful to deliver PR via telehealth in NZ (n=27)

Resources	**n**	**(%)**
NZ specific exercise and education videos	19	(70.3)
Televised PR programme	17	(62.9)
National telerehabilitation service	13	(48.1)
Text messaging programme	11	(40.7)
Mobile PR App	10	(37.0)
Other – written material which could be supported with telephone calls.	1	(3.7)

Note. PR = Pulmonary Rehabilitation

2.5 Discussion

This study has provided valuable information on the provision of PR services in Aotearoa NZ, updating knowledge gained from a previous national PR survey (Levack et al., 2012). Importantly, the study offered an opportunity to examine the impact of COVID-19 on service provision and how PR services adapted to the national restrictions and the perceived importance of maintaining this momentum in advancing the flexibility of PR service delivery.

2.5.1 Characteristics of PR in NZ

The main findings from Survey 1 showed that PR programmes demonstrate considerable homogeneity in their organisational aspects; they are largely funded by the public health system, delivered by a multidisciplinary team of healthcare professionals, with most programmes including people across a range of chronic respiratory conditions. The content of PR programmes was also consistent across the regions and, importantly, mirrors best practice guidelines (Alison et al., 2017; Bolton et al., 2013). The British Thoracic Society (BTS) PR guidelines (Bolton et al., 2013)

recommend services complete an annual review of individual outcomes and progress, yet our survey found this was not completed in 53% of NZ PR services. Developing a framework for a national audit programme similar to the UK programme (Steiner et al., 2015b) may assist smaller services to meet this recommendation and provide valuable information on service provision across NZ.

Provision of evidence-based PR is only part of the picture. Ensuring participants attend and complete the intervention is challenging (Candy et al., 2020a). Contributing factors have previously been identified that relate to both patient characteristics and how the service is delivered (Candy et al., 2020a; Cox et al., 2017; Harrison et al., 2015; Keating et al., 2011; Stone et al., 2021). The current study showed NZ PR services have responded to some of the known barriers with the setting of PR services moving away from hospital outpatient settings and into community settings; currently 52.7% of PR programmes are in hospital outpatient clinics compared to 71% in 2009 (Levack et al., 2012). NZ has one of the highest rates of community-based programmes in the world following Ireland, where 65% of programmes are in community venues (Desveaux et al., 2015). Community based programmes have been shown to achieve equivalent health outcomes to hospital outpatient services if delivered with a consistent format (Alison et al., 2017). The increase in community-based services in NZ is an important initiative to make programmes more accessible to participants and overcome barriers associated with travel and transport. In addition, the move to community centres with cultural importance, such as marae and church facilities demonstrate novel ways to improve engagement through making programmes more culturally engaging and meaningful to participants. Ethnicity is an important predictor of non-completion of PR (Candy et al., 2020a; Steiner et al., 2015a) and strategies which have been shown to assist with engagement include the setting for PR (Levack et al., 2016; Meharg et al., 2020), the staff delivering rehabilitation services (Hamilton et al., 2016; Levack et al., 2016) the use of interpreters (Jacobs et al., 2001). Survey 1 demonstrated PR services in NZ are working towards improving cultural participation through a variety of these strategies.

Whilst patient barriers to uptake may have been considered, there remain several organisational and structural components of PR in NZ which may potentially contribute to the poor uptake and completion of PR. Most services offered only one location for

PR, and operated only during work hours, limiting access for people who may be unable to attend during the day. The block style programmes were utilised by nearly 70% of the respondents, and whilst these programmes have been shown to be associated with improved completion rates (Stone et al., 2021) they can also be associated with a longer waiting time to start PR. Waiting time to commencement of PR is reported as a predictor of uptake (Marks, 2013) with people waiting longer than 90 days being less likely to complete PR (Stone et al., 2021). The length of waiting time is also an important consideration for people following an acute exacerbation who are recommended to start PR promptly following discharge from hospital (Puhan et al., 2016). Survey 1 found that there were waiting lists for most PR services in NZ, which increased following the COVID-19 restrictions. Services should examine their population needs in order to determine the optimal structure to balance uptake and completion rates.

Survey 1 found the number of PR services in NZ offering home-based rehabilitation was low. Clinical guidelines recommend home based PR, with regular contact, should be offered as an alternative to hospital-based PR (Alison et al., 2017), however it is estimated that this is offered in less than 5% of centres worldwide (Spruit et al., 2014) with Survey 1 echoing this finding in NZ. Emerging models to support home-based rehabilitation have been trialled internationally, including telephone support (Holland et al., 2017), videoconferencing (Stickland et al., 2011; Tsai et al., 2017) and web and mobile-based applications (Bourne et al., 2017; Chaplin et al., 2017; Park et al., 2020a; Whittaker et al., 2021) and have shown promising results. For the purposes of these surveys, home based rehabilitation was defined as PR delivered within the participant's home, with or without supervision and telerehabilitation was defined as delivering PR at a distance using information and communication technology (Cox, McDonald, Hill, et al., 2018). Survey 1 found four services in NZ were using home-based rehabilitation but no services in NZ were using telerehabilitation as a mode of delivery for home-based PR services prior to COVID emerging in NZ.

2.5.2 Impact of COVID 19 restrictions on PR services

Survey 2 showed the challenge of accessing PR services was intensified with the implementation of national restrictions in response to the COVID-19 pandemic. During this time, centre-based programmes were suspended, and delivery of PR services

needed to be taken to the participant in new and novel ways. Considering the low number of services offering home-based rehabilitation prior to COVID 19 lockdown, it is perhaps understandable that many services were unable to transition to new models of delivery and instead ceased services during this time. Of the services identified as offering home-based rehabilitation in Survey 1 (n=4), all continued to operate during COVID restrictions.

Of the respondents who continued to provide PR throughout the lockdown periods (n= 16; 59.2%), the most frequently used PR delivery modality was the telephone. Respondents reported the low digital literacy and access to devices for participants as one of the most challenging aspects of trying to deliver alternative PR services. Digital access and literacy has previously been reported as a potential barrier to remote delivery of PR in a NZ study investigating the potential for the development of technology-based PR programme (Dobson et al., 2019). Previous reports in NZ have shown digital exclusion can occur across all age demographics but is particularly prevalent in Māori and Pacific people (Bureau, 2020) where lower access to PR programmes and poorer outcomes from chronic respiratory conditions are seen (Telfar et al., 2015a). Furthermore, international audits have shown associations between deprivation and participation in PR with people from lowest socioeconomic status having lower odds of receiving PR (Spitzer et al., 2019) and reduced rates of completing PR (Candy et al., 2020a; Steiner et al., 2015a). An Australian survey investigated computer and internet access in patients admitted to hospital with COPD in an area of high poverty and found only 16% of patients had computer and 14% had internet access (Granger et al., 2018). It is therefore vital that the development of alternative delivery methods for PR ensures they do not further increase inequities.

Other challenges identified in this study involved the extra staffing time required in setting up and delivering alternative programmes, such as telerehabilitation. Almost all respondents reported having access to national resources would have assisted them in continuing to deliver PR services during the lockdown period. There are currently no evidence-based guidelines for alternative delivery methods of PR to guide clinicians. The development of NZ tailored and robustly tested resources for alternative methods of delivering PR could be helpful, in overcoming known barriers to accessing traditional centre-based services and by allowing rapid response to future pandemics.

2.6 Limitations

While every effort was made to ensure all PR programmes in NZ were identified and included in the study, there is a possibility a programme may have been missed. Strength of Survey 1 was the high response rate; however, this was lower than expected for Survey 2 impacting the results and may reflect the business of clinicians during the lockdown periods. Another limitation of the current surveys is that we are unable to determine capacity of PR programmes across NZ, nor estimate the uptake of PR services for people with COPD. Neither did this survey aim to look at discrepancies regarding availability of PR services across different communities, ethnicities, or socio-economic status. We realise this may influence the uptake and adherence to PR and warrants further investigation. In future, this information may be beneficial in understanding the discrepancy between PR service referrals, uptake, and completion.

2.7 Conclusion

Our study has provided important information on the structure, content, and organisation of PR services in NZ, and how services responded to COVID-19 lockdown restrictions. The surveys highlighted several factors which limit widespread access to PR services in NZ and has demonstrated the potential and necessity to expand and adapt current services provision. PR services need to increase flexibility in the delivery options for participants, including timing, venues, and modes of delivery of PR.

COVID-19 restrictions imposed in 2020 provided an unprecedented opportunity to compare how services-initiated adaptations to the pandemic in NZ. Our surveys demonstrated that the number of home-based PR services tripled during COVID-19 restrictions, and how tele-rehabilitation programmes emerged around the country as a result. This demonstrates different models of PR can be delivered in NZ and shows the ability of services to be flexible in their provision of PR and to respond and rapidly adapt, but we need to maintain this momentum.

Moving forward increasing the capacity and diversity of PR options is essential to address the lack of access to programmes in NZ. But it is essential that these services are designed with key stakeholders to ensure they are accessible and engaging for all participants and do not increase existing disparities. Consideration in the design of services must be given to digital divide, equity, and culturally engaging models. Finally

ensuring new models of care still adhere to best practice guidelines and are safe and effective is essential.

End of published paper.

2.10 Chapter Summary

The data collected from the National surveys provides valuable information for the development of an mHealth programme. Prior to the COVID-19 restrictions organisational barriers impacted the reach of PR services, including the time, location and type of services offered. Many PR services were able to pivot to telerehabilitation options during national restrictions, but these telerehabilitation services were not able to provide all the essential components of PR , particularly the components of assessment and the healthcare professionals being trained to deliver PR in the format provided. Additionally, services reported increased numbers of patients waiting for PR in 14/28 (50%) of the programmes and 17/28 of the programmes reported longer waiting times, reinforcing the need for increasing service provision of PR.

Chapter 3 Factors which influence participation in telerehabilitation – A scoping review of the literature

3.1 Prelude to manuscript

A scoping review of the literature was undertaken to identify the factors which influence participation in remotely delivered PR. This literature review aims to identify participant perceived barriers and enablers to undertaking remotely delivered PR programmes. This addresses the second research objective of this thesis:

To identify factors which influence patient participation in telerehabilitation

3.1.1 Contribution by the candidate

The candidate, with supervisor's guidance, developed the objective of the scoping review. The candidate designed and conducted the review including generating criteria and conducting the search. The candidate completed the data extraction and analysis, formulated the results, and wrote the chapter with supervisors' guidance.

Supporting documents

Supporting documents for this chapter are contained in Appendix including the study protocol, search strategy used for the review, data extraction tables and PRISMA checklist.

Publication

This manuscript is to be published in the November issue of the New Zealand Journal of Physiotherapy.

3.2 Abstract

Aim:

This scoping review aims to investigate the evidence relating to factors that influence patient uptake and participation in remotely delivered pulmonary rehabilitation (PR).

Introduction:

Pulmonary Rehabilitation (PR) is a high-value intervention for people living with a chronic respiratory disease. Uptake and completion of PR remains low, and telerehabilitation provides an alternative model for remotely delivering PR, which may improve the reach of this intervention. Whilst telerehabilitation is safe and likely equivalent to centre-based PR, little is known about the barriers to participation in telerehabilitation to date. This scoping review aims to better understand the factors that influence perception of and participation in telerehabilitation for people living with a chronic respiratory disease.

Methods:

Scopus, MEDLINE, and CINAHL were searched from July 27 to November 23, 2022. Articles were screened, and those fulfilling inclusion criteria were extracted to a standard template. Extracted data were analysed using narrative synthesis.

Results:

Twenty seven studies met the inclusion criteria. People living with a chronic respiratory disease perceive telerehabilitation to be convenient and flexible, but technically challenging and lacking in contact with clinicians and peer support. The experiences from a small number of people who have participated in these programmes counter this with praise for the therapeutic relationship they developed with their clinician and the social support they received.

Keywords

Pulmonary rehabilitation, telerehabilitation, mHealth, chronic respiratory disorders, barriers, uptake, participation, perspectives

3.3 Introduction

Pulmonary rehabilitation (PR) is a highly effective intervention in the management of chronic respiratory disorders (CRD). Despite the overwhelming evidence to support its effectiveness (McCarthy et al., 2015) uptake and completion of PR worldwide is low with 8 - 50% of those referred never attending. Of those who do start PR, 10-32% do not complete the intervention (Keating et al., 2011). Barriers to attendance and completion have been widely investigated and include transport and travel (Fan et al., 2008), socioeconomic (Johnston & Williams, 2017) , marital and social status (Young et al., 1999) and ethnicity (Candy et al., 2020b; Spitzer et al., 2020). PR delivered remotely through technology has been proposed to improve access to care and may reduce the burden of attending centre-based programmes.

There are many different models for delivering pulmonary telerehabilitation, including telephone, video conferencing and mobile/web-based applications (Bourne et al., 2017; Chaplin et al., 2017; Cox, McDonald, Alison, et al., 2018; Hansen et al., 2020; Holland et al., 2017; Tsai et al., 2017), some of which are synchronous (real time) and some asynchronous. A growing body of evidence evaluates some of these different models, including a recent Cochrane review by Cox et al. (2021), which has shown that these telerehabilitation interventions are likely to be as safe and effective as traditional centre-based PR, however, the small number of studies, low sample sizes and methodological heterogeneity make this a cautious conclusion (Cox et al., 2021). Whilst telerehabilitation interventions have shown promising results, this form of PR has yet to be widely implemented in clinical practise in NZ (Candy et al., 2022). Studies involving telerehabilitation have reported challenges in recruiting participants as high numbers decline due, reportedly, to an intervention preference for in person PR (Holland et al., 2017). There is a lack of information regarding which, if any, patients prefer telerehabilitation and different delivery modes.

Prior to this scoping review, we conducted a preliminary search of MEDLINE and the Cochrane Database of Systematic Reviews to determine the extent of the evidence regarding factors influencing participation in telerehabilitation, and no current systematic reviews or scoping reviews were identified. A scoping review was determined as necessary to be undertaken as telerehabilitation is an emerging field in PR. To provide information on the barriers to uptake, the perception of, and participation in remotely delivered PR, a range of information sources were determined to be required. Scoping reviews allow consideration of a range of research evidence, including qualitative and non-clinical trial data, and allows

summation of all existing data. This scoping review aimed to explore the factors impacting participation in PR telerehabilitation.

3.3.1 Review questions

The scoping review will address three questions from available literature:

1. What factors influence the uptake of PR delivered via telerehabilitation?
2. What are patient perceptions towards telerehabilitation?
3. What were patient's experiences of participating in telerehabilitation?

3.4 Methods

The scoping review follows the steps detailed in the Joanna Briggs Institute manual for conducting scoping reviews (Tricco et al., 2018). A protocol was developed prior to undertaking the review (see Appendix H). An experienced librarian gave guidance on the search strategy.

Eligibility criteria

Due to the contemporary nature of telerehabilitation interventions, studies published from 01/01/2011 were included. Only studies published in English were included.

Participants

Adults (>18 years) living with a CRD who are eligible for referral to PR (according to Australian and NZ PR Guidelines (Alison et al., 2017)) including: COPD, ILD, asthma, bronchiectasis, pre and post lung surgery.

Concept

Studies involving PR (as defined by the American Thoracic Society (ATS)/European Respiratory Society (ERS)) (Martijn A. Spruit et al., 2013), remotely delivered in the home via technology (telerehabilitation). The technology includes but is not limited to telephone, video conferencing (VC) and web-based interventions.

Context

What factors impact willingness to participate in home-based telerehabilitation. Perceptions toward participation and end-user experience were included.

Types of Sources

This scoping review included quantitative, qualitative studies and mixed method designs. Grey literature was also included. The search strategy aimed to locate both published and unpublished studies.

3.4.1 Search strategy

An initial search of MEDLINE was undertaken to identify potential keywords for the full search strategy. The key words contained in the titles and abstracts of potentially relevant studies were used to develop a full search strategy for Scopus, MEDLINE and CINAHL. The search strategy was adapted for each included database (see Appendix I). The reference list of all included sources of evidence was screened for any additional studies not identified by the initial search.

Screening, data extraction and synthesis

All identified citations were uploaded into EndNote 20.4 and duplicates removed. Titles (and abstracts where available) were screened for assessment against the inclusion criteria by the primary author. All relevant sources were retrieved in full, and their citation details imported into excel. The full text of selected citations was assessed to determine if they met the inclusion criteria.

Data were extracted from the papers ultimately included in the scoping review using a standard data extraction tool (Pollock et al., 2023) which included author, date, country, study design, participant characteristics, PR concept, and outcomes of interest. Data was analysed in alignment with the research questions:

1. rates of uptake of telerehabilitation in studies,
2. the patient perception of telerehabilitation (including willingness to participate),
3. the patient experience of participating in telerehabilitation.

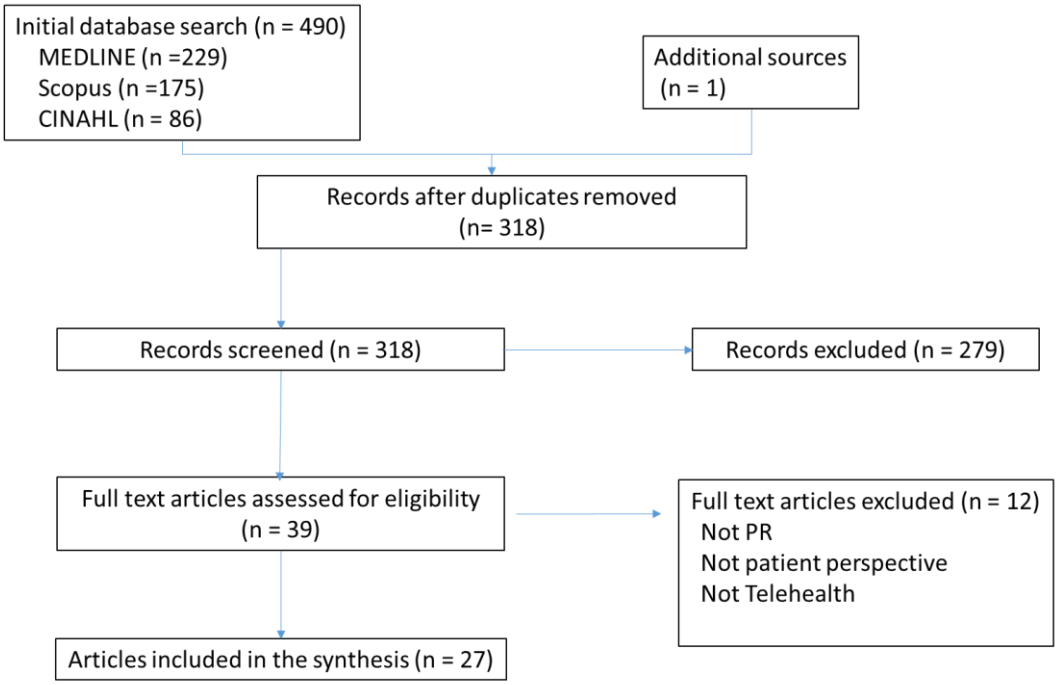
Quantitative and qualitative data syntheses were undertaken. The quantitative data included counts of studies reporting uptake of remote PR. The number of participants declining participation was converted to rates and percentages, and where possible counts of reasons for declining across the studies were collated. Qualitative analysis included descriptions of studies and delivery methods used. Themes relating to barriers and enablers derived from the qualitative studies have been reported through narrative synthesis (Lisy & Porritt, 2016). Data was first analysed by organising the studies based on the research question they addressed. Data was extracted by reading and collating the stated themes and subthemes, along with recording descriptions of themes with supporting quotes. The studies were then re-read to identify any other concepts or potential themes that may arise across the studies. Similar themes were grouped together by SC and then discussed and refined by JR and DT until consensus on final themes was reached. Final themes were grouped and reported as barriers and enablers to participation.

Results

The initial search yielded a total of 490 potentially relevant papers. When duplicates were removed and titles/abstracts screened, 39 full papers were retrieved, of which 27 were included in the final analysis. A flow chart detailing the flow of included and excluded studies can be seen in Figure 4.

Figure 4

Flow Diagram of studies included in scoping review



Included studies

The review included 27 studies involving 2094 participants with sample sizes ranging from 10 – 254. The mean age of participants in the studies ranged from 54 to 73 years, and 48% of the participants across all the studies were female. Studies included people living with COPD (n = 19), or CRD (n =7), and one study did not specify. Three different methods of remotely delivered home-based telerehabilitation were detailed in the studies: telephone support (n=2), supervised group exercise and education using VC facilities (n=11) and web-based programmes (n =11). A combination of differing modes of technology was described in two studies, and a further study did not describe the method of delivering telerehabilitation. The design of included studies was: eight randomised control trials, seven non-randomized trials (RCT), four survey design and eight mixed methods studies (survey and interviews). The characteristics of the included studies can be seen in Table 8.

Table 8

Characteristics of studies included in the review

Author (year)	*Country*	*Study Design*	*Participants, n, diagnosis, age (SD), sex*	*PR Concept*	*Reports Uptake Data*	*Reports Intent / willingness*	*Report barriers*	*Report enablers*
Almojaibel (2021)	USA	Survey	134 diagnosis not stated 66 (10.7) years Female 50%	Willingness to participate in telerehabilitation	No	Yes	Yes	Yes
Alwashmi (2020)	Canada	Mixed methods Survey + interviews	77 COPD 65 years Female 60%	Perceptions of Web-based PR	No	No	Yes	Yes
Bairapareddy (2021)	India	Survey	30 COPD 54 (12) years Female 20%	Perceptions of Web-based PR	No	Yes	No	No
Benzo (2021)	USA	RCT + interviews	78 COPD 69 (8.1) years Female 53%	Participated in Web-based + telephone calls	Yes	No	Yes	Yes
Bourne (2017)	UK	RCT	90 COPD 70 (8.6) years Female 35%	Web-based V centre-based	Yes	No	No	No
Burkow (2015)	Norway	Mixed methods: Survey + interview	10 COPD 62 years Female 50%	Participated in VC + phone calls	No	No	Yes	Yes
Cerdan-De-Las-Heras (2022)	Denmark	RCT	54 COPD 67 (10.2) years Female 43%	Web-based Vs centre-based	Yes	No	Yes	No
Chaplin (2017)	UK	RCT	103 COPD 66 (8.1) years Female 31%	Web-based Vs centre-based	Yes	Yes	Yes	No

Author (year)	*Country*	*Study Design*	*Participants, n, diagnosis, age (SD), sex*	*PR Concept*	*Reports Uptake Data*	*Reports Intent / willingness*	*Report barriers*	*Report enablers*
Cox (2021)	Australia	RCT	142 COPD 68 (9) years Female 56%	VC Vs centre-based	Yes	No	Yes	No
Dobson (2019)	NZ	Mixed methods - Survey & interview	30 CRD 73% > 65 years Female 43%	Perceptions of Web-based PR	No	No	Yes	Yes
Grosbois (2021)	France	Retrospective audit	105 CRD 63 years Female N/A	Telephone or VC Vs no PR (COVID-19)	Yes	No	Yes	No
Hansen (2020)	Denmark	RCT	134 COPD 68 (9) years Female 55%	VC Vs centre-based	Yes	No	Yes	No
Hoaas (2016)	Norway	Survey + focus group	10 COPD 55 years Female 50%	Participated in VC PR	No	No	Yes	Yes
Holland (2017)	Australia	RCT	166 COPD 69 (13) years Female 40%	Telephone Vs Centre-based	Yes	No	Yes	No
Houchen-Wolloff (2021)	UK	Feasibility Non-randomised + interviews for select sample	100 COPD (AE) (n=14 interviewed) 71 (9.3) years Females 45%	Web-based Vs no PR	Yes	Yes	Yes	Yes
Inskip (2018)	Canada	Survey & Focus groups	26 CRD 71 years Female 50%	Perceptions of telerehabilitation	No	No	Yes	Yes

Author (year)	*Country*	*Study Design*	*Participants, n, diagnosis, age (SD), sex*	*PR Concept*	*Reports Uptake Data*	*Reports Intent / willingness*	*Report barriers*	*Report enablers*
Lahham (2018	Australia	Semi structured interviews	13 COPD 66 years Female 77%	Telephone	No	No	Yes	Yes
Lewis (2021)	UK	Service evaluation	17 CRD 69 (11) years Female 50%	VC + telephone call	Yes	No	Yes	Yes
Marquis (2015)	Canada	Observational study	26 COPD 65 (7) years Female 58%	VC	Yes	Yes	No	No
Nolan (2019)	UK	Non-randomized trial	154 COPD 71 (9) years Female 52%	Telephone calls	Yes	Yes	No	No
Polgar (2022)	UK	Survey (x 2)	99 + 101 CRD 74 years Female 47%	Perceptions of Web-based PR	No	Yes	Yes	No
Seidman (2017)	Australia	Survey	254 CRD 73(10) years Female 59%	Perceptions of VC delivered PR	No	Yes	Yes	Yes
Simony (2019)	Denmark	Non-empirical	15 COPD 62 years Female 47%	VC	Yes	No	Yes	yes
Skibdal (2022)	Denmark	Mixed methods Survey & interviews	84 COPD survey, 9 COPD int. 70 (9) years Female 53%	Perceptions of VC, telephone, or text messages	No	No	Yes	yes

Author (year)	*Country*	*Study Design*	*Participants, n, diagnosis, age (SD), sex*	*PR Concept*	*Reports Uptake Data*	*Reports Intent / willingness*	*Report barriers*	*Report enablers*
Tsai (2017)	Australia	RCT	37 COPD 73 (8) years Female 50%	VC Vs centre-based	Yes	No	No	No
Tsai (2016)	Australia	Survey + Interview	11 COPD 72 year Female 36%	Participated in VC PR	No	No	Yes	Yes
Whittaker (2021)	NZ	Feasibility study	26 CRD 70 years Female 50%	Participated in web-based PR	No	No	Yes	Yes

Note. AE= acute exacerbation, CRD = chronic respiratory disease, COPD = chronic obstructive pulmonary disease, VC = videoconferencing, RCT = randomised control trial, UK= United Kingdom, NZ= New Zealand. Vs = versus,

Data are presented as mean (SD) or n or (%) unless otherwise stated.

3.4.2 Uptake of Telerehabilitation

Data on the uptake rate of telerehabilitation was extracted from both RCTs and non-randomised clinical trials but pooled separately. The reasons why participants did not participate is not clearly defined in all studies and studies used different methodologies for recruitment making direct comparison limited.

Randomised Control Trials

A total of 3289 participants from eight RCTs were screened for inclusion in the RCTS, of which 2399 (73%) were either deemed ineligible or declined uptake (Table 9). In the seven studies that documented the number of patients who declined, six studies documented the reasons for declining. Five studies reported excluding between 4 – 26% of the participants screened due to patients stated preference for centre-based rehabilitation and declining participation (Chaplin et al., 2017; Cox, McDonald, Alison, et al., 2018; Hansen et al., 2020; Holland et al., 2017; Tsai et al., 2017). Other reported reasons for declining telerehabilitation included lack of digital competence, not having a suitable home environment or the perceived time commitment.

Table 9

Number of participants screened, excluded or declined in randomised control trials of telerehabilitation

Author (date)	# Screened	# Excluded	# Declined
Bourne et al (2017)	163	73	n/a
Cerdan-De-Las-Heras et al (2022)	95	20	21
Chaplin et al (2017)	641	244	294
Cox et al (2021)	651	499	246
Hansen et al (2020)	1099	714	251
Holland et al (2017)	295	129	67
Tsai et al (2017)	128	91	40
Benzo et al (2021)	217	63	33

Non-randomized studies

Six observational studies were identified offering telerehabilitation to participants under different circumstances:

1. during the COVID pandemic when centre-based were closed (Grosbois et al., 2021; Lewis et al., 2021),
2. to bridge the gap to centre-based PR for patients with an acute exacerbation of COPD (Houchen-Wolloff et al., 2021),
3. while on PR waiting lists (Marquis et al., 2015; Simonÿ et al., 2019)

Across the included non-randomised studies, between 12 to 95% of the patients screened declined participation (Table 10). Three of the studies reported reasons for decline and these are included in Table 11.

Table 10

Uptake of telerehabilitation in observational studies

Author (date)	# Screened	# Uptake	(% Uptake)
Grosbois et al (2021)	65	57	(88%)
Houchen-Wolloff et al (2021)	2080	100	(5%)
Lewis et al (2021)	30	17	(57%)
Marquis et al (2015)	77	26	(37%)
Simony et al (2019)	28	15	(54%)
Nolan et al (2019)	1593	154	(10%)

Intention to participate in telerehabilitation

The intent or willingness of people living with a CRD to participate in telerehabilitation was explored in four studies (Almojaibel et al., 2020; Polgar et al., 2022; Seidman et al., 2017; Skibdal et al., 2022). Three studies surveyed current centre-based PR participants (Almojaibel et al., 2020; Polgar et al., 2022; Seidman et al., 2017) and one study surveyed participants after declining centre-based PR (Skibdal et al., 2022). Studies found those who wished to engage with telerehabilitation, perceived telerehabilitation would result in clinical benefits (Almojaibel, 2016), had a higher education level (Seidman et al., 2017) and had greater familiarity with, and access to, digital devices (Seidman et al., 2017; Skibdal et al., 2022). The observation studies used

different methodologies to define and describe the telerehabilitation intervention to participants which may have impacted the patient perception.

Participant preference

Two studies reported on the patient preference for how PR is delivered. Nolan et al. (2019) reported only 10% of participants opted for home-based PR when given the option of centre-based PR or home-based PR with weekly telephone calls. Chaplin et al. (2017) conducted a RCT comparing centre-based with web-based PR, but surveyed consented participants on their preference of centre-based or web-based PR prior to group randomisation; 38% stated a preference for the web-based PR intervention (Chaplin et al., 2017).

3.4.3 The patient perception of telerehabilitation

Data regarding patients' perception of telerehabilitation was gathered from people who had a range of prior experience and knowledge of centre-based PR; some had or were attending centre-based PR (Bairapareddy et al., 2021; Dobson et al., 2019; Inskip et al., 2018; Seidman et al., 2017), had been referred to PR (Polgar et al., 2022) or had declined PR (Dobson et al., 2019; Inskip et al., 2018; Skibdal et al., 2022). One study did not state participant's prior participation in centre-based PR (Alwashmi et al., 2020b). None of the participants in any of the studies had prior experience with telerehabilitation.

Data were collated from five studies employing surveys, patient interviews and focus groups. Participants in all the studies perceived telerehabilitation to be less onerous than centre-based PR with reduced time, travel, and financial burden. Synthesis of these studies identified several factors which appear to play a role in influencing the patient perception of telerehabilitation. These factors have been described as barriers and enablers and are discussed below.

Perceived barriers to participation in telerehabilitation

Technical competence

Technical competence was reported by all studies as a perceived barrier to telerehabilitation with up to 39% of participants reporting they believed they would not have the necessary technical skills to partake in telerehabilitation (Alwashmi et al.,

2020b; Bairapareddy et al., 2021; Dobson et al., 2019; Inskip et al., 2018; Polgar et al., 2022). Age and education level were shown to be associated with technical confidence (Seidman et al., 2017; Skibdal et al., 2022).

Device and data access

An inability to access the required digital device and/or limited data access was reported as a perceived barrier to telerehabilitation (Alwashmi et al., 2020b; Bairapareddy et al., 2021; Dobson et al., 2019; Polgar et al., 2022; Seidman et al., 2017). Four studies explored device access and found that the most ubiquitous device was a mobile phone, with ownership rates between 73% and 88% of the cohorts sampled (Almojaibel, 2016; Alwashmi et al., 2020b; Dobson et al., 2019; Seidman et al., 2017). However, the same study showed smartphone ownership rates were reported between 23 – 66%, with many participants reporting limited functional device ability. Two studies explored predictors of access to a device, and both found that smartphone ownership (like technical competence) was directly related to education level defined as beyond high school (Alwashmi et al., 2020b; Seidman et al., 2017). In an implementation study conducted during the COVID-19 pandemic, 75% of the participants who transitioned to remotely delivered PR could not participate in VC classes due to lack of device access, and could only receive telephone support (Grosbois et al., 2021).

Supervision and contact with HCP

The concept of direct contact with a clinician was discussed in seven reviewed studies (Alwashmi et al., 2020b; Bairapareddy et al., 2021; Dobson et al., 2019; Inskip et al., 2018; Polgar et al., 2022; Seidman et al., 2017; Skibdal et al., 2022). In three studies, participants reported a lack of supervision or contact with a clinician as a potential downside of telerehabilitation (Dobson et al., 2019; Seidman et al., 2017; Skibdal et al., 2022). Survey participants reported that whilst telerehabilitation might offer a more convenient way of communicating with their clinician, they thought the clinician may lack a good understanding of their condition (Bairapareddy et al., 2021) or would prefer ‘in-person’ contact with a physiotherapist (Seidman et al., 2017).

Peer support

Studies found that peer support and social connections were considered important components of centre-based PR, with the potential lack of peer support perceived a barrier to telerehabilitation for many participants (Dobson et al., 2019; Inskip et al., 2018; Seidman et al., 2017; Skibdal et al., 2022). Pulmonary telerehabilitation delivered through group-based VC delivered sessions may minimise this barrier by allowing for sharing experiences of living with COPD (Skibdal et al., 2022).

Other barriers

The length of time a participant has lived with their CRD and the degree of symptom burden were identified as perceived barriers to participation (Almojaibel, 2016; Skibdal et al., 2022). These studies suggested that greater the duration and severity of the disease, the greater the perception of no benefit from telerehabilitation PR.

Language was reported as a potential barrier to participation in telerehabilitation, with the option of the intervention being delivered in other languages required in order to partake (Bairapareddy et al., 2021; Dobson et al., 2019; Houchen-Wolloff et al., 2021). In addition to these barriers, participants also reported caution around the security and privacy of data transmitted through technology potentially impacting their participation (Alwashmi et al., 2020b; Bairapareddy et al., 2021; Dobson et al., 2019).

Perceived enablers to participation in telerehabilitation

Factors which were perceived to positively influence uptake of telerehabilitation were less commonly reported in the literature, however, understanding the benefits gained and the perceived usefulness of remote PR was shown to impact willingness to participate (Almojaibel et al., 2021; Alwashmi et al., 2020b; Skibdal et al., 2022). Components participants wished to see included in telerehabilitation programmes have been reported and include regular communication with a clinician (Bairapareddy et al., 2021; Skibdal et al., 2022), and monitoring and feedback on their rehabilitation performance (Dobson et al., 2019; Inskip et al., 2018). The perceived barriers and enablers to participating in telerehabilitation have been summarised in Table 11.

Table 11

Barriers and enablers to uptake of telerehabilitation in studies

		Almojaibel (2021)	Alwashmi (2020)	Bairapareddy (2021)	Dobson (2019)	Inskip (2018)	Polgar (2022	Seidman (2017)	Skibdal (2022)	Chaplin (2017)	Houchen-Wolloff (2021)	Simony (2019)	Lewis (2021)
Barriers	Technical competence of participant	●	●	●	●	●	●	●	●	●	●	●	●
	Reduced interaction with HCP		●	●	●	●	●	●	●				
	Lack of peer support/social interaction				●	●		●	●			●	
	Personal preference of participant		●		●		●		●	●	●		●
	Cultural/language			●	●						●		
	Access to a device and data		●	●	●			●					
	Privacy/security of health information		●	●	●								
	Lack of monitoring available (HR, SpO2)			●		●							
	Participant education level							●					
	Duration of CRD	●											
	Space/environment/equipment									●			
	Impact of Co-morbidities									●	●		

		Almojaibel (2021)	Alwashmi (2020)	Bairapareddy (2021)	Dobson (2019)	Inskip (2018)	Polgar (2022	Seidman (2017)	Skibdal (2022)	Chaplin (2017)	Houchen-Wolloff (2021)	Simony (2019)	Lewis (2021)
Enablers	Perceived usefulness	●	●						●				
	Ease of use		●		●								
	Availability of technical support		●										
	Less burden c/w centre-based			●	●			●	●				
	Flexible/ timing				●			●	●				
	Family involvement				●								
	Cultural considerations	●											
	Feeling safe in own environment								●				
	Receiving feedback and monitoring				●	●							

Note. CRD = chronic respiratory disease, c/w = compared to

Key

● Enabler ● Barrier

3.4.4 Experiences of participation in telerehabilitation

Eight studies explored the patient experience of participating in telerehabilitation. Data were collected through interviews (Benzo et al., 2021; Burkow et al., 2018b; Houchen-Wolloff et al., 2021; Lahham et al., 2018a; Tsai et al., 2016; Whittaker et al., 2021), focus group (Hoaas et al., 2016) and questionnaires (Benzo et al., 2021; Hoaas et al., 2016; Tsai et al., 2016). The models of delivery of PR used were; telephone calls (Lahham et al., 2018b), videoconferencing (Benzo et al., 2021; Burkow et al., 2015; Hoaas et al., 2016; Simonÿ et al., 2019; Tsai et al., 2016)and web-based models (Houchen-Wolloff et al., 2021; Whittaker et al., 2021). The web-based models allowed participants to complete PR independently at a time convenient to them, and allowed patient initiated interactions with clinicians, with one of the programmes offering individual VC consultations with a clinician (Houchen-Wolloff et al., 2021). 178 participants across eight studies reported their experiences of participating in telerehabilitation, with study sample sizes ranging from 10 to 78 participants. The mean ages of participants ranged from 55 to 69 years and 52% of participants across the studies were female. Some participants had previously attended centre-based PR and others had never attended centre-based PR. Two studies included participants who started but did not complete telerehabilitation. In nearly all the studies exploring participation in telerehabilitation (n=7/8), the technical equipment was provided for participants, with the remaining study requiring participants to use their own device (Whittaker et al., 2021). See Table 12 for characteristics of studies included.

Table 12

Characteristics of studies exploring the participant experiences with remotely delivered PR

Author (year)	Sample size (n)	Age (years) mean (SD)	PR delivery mode	Participant experience of PR		Participant digital literacy at baseline	Study provision of digital equipment
				No previous PR experience	Previously Attended centre-based based PR		
Benzo et al (2021)	78	69	VC			Not stated	Provided
Burkow et al (2015)	10	62	VC	✔	✔	All regular computer users	Provided
Lahham et al (2018)	13	66	Telephone	✔	✔	N/A	N/A
Hoaas et al (2016)	10	55	VC			8/10 used internet daily, 2 technology naive	Provided
Houchen-Wolloff et al (2021)	14	71 (9)	Web-based	✔		Needed to be web literate + have email	Provided or used own
Simony et al (2019)	15	62	VC			Not stated	Provided
Tsai et al (2016)	11	72 (8)	VC	✔	✔	Not stated	Provided
Whittaker et al (2021)	26	70	Web-based		✔	Not stated	Needed own mobile phone

Note. VC = video conferencing, N/A = not applicable

Telerehabilitation participants across all studies reported health benefits from the intervention and high levels of acceptability and usability when taking part in telerehabilitation. The key themes emerging from the studies reporting participant's experiences of being involved in telerehabilitation have been grouped as enablers and barriers.

Enablers

Communication with HCP

Five of the eight studies reported positive experiences with the communication and support they experienced from the attending clinician whilst using telerehabilitation (Benzo et al., 2021; Burkow et al., 2018a; Hoaas et al., 2016; Lahham et al., 2018a; Tsai et al., 2016). This positive feedback was reported predominantly in programmes which included individual consultations (Burkow et al., 2018a; Hoaas et al., 2016; Lahham et al., 2018a) but also for one of the group VC programmes (Tsai et al., 2016). Clinician contact was reported to be associated with improved participation (Lahham et al., 2018a) and increased health benefits (Tsai et al., 2016). The regular clinician contacts reportedly facilitated complete and safe completion of the programme (Hoaas et al., 2016). Two studies providing optional clinician consultations reported low rates of uptake of the consult (Bourne et al., 2017; Chaplin et al., 2017)which prompted the recommendation that these consultations should be scheduled and structured, rather than optional and patient led (Simonÿ et al., 2019).

Feeling supported

A theme of patients feeling supported with their health condition during telerehabilitation was reported in many of the studies. Participants reported support came from clinicians (Benzo et al., 2021), family and friends (Lahham et al., 2018a) (Whittaker et al., 2021), and other participants in VC-based programmes (Burkow et al., 2015). Group-based education sessions enabled sharing of ideas and challenges between participants (Burkow et al., 2015). One web-based study allowed family members to register for the programme along with the person living with a respiratory condition, resulting in important benefits for both the family and participant (Whittaker et al., 2021). The Whittaker et al (2021) study also used text messaging to

inform, encourage and support participants, and this messaging was perceived as being supportive by participants.

Flexibility

A frequently reported key enabler of participation in telerehabilitation was the flexibility it provided. It allowed those with daytime commitments, such as paid employment, to participate (Hoaas et al., 2016; Lahham et al., 2018a; Tsai et al., 2016; Whittaker et al., 2021). This flexibility in training time was an important component in allowing commitment to the exercise routine (Lahham et al., 2018a).

Reduced burden

Most participants across the studies reported a reduction in burden associated with telerehabilitation which allowed participation in PR without the expense of travel and parking (Lahham et al., 2018a; Tsai et al., 2016), and reduced the time and fatigue participants associated with travelling (Burkow et al., 2018a; Hoaas et al., 2016; Tsai et al., 2016).

Monitoring and feedback

Different tools for monitoring participants during telerehabilitation were described in studies. These included activity monitors to gather data on steps taken (Benzo et al., 2021; Burkow et al., 2015; Lahham et al., 2018a; Whittaker et al., 2021), and providing pulse oximeters for data on peripheral oxygen saturations and heart rates. The data were monitored real-time via VC (Lewis et al., 2021; Tsai et al., 2016) or recorded in digital diaries (step count, observations, and symptoms) (Benzo et al., 2021; Burkow et al., 2015; Hoaas et al., 2016), and was available to both the participant and clinicians. Participants perceived the data differently; some report the data as motivational and providing a learning opportunity (Houchen-Wolloff et al., 2021) (Hoaas et al., 2016), while others did not wish to view their own data, but felt it was useful for their clinician (Burkow et al., 2015).

Barriers to participation

Whilst most of the feedback was positive, participants reported aspects which made engaging in telerehabilitation challenging. Commencing the telerehabilitation programme was found to be a particularly difficult time due to their prolonged

sedentary lifestyle (Lahham et al., 2018a), along with technical disruptions. Whilst most participants reported the digital equipment was generally easy to use, internet disruptions impacted participation (Tsai et al., 2016), and there were reports of stress when the VC technology did not work (Hoaas et al., 2016), or difficulty downloading and logging onto the app (Whittaker et al., 2021). One web-based application received feedback from participants that the programme was complex and technical challenges reduced their motivation or caused them to disengage entirely (Houchen-Wolloff et al., 2021).

Participants provided feedback that more variation in the exercise programme would have been beneficial, and options for adapting exercises when they were having a bad day or pain or weather limited participation (Hoaas et al., 2016; Lahham et al., 2018a; Whittaker et al., 2021). The barriers and enablers to participating in telerehabilitation are summarised in Table 13.

Table 13

Barriers and enablers experienced during participation in remotely delivered PR

		Benzo (2021)	Burkow (2015)	Lahham (2018)	Hoaas (2016)	Houchen-Wolloff (2021)	Simony (2019)	Tsai (2016)	Whittaker (2021)
Barriers	Getting started			🟠					
	Variation & modification			🟠	🟠		🟠		🟠
	Technical challenges				🟠	🟠		🟠	🟠
	Not tailored								🟠
Enablers	Health benefits	🟢		🟢	🟢			🟢	🟢
	Interaction with HCP	🟢	🟢	🟢	🟢		🟢		
	Feeling Supported	🟢	🟢	🟢					🟢
	Usability of technology	🟢	🟢		🟢			🟢	
	Flexibility			🟢			🟢	🟢	
	Reduced burden								
	Feedback	🟢						🟢	

Key
🟠 Barriers
🟢 Enablers

3.5 Discussion

This scoping review has explored the literature on end-user's perceptions of telerehabilitation. This data informs our understanding of the barriers and enablers to telerehabilitation which are both anticipated and experienced by participants, and supports the need for future models to be developed through a process of co-design with potential end users to enhance the reach of PR.

This review found limited literature reporting the uptake of telerehabilitation in the clinical setting. Many studies involved randomisation which dictates group allocation, and the studies frequently reports patient preference for centre-based rehabilitation as a reason for declining participation. It is acknowledged recruitment to these studies was frequently from PR waitlists, with patients having expectation of attending centre-based PR.

The most frequently reported barrier to telerehabilitation was technical competence with the devices used to deliver telerehabilitation. Whilst this may change as technology becomes a more integral part of people's lives, the sequential surveys in the UK pre and post COVID have shown that despite the growing use of and confidence with technology, the appetite for telerehabilitation remains low and relatively unchanged (Polgar et al., 2020; Polgar et al., 2022). Competence with technology is associated with age, education level and device access (Seidman et al., 2017; Skibdal et al., 2022), suggesting the possibility that providing telerehabilitation may widen the equity gap by promoting options that are not accessible to those who may need it the most. For example, a survey conducted in a UK inner city, high-poverty area showed only 16% of people admitted to a hospital with a COPD exacerbation had computer access and only 14% had internet access (Granger et al., 2018). A key feature of remote delivery is to reduce the burden associated with attending centre-based PR programme and developers must ensure that those for whom this may be useful are not disadvantaged by lack of access to devices. Access to mobile phones appears most common, however, these are not always smartphones and reports of internet data access are variable. Given the widespread ownership of mobile phones it is the ideal device for delivery of PR.

Holland et al. (2021), recently suggested that the uptake of PR is influenced by perceptions of what participation in telerehabilitation might mean for people living with a CRD (Holland et al., 2021). For many participants, the perception of telerehabilitation is that it is technically challenging and beyond their digital skills. However, in participants who have completed telerehabilitation, technical challenges were retrospectively considered minor. Differing theoretical models consider the readiness to engage with technology and support these findings. For example, The Unified Theory of Acceptance and Use of Technology (UTAUT) (Venkatesh, 2022) model suggests the perceived likelihood of adopting the technology is dependent on the direct effect of four key constructs namely performance expectancy, effort expectancy, social influence, and facilitating conditions. The use of such models assist with understanding how we can facilitate uptake by employing strategies to assist participant to understand how the telerehabilitation programme works and the potential benefits to the participant. Many of the studies included in this review

provided both equipment and significant technology support, which may have positively influenced the participant experience. Ensuring the allocation of such resources in telerehabilitation programmes may be an essential part of successful implementation. Including training and support as an opt-out rather than opt-in model for telerehabilitation participants may enhance uptake and outcomes.

Developing a therapeutic relationship with attending clinicians has been shown to be important to people living with a CRD. This review showed that a lack of supervision and direct contact with staff is a perceived barrier to participation in telerehabilitation. Studies of remotely delivered PR have used differing methodologies making it challenging to compare and identify optimal models for telerehabilitation, for example, some web-based models use 'stand-alone' models with no scheduled clinician contact, whilst others use weekly telephone coaching and supervised group exercise and education models. Despite this, communications with clinicians were identified as an important facet of programmes by participants. Many studies report the remote communication as effective and as engaging as face-to-face (Benzo et al., 2021). It could be suggested participants have more individual and personalised communication with a clinician in telerehabilitation models than centre-based, where they are competing with other participants for attention. The optimal dose of clinician contact in telerehabilitation has not been determined, but future programmes should consider scheduled, structured consultations that may evolve over time with more support required at the start of the programme.

An important part of PR is developing a support network. In centre-based PR this network is developed with peers at the programme. Studies reported concerns that telerehabilitation would not be able to provide the same peer support as centre-based (Dobson et al., 2019; Inskip et al., 2018). However, participants who completed telerehabilitation reported feeling supported in different ways to those in centre-based PR. In remotely delivered group sessions using VC facilities, social support was reported as received through other participants in the programme (Burkow et al., 2018a; Tsai et al., 2016). For telephone and web-based models this support was received from family and friends (Lahham et al., 2018a; Simonÿ et al., 2019; Whittaker et al., 2021), who often participated alongside the patient and became more aware of

the participant's condition and how to best provide support. In developing telerehabilitation models consideration of support networks is vital and allowing for inclusion of family members appears beneficial.

Key points

1. Providing information on expected benefits of telerehabilitation may improve the patient's perception
2. Provision of devices and data may allow increase inclusivity
3. Technical support should be provided for all participants
4. Provide regular scheduled clinician contact points

3.6 Conclusion

PR is an effective and essential component in CRD management. Whilst centre-based programmes have proven efficacy, they are not always accessible for all. Telerehabilitation can provide a flexible and convenient programme which can reduce the burden associated with accessing centre-based programme whilst still maintaining a supportive and motivating environment.

Participants have preferences for how their healthcare is delivered. A range of delivery options is required to optimise the uptake and completion of PR. For some participants, concerns about digital competence, device access or lack of perceived benefit can restrict participation in digital options. Services should consider adequate resourcing for new models of telerehabilitation to be implemented to allow inclusivity for all participants and provide sufficient training and support to overcome technical challenges. Developing a therapeutic relationship appears critical to programme success and strategies to enable this, such as regularly scheduled clinician interactions, must be considered to optimise the success of such programmes.

Chapter 4 Development of an mHealth application for pulmonary rehabilitation

4.1 Prelude to chapter

This Chapter describes developing the content of an mHealth application for PR in NZ to increase the access to and uptake of PR. This chapter will address Objective 3 and 4 of the theses:

> *To develop the content for a NZ based mHealth PR programme, and*
>
> *to evaluate the content for a NZ based mHealth PR programme*

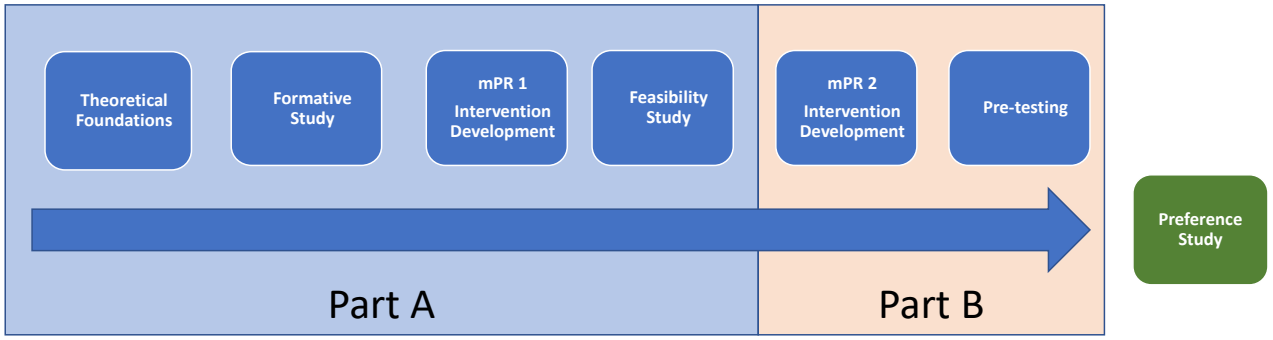
The chapter builds on the information gathered in Chapters 2 and 3. Chapter 2 determined current PR service provision in NZ and an understanding of the content and organisation of PR across NZ. Chapter 3 identified potential barriers and enablers to uptake and participation in telerehabilitation. These chapters identified a need for a different model of PR, to increase the reach of PR. This, together with discussions with our stakeholders informed the content development of an mHealth PR programme for NZ which we called mPR. This development of this programme is described in this chapter.

4.1.1 What was undertaken?

The development of our mPR intervention involved a six-step process based on a framework previously described for developing and evaluating mHealth interventions (Whittaker et al., 2012) shown in Figure 5.

Figure 5

mPR Content Development and Evaluation Framework



Note. Adapted from mHealth Development and Evaluation Framework (Whittaker et al., 2012)

Two of our previously published studies were embedded in the development of the mPR intervention. These were:

- formative study investigating end-user perceptions of mHealth delivered PR (Dobson et al., 2019) (see Appendix L)
- feasibility study investigating the usability of the first mPR V1 (Whittaker et al., 2021) (see Appendix M).

This chapter is divided into two parts:

Part A considers the theoretical underpinnings and the *formative* study (Dobson et al., 2019) and how these were used to create the inceptive mPR prototype. This was tested in the *feasibility* study.

Part B considers how mPR evolved following the results from the *feasibility* study (Whittaker et al., 2021), outlines the content refinement and the pre-testing of mPR V2.

4.1.2 Contribution by candidate

The candidate was involved in all stages of intervention development, from designing the intervention, developing the content for the mPR programme, and testing the protocols. Support was provided by PhD supervisors and the National Institute for Health Innovation (NIHI). The candidate led the two content development stages, designing the exercise and education modules. The candidate led the pre-testing phase with support from cultural experts. The candidate was involved with but did not lead the *formative study* (Dobson et al., 2019) or the *feasibility study* (Whittaker et al., 2021).

The candidate wishes to acknowledge the contribution of the following work presented in this chapter:

1. mPR co-investigators and advisory group,
2. the NIHI IT and project teams, in particular Cindy Chong and Taria Tane,

3. students at bioengineering school and Kelly Burrows,
4. the content reviewers, and the participants of feasibility and pretesting studies, and usability testing.

PART A -mPR V1 Development and evaluation

The development process for mPR started with synthesising and evaluating the theoretical underpinnings to inform the content. This, and input from people who would benefit from PR, ensured a person-centred approach to the intervention design.

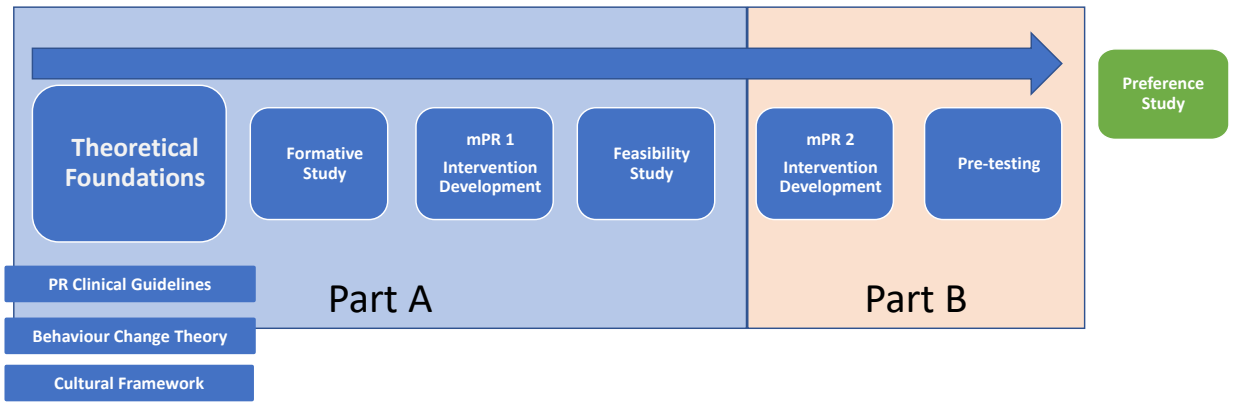
4.2 Theoretical Foundations

Three key theoretical frameworks formed the building blocks for the mPR intervention content; (see Figure 6).

- PR clinical guidelines (Alison et al., 2017; Bolton et al., 2013)
- Theoretical models of behaviour change (COM-B, Social Cognitive Theory) (Bandura, 2004; West & Michie, 2020)
- Cultural framework (Te Whare tapa wha)

Figure 6

mPR Development Framework; highlighting the steps undertaken to form the theoretical foundations



Note. Figure adapted from mHealth Development and Evaluation Framework (Whittaker et al., 2012)

4.2.1 PR Clinical Guidelines

As there are clear clinical guidelines for effective PR when delivered in a centre-based model (Alison et al., 2017; Bolton et al., 2013), it was determined that the mPR intervention should follow these guidelines as closely as possible. The Australian and New Zealand PR guidelines (Alison et al., 2017) provide recommendations most

appropriate to the NZ context and along with the British Thoracic Society (BTS) (Bolton et al., 2013) and the American Thoracic Society (ATS) /European Respiratory Society (ERS) joint statement (Martijn A Spruit et al., 2013) shaped the development of mPR. The guiding components are summarised in Table 14.

Table 14

Summary of key components in Pulmonary Rehabilitation Guidelines for PR

Key Component	Details	Australian/NZ guidelines (Alison et al., 2017)	BTS guidelines (Bolton et al., 2013)	ATS/ERS joint statement (Martijn A Spruit et al., 2013)
Participants	People with stable COPD should undergo PR	✔	✔	✔
	People with Bronchiectasis should undergo PR	✔		✔
	People with ILD should undergo PR	✔		✔
	People with Pulmonary Hypertension should undergo PR	✔		✔
Programme structure	PR should be minimum twice weekly		✔	
	Encouragement of physical activity five times per week		✔	
	Programmes of 6 – 12 weeks are recommended	✔	✔	
	Home based PR needs to consider; mechanism for remote support/supervision, provision of equipment and patient selection		✔	
Exercise	Combination of muscle resistance and aerobic exercise should be delivered		✔	✔
	Prescription of progressive strength training should be individualised		✔	✔

Key Component	Details	Australian/NZ guidelines (Alison et al., 2017)	BTS guidelines (Bolton et al., 2013)	ATS/ERS joint statement (Martijn A Spruit et al., 2013)
Self-management	PR should provide opportunities for smoking cessation advise		✔	
	Opportunity to screen and educate on nutrition		✔	
	PR offers an opportunity to check and optimise inhaler technique		✔	
	Symptoms of anxiety and depression are prevalent in CRD and may affect outcomes and can be ameliorated by PR			✔
Outcome measures	Patient satisfaction and feedback should be sought		✔	
	Efficacy of programmes need to be regularly assessed		✔	
Maintenance	All participants should be given a written programme to continue with post PR	✔	✔	

Note. CRD = Chronic respiratory disease, COPD = chronic obstructive pulmonary disease, ILD = interstitial lung disease, PR = pulmonary rehabilitation,

More recently, a consensus report was published providing guidelines on the essential components of emerging PR programmes see Figure 7. (Holland et al., 2021)

Figure 7

Essential components of Pulmonary Rehabilitation (Holland et al., 2021)

1. An initial centre-based assessment by HCP
2. An exercise test at assessment
3. A field exercise test
4. Quality of life measure
5. Nutrition status evaluation
6. Occupation status evaluation
7. Endurance training
8. Resistance training
9. An individually prescribed exercise programme
10. An individually progressed exercise programme
11. Team includes HCP with experience in exercise prescription + progression
12. HCP trained to deliver the components of model deployed.

4.2.2 Behaviour Change Theory

A key objective of PR is to support behaviour change to improve the physical and psychological condition of people with CRD. The content development of mPR was informed by behaviour change theories to enable participants to make sustained changes. Behaviour change interventions are defined as 'coordinated sets of activities designed to change specific behaviour patterns' (Michie et al., 2011), and technology provides a valuable medium for promoting health-enhancing behaviours. A systematic review has shown that internet-based interventions are most effective when they incorporate multiple behaviour-change techniques and modes of delivery (Cole-Lewis et al., 2019). The mPR programme was underpinned by two behaviour change theories; the COM-B model (West & Michie, 2020) and social cognitive theory (SCT) (Bandura, 2004), both of which are grounded by the concept of self-efficacy.

Perceived self-efficacy refers to how confident people are to perform actions required to deal with situations (Bentsen et al., 2010). Low self-efficacy and perception of personal capability are associated with low participation in physical activity (Arnold et al., 2006), and this appears to be particularly important in people living with a CRD. In CRD, the experience of breathlessness leads to a sense of loss of control and low self-efficacy. Patients avoid activities they perceive as out of their ability leading to reduced

physical activity, reduced social interaction, deconditioning, and poor health related quality of life (HRQoL). Studies have shown that activity levels are significantly lower in people with stable, mild chronic obstructive pulmonary disease (COPD) compared to healthy individuals (McAuley & Blissmer, 2000; Troosters et al., 2010).

Previous studies of COPD patients have found that higher levels of self-efficacy can predict improvements in exercise capacity, psychological and social function (Arnold et al., 2006), illustrating the importance of consideration to low self-efficacy in PR. The COM-B Model proposes that to perform an activity; an individual must feel they are physically and psychologically able to do so (West & Michie, 2020).

COM –B Model

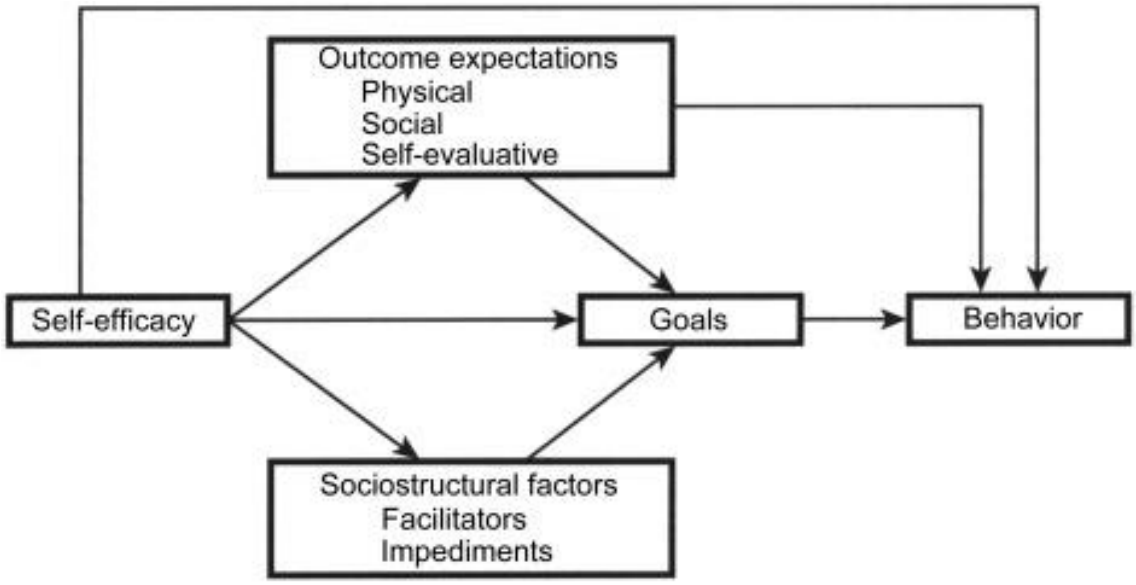
The COM-B framework states that for an intervention to be effective in changing behaviours, Capability, Opportunity, and Motivation should be addressed. This model, developed in 2011, forms part of the behaviour change wheel framework (Michie et al., 2011). The three components in this model all interact with each other and successful behaviour requires at least one of the three components to be targeted. All three key components may impact participation in PR and have been included in the content development of mPR.

Social cognitive theory (SCT)

Social cognitive theory (SCT) considers the interaction between the person, environment, and behaviour (see Figure 8) (Bandura, 2004). For example, if a person believes they can complete the exercise and it will improve their HRQoL, then they are more likely to engage.

Figure 8

Social Cognitive Theory (Bandura, 2004)



According to (Bandura, 2004), there are several ways of enhancing self-efficacy. These include mastery experiences, in which the person gains confidence by achieving a modest goal and observing someone like themselves successfully performing a behaviour, such as modelling, and verbal persuasion. By incorporating behaviour change techniques targeting these constructs in our mPR programme it is proposed this will support participants to make changes in their behaviour.

4.2.3 Cultural Framework - Te Whare Tapa Wha

Māori experience poorer outcomes from respiratory disease and have lower PR completion rates (Candy et al., 2020a; Telfar et al., 2015b). Consideration of Māori specific models of health will help to ensure that the mPR programme can work toward reducing inequities for this group. Te Whare Tapa Wha provides a framework to shape mPR for our NZ context, as it addresses four key dimensions of Māori health: taha tinana (physical), taha hinekaro (mental/emotional), taha whānau (family/social) and taha wairua (spiritual) and is based on a firm foundation (whenua) (Rochford, 2004). These essential foundations form the walls of the whare (home) and illustrate the foundations of well-being. If one of the foundations or walls is missing or damaged, the whare becomes insecure or imbalanced, and the person becomes unwell. This framework guided mPR development to ensure all dimensions of health and wellness were considered during the development process.

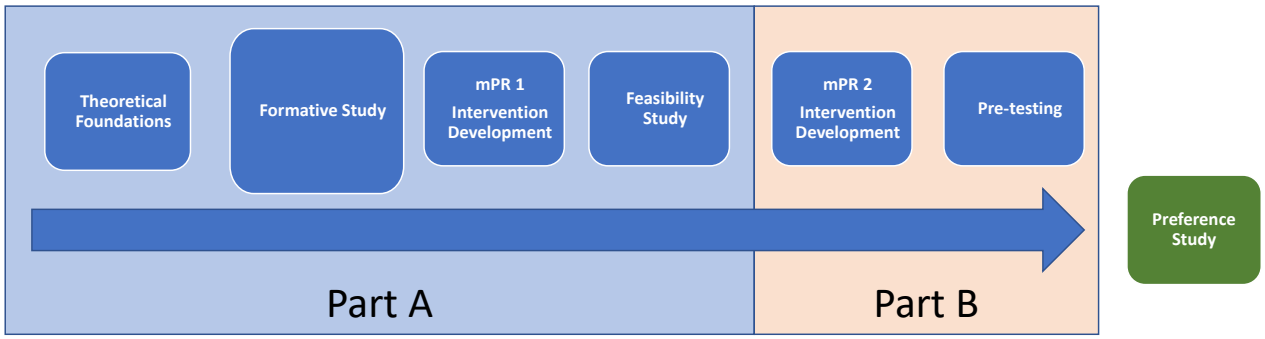
4.3 Formative Study – End-user involvement

The second step in the mPR development process involved a formative study to gather the perceptions of the patients and clinicians directly involved in PR regarding the option of an mHealth application for PR (see Figure 9). This step ensured a person-centred approach, with the content development being shaped to meet the needs and preferences of the end users. The full manuscript can be seen in the appendices and is briefly described here for the purpose of how it informed the design of the mPR intervention.

The candidate contributed to the study design and procedures. She contributed to the data collection, contributed to the data analysis and interpretation, and provided input to the writing of the paper.

Figure 9

mPR development and evaluation framework



Note. Adapted from mHealth Development and Evaluation Framework (Whittaker et al., 2012)

Aim:

The aims of the study were:

1. Understand the preferences and priorities for patients in participating in PR and how a mHealth PR application may support this.
2. Understand the needs, preferences and priorities of the healthcare professionals directly involved in caring for people who would benefit from participating in PR, including a general practitioner (GP), a respiratory physician, a physiotherapist, a health psychologist, and nurses.

Methods:

The study was a mixed methods sequential design, using a survey of participants living with chronic respiratory disease (n=30), and clinicians working with patients with CRD (n=8). Participants were recruited from respiratory outpatient clinics, respiratory inpatient wards, and PR services at two large hospitals in Auckland, New Zealand. The study received ethical approval from the health and disability ethics committee (HDEC) (18/NTS/105).

Results:

The sample consisted of participants who had completed PR (14/30), started but did not complete (7/30), were offered but declined (3/30) or had never been offered PR (6/30). The participants' demographics showed the majority were over 65 years (73%), 40% were female, 23% identified as Māori, 13% as Pacific and 57% as NZ European. The majority of participants had access to a mobile phone (87%) and/or home internet (77%). Healthcare professionals who cared for people with CRD were invited to complete a semi-structured interview (n=8). The sample included two doctors, two nurses, three physiotherapists and one health psychologist.

Participants (patients and HCP) believed an mHealth PR programme would reduce some of the burden associated with attending centre-based programmes, including travel, parking time, and expense. Both patients and HCP expressed concern that digital access and digital confidence may be a barrier for many people, and participants may miss out on the positive gains from peer support networks at centre-based PR programmes.

Of the participants who liked the concept of an mHealth PR programme, the key features they wished to see included in the mPR intervention included: tips for managing breathlessness (86%), information and education on their respiratory condition (77%), access to their own health information (54%), a means of tracking their health data (50%) and motivational and supportive messages (41%).

Implications:

The findings from the study showed a high interest from participants in mHealth PR, particularly from the patient group. Results reinforced the burden for some

participants to attend a centre twice weekly for eight weeks. Findings suggest the ongoing development of any mHealth PR programme must consider device access and digital literacy to facilitate participation.

4.3.1 Synthesis of thesis findings informing content of mPR

The theoretical underpinnings together with the findings from the formative study formed the base content of mPR. This content was informed and shaped by findings in Chapters 2 and 3, and candidates previous research findings (Candy et al., 2020a) (see Appendix N), and summarised in Table 15. In summary, the findings indicated that the mHealth intervention must:

1. Be inclusive of a range of CRDs and designed to reach those who experience greater access barriers to traditional PR.
2. Prioritise digital inclusion by ensuring that it utilises simple and accessible technology.
3. Be individually tailored and personalised.
4. Provide information and support alongside prompts to engage in behaviours and instructions and modelling of behaviours for correct and safe engagement.

Table 15

Bringing together research findings of key components for mPR development

		Non-completion Study (pre thesis) Candy et al (2020)	NZ PR Survey. Candy et al (2021) (Chapter 2)	Review of literature of barriers (Chapter 3)	Theoretical Foundations (Chapter 4)	Formative study (Dobson et al 2019) (Chapter 4)
Population	People living with CRD, including COPD, asthma, bronchiectasis, ILD		✔	✔		
	Māori and Pacific people	✔			✔	✔
	Low socio-economic	✔				
	Younger	✔	✔			
Features	Include family/whanau				✔	
	Culturally tailored	✔	✔		✔	✔
	Personalised				✔	✔
	Low digital confidence			✔		✔
	Device access			✔		✔
	Free of charge			✔		✔
	Digital support			✔	✔	✔
	Prompts/cues				✔	
Content	Information on breathing strategies				✔	✔
	Provide feedback				✔	✔
	Social support				✔	✔
	Modelling behaviour				✔	
	Instructions				✔	
	Goal setting				✔	

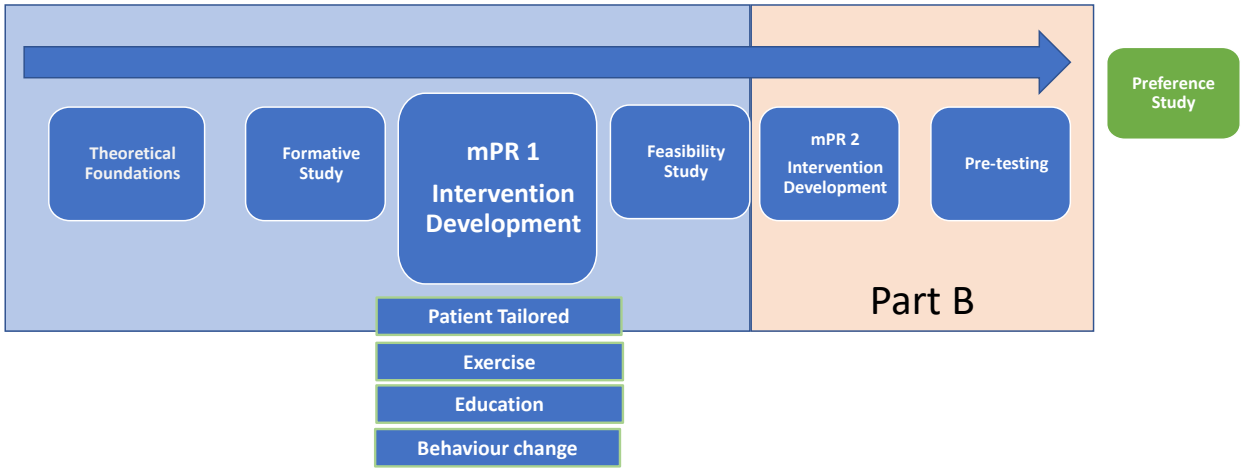
Note: CRD = chronic respiratory disease, COPD = chronic obstructive pulmonary disease, ILD = interstitial lung disease

4.4 Developing the mPR V1

As defined by ATS/ERS (Martijn A Spruit et al., 2013) PR must be based on thorough patient assessment and involve patient-tailored interventions including exercise, education, and behaviour change interventions. This section describes how each of these essential elements has been developed in mPR (Figure 10). The candidate led the content development supported by experts in the wider team.

Figure 10

mPR Development Framework; highlighting the steps undertaken to develop initial prototype



Note. Figure adapted from mHealth Development and Evaluation Framework (Whittaker et al., 2012).

The mPR V1 programme was designed to be delivered through a short messaging service (SMS) with an optional phone-based application. SMS is an accessible and acceptable method of communication for many older adults (Cole-Lewis et al., 2019), is free of charge and does not require complex digital skills. The use of SMS for mPR V1 was designed to deliver a weekly progressive exercise plan and utilised behaviour change techniques to inform, support, remind and provide feedback through the 8-week intervention. The programme for each participant was personally tailored based on an initial centre-based assessment.

4.4.1 Patient tailored

A modular PR programme was developed allowing mPR to be individually tailored, based on initial assessment findings, preferences, and demographics. Modules were designed to address target behaviours important for self-management of a chronic respiratory condition and are based on clinical guidelines (Alison et al., 2017; Bolton et

al., 2013; Holland et al., 2021; Rochester et al., 2015). The SMS were personalised using participants preferred name, their support person's name, their personal motivators, and a culturally appropriate greeting.

Family/whānau members could sign up for the programme to support the person living with a CRD. A description of the different modules for mPR V1 can be seen in Table 16.

Table 16

Description of the different modules available in mPR V1

Module name	Description	Sub modules	Who can receive this module
Compulsory	Core motivation, support and information messages designed to encourage engagement with the programme, PR associated behaviours, and the healthcare system Motivational messages General wellbeing Links to support services Advanced care planning (ACP) General PR information/education Flu vaccinations Staying well	Messages are tailored for: Māori Pacifica Whānau	All
Breathing	Messages on effective breathing pattern. Strategies for managing breathlessness.		All (patients and whānau)
Inhaler user	Information about correct use of inhalers		Patients only Optional
Exercise prescription information	Messages covering information and safety for exercise prescription Introduction to VAS BORG breathlessness scale Warm up information Cool down information Safety e.g., when not to exercise		Patients only
Exercise prescription	Weekly exercise prescription. Programme includes aerobic, resistance and balance exercises. Stratified to three levels based on: 6MWT, mMRC, balance	Ex. Level 1 Ex. Level 2 Ex Level 3	Patients only

Module name	Description	Sub modules	Who can receive this module
Smoking	Encouraging patients/family to consider quitting smoking Offering a smoking cessation programme.	Smoking Smoking-family	Current smokers
Smoking cessation	Free reply text 'quit' for automatic enrolment in a smoking cessation programme (adapted version of STOMP)		Current smokers who identify as wanting to quit
Mood/ Mental health/ Stress	Messages around mood management and self-care. Encourage self-care Provide education around stress and mood management techniques Increase engagement in healthy behaviours Provide motivation and support		All patients Optional whānau
Nutrition	Messages around healthy eating and nutrition Provide education around healthy eating specific to BMI (low or other) Increase engagement in healthy eating behaviours Provide motivation and support	Nutrition – low BMI Nutrition-other	All patients
Physical Activity	PA related messages designed to decrease sedentary behaviour and increase general PA through providing education, tips, goal setting, motivation, and support		All patients
Secretion	Education and reminder messages regarding secretion clearance techniques		Patients with retained secretions

Note: ACP = advanced care planning. 6MWT = six-minute walk test, mMRC= modified medical research council scale, VAS = visual analogue scale.PA = Physical activity. BMI = body mass index.

4.4.2 Exercise

The exercise component of mPR was delivered as an asynchronous, unsupervised exercise programme to be completed using equipment readily available in the home. Safety was paramount; exercise prescription was based on patient assessment. The exercise prescription was based on a stratification system (see Table 17) developed by the candidate. The stratification guide was piloted with clients in centre-based PR programmes prior to the implementation in the mPR V1.

Table 17

Exercise stratification guide

Exercise Level	6MWT distance	mMRC	Balance
1 (least challenging)	< 200 m	>3	Uses walking aid
2	200 – 450 m	2 – 3	No walking aid
3 (most challenging)	>450 m	<2	No walking aid

Note. 6MWT = six-minute walk test, mMRC = modified medical research council scale, m = metre

The mPR Exercise programme

Initial centre-based assessment included information on

1. Warm up and cool down
2. Programme frequency
3. Exercise intensity using BORG breathlessness scale (Ries, 2005).
4. Correct exercise technique

Each week participants received a message asking for their current rating of health on a visual analogue scale (VAS); if they reported their health was ok (>4 on VAS), they received a reply message with the exercise prescription for that week. If their current health was low (4 or lower on VAS), no exercise prescription message was sent, and a general self-care message was sent instead. An example of the exercise message for level 1:

> "mPR Exercise Plan: [hi] [name]. On 5 days this week aim to go for one 5-minute walk, and do 5 of each of your arm, leg, and balance exercises."

Exercise Progression

The programme was designed to monitor engagement with exercise by 2-way messaging; each week on day 6, a message was sent asking whether the participant had completed the recommended exercise or not (Yes/No). If 'yes', the participant received a message reinforcing their behaviour, and if 'no', a general encouragement message was sent. Each of the three stratified level of exercise had eight prescript programmes. The exercise prescription was stepped up using the reply to the weekly administered day 6 message; if 'yes', the following week's prescription was stepped up. If 'no', the following week's prescription stayed at the same level. At the halfway point (4 weeks), new exercises were prescribed.

Exercise Information

Information on how to safely exercise was included as a core module and delivered using SMS. The messages reminded participants to warm-up and cool-down, to use the BORG breathlessness scale for intensity and when not to exercise. See Figure 11 for examples of messages sent.

Figure 11

Examples of core exercises SMS in mPR V1

mPR: [hi] [name]. Always contact your doctor if exercising causes you any dizziness, chest pain or severe shortness of breath.
mPR: [hi] [name]. When exercising always start with a warmup & finish with a warm down (e.g., marching on the spot for 2 minutes).
mPR: It is normal to feel a bit stiff after you first start to exercise as your muscles may not be used to the exercises. Keep going - the stiffness will ease.
mPR: [hi] [name]. Drink plenty of fluids why exercising, and if you have oxygen at home, use this when you exercise.
mPR: [hi] [name]. If you are not sure how to do any of the exercising remember to check your handbook or look at the videos on the mPR app.
mPR: When exercising aim for moderate intensity (3 or 4 on the BORG breathlessness scale), you should be able to 'walk and talk'. Check your handbook for more information.
mPR: [hi] [name]. You should be aiming to exercise five times per week. It's important to have rest days to allow your body to recover.
mPR: [hi] [name]. You can divide your exercises up during the day. They do not all have to be done at the same time.

4.4.3 Education

Education on managing a CRD was provided through SMS to inform, support, motivate and encourage healthy behaviours. All participants received the compulsory modules, see Table 16 (general information, breathing education, inhaler use, mood, and physical activity) and optional modules were delivered when indicated (smoking cessation, nutrition, and secretion clearance techniques). The content was mapped from centre-based PR programmes and based on clinical guidelines (Alison et al., 2017; Bolton et al., 2013) and translated into messages of 160 characters to create an SMS library. For topics where there were existing evidence-based mHealth libraries (smoking cessation, physical activity), their content was reviewed and revised for mPR.

4.4.4 Behaviour Change

SMS may provide an ideal method for delivering theoretically based behaviour change techniques. The message library content was developed drawing on behaviour change techniques (Michie et al., 2011), and examples of the constructs and messages can be seen in Table 18. SMS has been used successfully in a range of health behaviour and disease self-management areas including for medication adherence (Sarabi et al., 2016), smoking cessation (Whittaker et al., 2016), diabetes management (Dobson et al., 2018), and physical activity interventions (Head et al., 2013).

Table 18

Behaviour change techniques from Michie et al (2013) incorporated into mPR intervention

BCT Grouping	Specific BCT employed	Example content
Shaping knowledge	4.1 Instructions on how to perform activity	Breathing Module- mPR: [hi]. Good breathing starts with the nose. Try to breathe in through your nose to warm & filter the air before it gets to your lungs!
		Exercise video demonstrating exercise technique
Social Support	3.2 Practical support	mPR: [hi] [name]. Remember your nurse & doctors are only a phone call away if you need them
	3.3 Emotional support	mPR: If you are losing motivation for exercising, remind yourself about why you want to become more physically active. Do it for your [motivation]
		mPR: Even when you are physically unwell it's still important to try and take care of your body. Try to get good sleep, eat well and practice relaxation.
	3.1 Whānau Support	Providing family with support
Natural consequences	5.1 Information about health consequences	Benefits of exercise
		mPR: [hi]. Your health can be controlled so it has less impact on your life. Do it for your (motivation).
Feedback & Monitoring	2.3 Self-monitoring of behaviour	Replying to text message with health score and readiness to progress
	2.2 Feedback on behaviour	Sit to stand results on mPR-app
		Text messages mPR reply: Great work [name]!
	7.1 Prompts and Cues	mPR: [hi] [name]. Take some time to practise better breathing in a relaxed position, thinking nose, tummy, and slow breathe out!

BCT Grouping	Specific BCT employed	Example content
Comparison of behaviour	6.1 Demonstration of the behaviour	Exercise demonstrations using models with CRD
Self-belief	15.3 Focus on past success	Feedback on average step count and number of exercises completed.
	8.1 Behaviour practise/rehearsal	Daily exercise
	15.4 Self talk	Try to find things to do each day that give you a sense of achievement e.g. finishing a crossword or puzzle, or even finishing a job such as weeding the garden.
	8.7 Graded tasks	Exercise prescription Progresses with time and patient readiness
	6.1 Demonstration of the behaviour	Exercise instructions 7 video
Goals and Planning	1.1 Goal setting	Goal of completing exercises five days of the week
	1.2 Problem solving	Finding it tough to manage your health? Remember why you want to manage your health – for (motivation)

Note. CRD = Chronic respiratory disease

4.4.5 Optional web-based application for mPR V1 (mPR-app)

Participants were given the option of accessing an additional web-based application (mPR-app) which complemented the SMS. The mPR-app reinforced the same exercise prescription with instructional videos demonstrating correct technique for each exercise. It also included assessment: an exercise test (1-minute site to stand) and a symptom scale (CAT questionnaire), which participants were encouraged to complete fortnightly for feedback on their progress. Further features of the mPR-app are described in Table 19.

Table 19

Description of components included in mPR-app

mPR-app Component	Description
Exercise prescription and videos	Tailored exercise prescription (corresponding to SMS). Exercise videos demonstrating exercise technique.
1 minute sit to stand test	Instructions, timer, and ability to input number of repetitions completed. Reminder to complete every two weeks
CAT questionnaire	Questionnaire that could be completed in the app with reminder to complete every 2 weeks.
Action Plan	The standard action plan for respiratory disease exacerbations that could be completed in the app by the participant
Lung model visualisation video	An educational tool to demonstrate to participants how their lungs work and changes that may have occurred related to the structure, to provide a visually appealing and accurate representation of the lungs.
Relaxation and audio files	Freely available audio for participant to listen to and assist with relaxation.
Information for family	Brief information on how to support your loved one with the CRD.

Note. CAT = COPD assessment test, SMS = short messaging service, CRD = Chronic respiratory disease

4.4.6 Incorporating Te Whare Tapa Wha

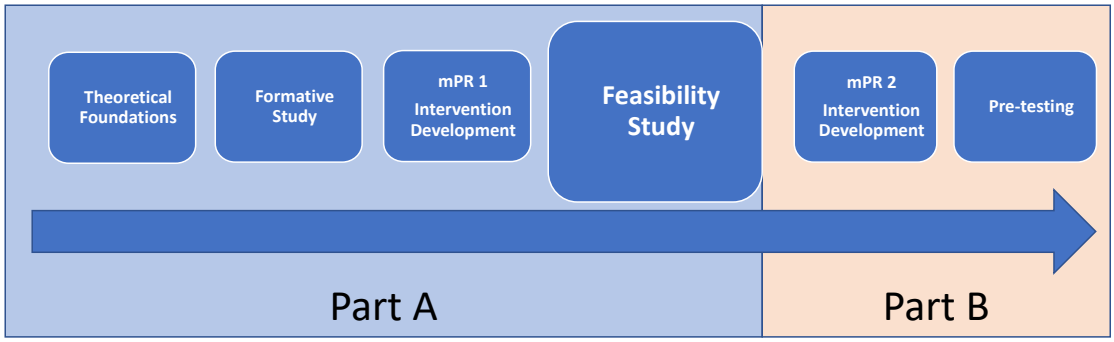
The foundations of the Whare were considered in the intervention design and content. Taha Tinana (physical wellbeing) was enhanced through providing instruction and support to become more active and encouraging healthy lifestyle habits, including exercise, nutrition, smoking cessation, and optimal medical adherence. Taha Wairua (spirituality) was supported through relaxation modules to guide and encourage mindfulness and spirituality. Family members were invited to participate in the programme to learn more about the CRD and to support the participant (taha

whānau), and taha hinegaro (mental health) was supported through content related to enhancing mental well-being in the core module, mana enhancing language and links to mental health services/support. In addition, text messages can be viewed anytime, anywhere, even multiple times, allowing patients to receive the information at the right time. The timing aligns with Tana Whare and feeling grounded to take on new information to learn and support wellness.

The first iteration of mPR was developed using a triangulation of methods. By weaving together, the findings from earlier chapters with theoretical underpinnings and end-user perspectives, we created an mHealth PR programme incorporating SMS and a mobile application. The final step in Part A of the development of mPR involved testing mPR V1 in a feasibility study.

Figure 12

mPR Development Framework; highlighting the feasibility study phase



Note. Figure adapted from mHealth Development and Evaluation Framework (Whittaker et al., 2012)

4.5 Feasibility testing

The fourth step in the development process involved taking the first mPR prototype to patients and their whānau to explore if the intervention met the needs and preferences of end-users and if the intervention was fit for purpose. An overview of the study can be found below, the full manuscript can be seen in the appendix N and is summarised below.

The candidate contributed to the study design, study procedures, data analysis and interpretation, and manuscript preparation. She led the data collection.

Aims

The feasibility study aimed to assess the feasibility, acceptability, and usability of the mPR V1 to inform further development of the intervention.

Methods

A nine-week, non-randomised pilot study was undertaken at two hospital outpatient departments in Auckland, NZ. The study included participants over the age of 16 years who had been diagnosed with a CRD and were eligible for PR. Potential participants were required to be able to read English and have access to a mobile phone. The patient's family members could also register. Participants provided written informed consent, and the study received ethical approval from Health and Disability Ethics Committee (19/NTA/74) and was registered with the Australian and New Zealand Clinical Trials Registry (ACTRN12619000884101).

Participants completed an initial centre-based PR assessment and received exercise, education and behaviour change strategies delivered through a text messaging programme (as described earlier pages 93-97). Additionally, participants had the option of accessing the mPR V1-app. At the end of the intervention, a follow-up assessment and semi-structured interview were completed.

Results

The study included 26 participants and four whānau members. The mean age of participants were 70 years and included 4/30 (15%) Māori, 17/30 (65%) European, and 5/26 (19%) other ethnicities. 20/26 (77%) were currently or had attended centre-based PR, and 6/26 (23%) had never attended PR.

Six participants were lost to follow-up, and 20/26 (77%) completed a follow-up assessment, of which (55%) of those followed up had opted for SMS only (n=11) and 45% (n=9) for SMS + mPR-app. All 20 participants reported they would recommend the programme to other people with a CRD, with 95% stating they felt supported with their lung condition and 85% feeling they had learnt about their lung condition. When asked which components they liked the best, common themes included: it was motivational and empowering (40%, n=8) and provided reminders and prompts (40%, n=8). When asked about the components they liked the least, answers included:

exercises were too hard or progressed too quickly (25%, n=5), and messages were not personal enough (20%, n=4) and a lack of feedback in the programme (5%, n=1). Of the participants included in the study, exercise stratification was level 1 (12%), level 2 (77%) and level 3 (12%).

At registration, 69% (n=18) participants opted for the mPR-app, and 42% (n=11) accessed the mPR-app (completed app registration and logged in), with one participant only accessing the mPR-app on the day they logged in. In the follow-up interview, of those participants who had not accessed the app were asked their reasons, with two stating they had forgotten to do this, three reporting they needed help downloading the app, one participant believing the app did not add anything above the SMS, and one needing help to log into the app. Four participants felt they needed more information on how to use the app.

Implications

The feasibility study provided valuable information on the strength of mPR V1 programme and how it could be improved. The number of participants who opted for SMS only was higher than anticipated (42%, n=11) and this showed the importance of providing an SMS option. Importantly, feedback suggested that the information for this group could be enhanced with a paper manual to provide information that would support and enhance their participation.

The participants' feedback on the exercise component, and the most common exercise commencement level, indicated the stratification banding needed further development to ensure appropriate and tailored exercise prescription.

Many participants did not access or engage with the mPR-app as hoped. One of the findings of the feasibility study was that the registration process was complicated and arduous, indicating that the registration process should be simplified, along with more information on how to use the mPR-app to maximise engagement.

Synthesis of findings

A summary of the key learnings from Part A can be seen in Table 20. Part B of this Chapter refers to the development and evaluation of mPR V2.

Table 20

Summary of key changes from pretesting and feasibility studies

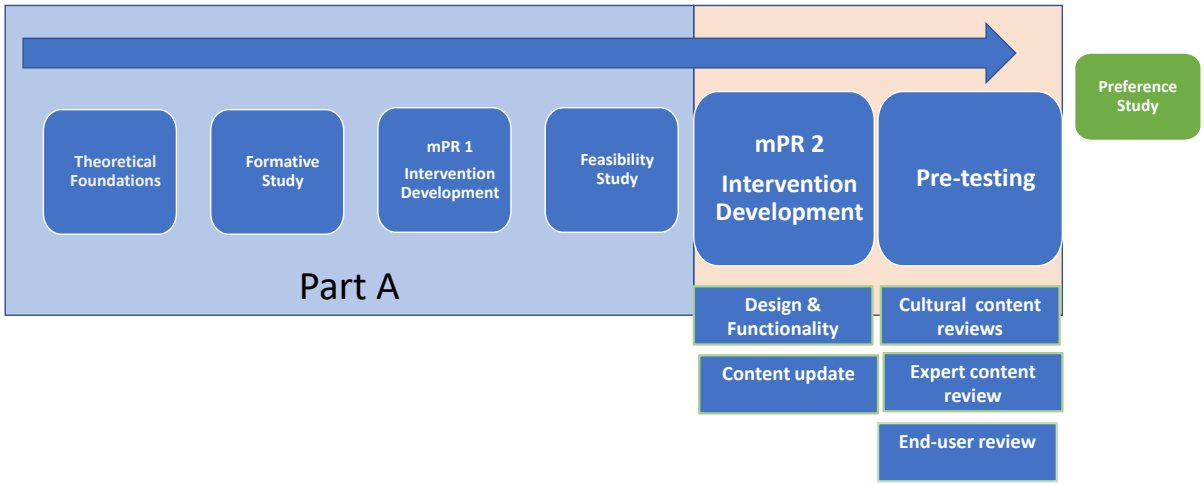
Component	Key Recommendations
Sign in process	Simple Completed by team at initial visit.
Technology	Ensure suitability for use across different device modalities (e.g., laptop computers)
Exercise	Videos to include patient diversity Visibility of exercise completion Increased stratification to four exercise levels Provide alternative exercises where necessary
Education	Provide tips and tools page on app Ensure key topics covered by text, short video content and links to further information pages
Option to pause	Enable a programme pause for 7 days if required
Contact us page	Allow contact with PR clinician
Feedback	Initiate Myprogress page for participant feedback Provide feedback on number of days exercise completed and step count data.

PART B mPR V2 Development and evaluation

Part B of this chapter includes the development and pre-testing of mPR V2, see Figure 13.

Figure 13

mPR Development Framework; highlighting the steps involved in Part B



Note. Figure adapted from mHealth Development and Evaluation Framework (Whittaker et al., 2012)

4.6 mPR V2

The fifth step in the mPR development framework involved refining the mPR V1 intervention to develop the mPR V2 intervention. The feasibility study described above (Whittaker et al 2021) provided valuable information to enable iterative improvements for the mPR V2. The fundamental changes incorporated feedback from participants, whanau and the mPR team. Whilst the SMS remained an essential component of mPR V2, the majority of changes occurred in the mPR-app.

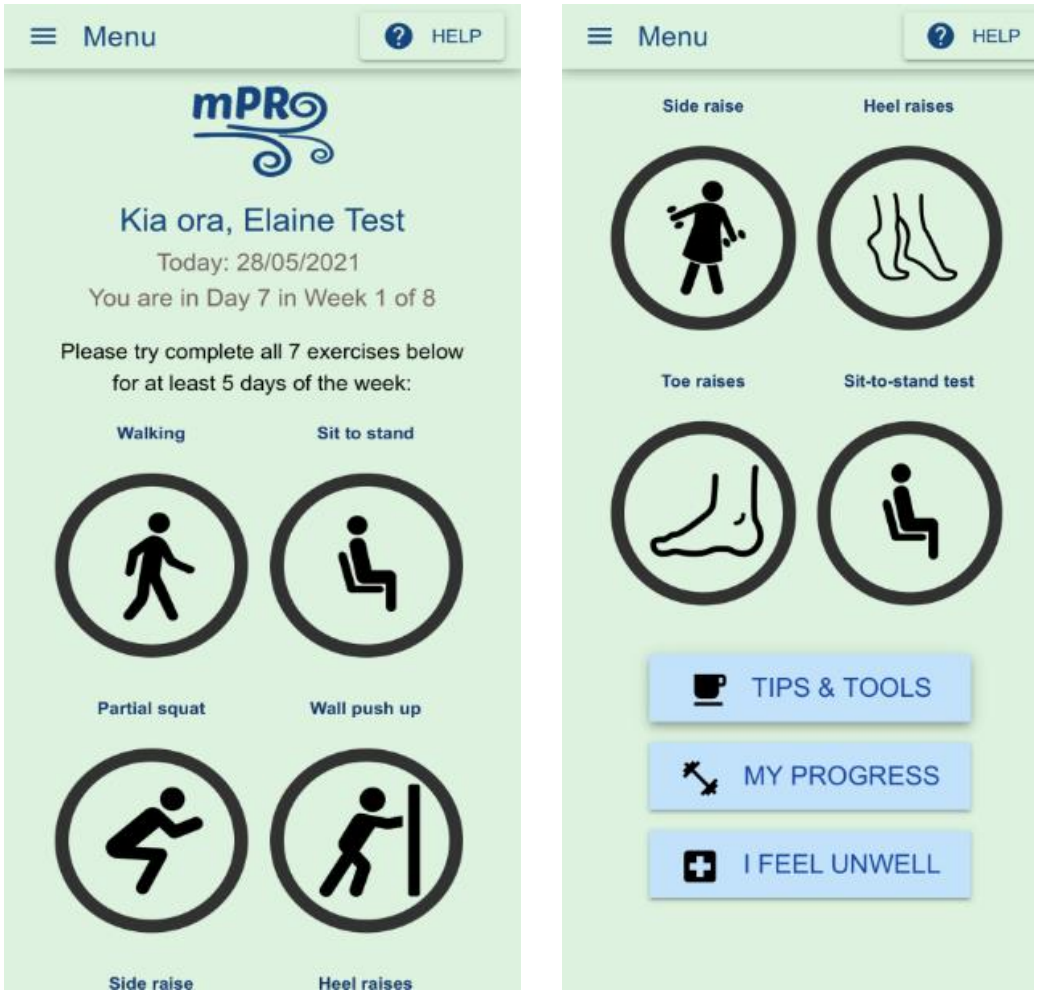
4.5.1 Design and Functionality

The design and functionality of the mPR V2 underwent several changes to improve usability. The sign-in process was simplified to allow the research team to sign participants onto the app at the initial assessment to overcome the technical challenges experienced in the initial feasibility study, the mPR-app became integrated with SMS, linking data and providing participants with feedback as requested by participants in the formative and feasibility studies.

A new design of the mPR V2 front page was designed to place the required exercise prescription overtly upfront in the app. Based on findings from the feasibility study (see Table 20), the new front page also included additional features, including a 'tips and tools' page, a 'my progress' , and an' I feel unwell' page. The front-page wireframe for mPR V2can be seen in Figure 14.

Figure 14

mPR front-page wireframe



The 'Tips and Tools' page

A comprehensive education package was added to the mPR-app to include 11 'Tips and Tools' modules for informing participants on managing their condition. These modules were developed based on topics delivered in centre-based programmes and following recommendations from PR guidelines (Blackstock & Evans, 2019). Tips and tools were developed to complement and expand on the education delivered through SMS. The topics covered can be seen in Figure 15.

Figure 15

'Tips and Tools' Modules

1. How do I get started with exercise?
2. What can I do when I feel breathless?
3. How can I stop running out of energy?
4. How can I become more active?
5. What can I do to keep myself well?
6. What is self-care?
7. How can I get a good night's sleep?
8. What are the best foods to be eating?
9. How can I clear the extra phlegm?
10. Better Bladder and bowels
11. How can I give up smoking?

Within the tips and tools page of the mPR V2 the information was provided in various formats including written text, a short video clip, and links to websites to allow participants to seek additional information.

The 'My Progress' page

The formative and feasibility studies reported that patients wanted feedback on their progress. The 'My progress' page was added to show the number of exercises participants had completed each week. All participants were offered the option of a commercially available sensor (Fitbit or Withing) which could be linked to the mPR V2 and provide feedback on their daily step count. The step count data is presented in graphical format within the mPR V2 in two ways, daily step count and average weekly step count.

The 'I feel unwell' page

If participants became unwell during the programme or needed to take a break for other reasons, they were able to 'pause' the programme for 7 days. A drop-down menu provided information on how to contact the team if required.

4.5.2 Content Updates

Exercise modifications

Several modifications were made to the exercise programme based on feedback from the feasibility trial (Whittaker et al., 2021). The exercise level stratification system was reviewed and modified to include four levels instead of three (see Table 21), allowing for a more tailored exercise prescription.

Table 21

Amended Exercise Stratification System

Exercise Level	6MWT distance	mMRC	Balance
1 (least challenging)	< 200m	4	Uses walking aid
2	200 – 350	3	No walking aid
3	350 -500	2	No walking aid
4 (most challenging)	>500	1	No walking aid

Note. 6MWT = six-minute walk test, mMRC = modified medical research council scale, m = metre

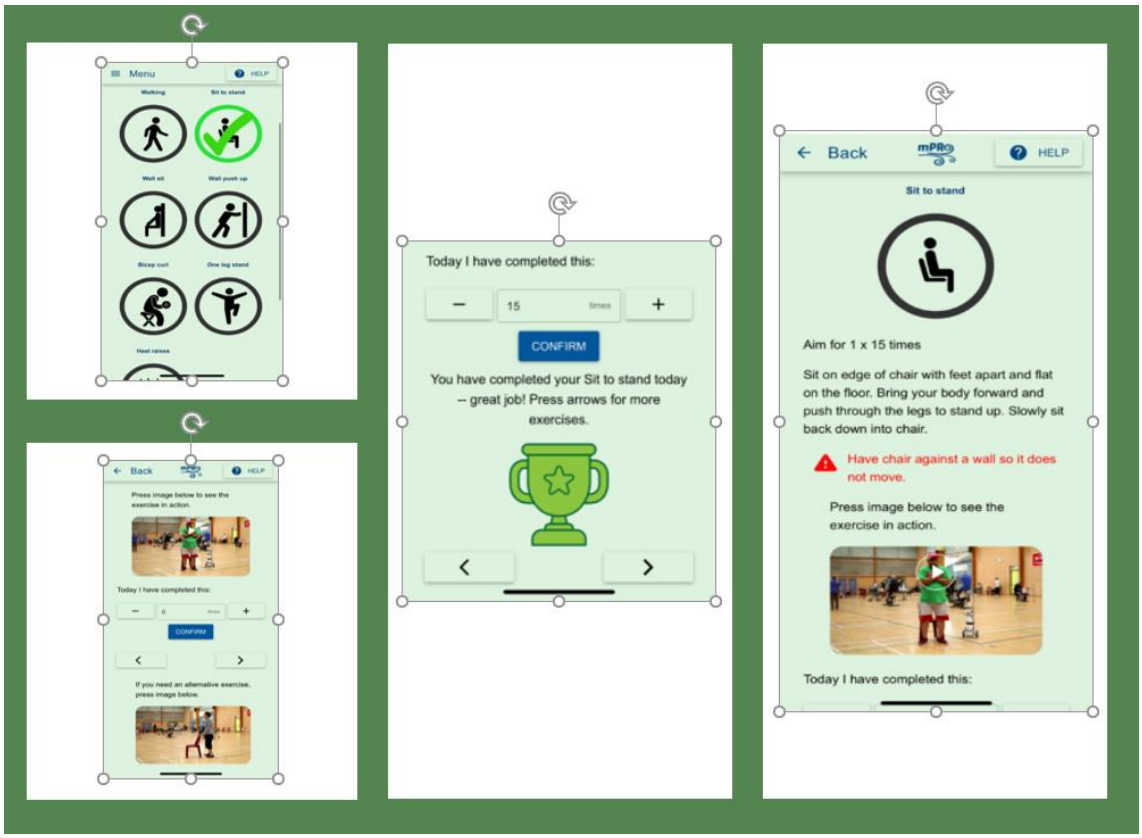
Other changes to exercise programme included

1. Alternative exercise options were provided with video instructions
2. Improved exercise instructions
3. Safety alert provided for each exercise
4. Diversity in exercise videos incorporated (age, ethnicity, and disease severity)

Additionally, the exercise page was modified to see which exercises had been completed on that day to enable patients to see what required completion. An example of the exercise page wireframes can be seen in Figure 16.

Figure 16

Exercise wireframes from mPR

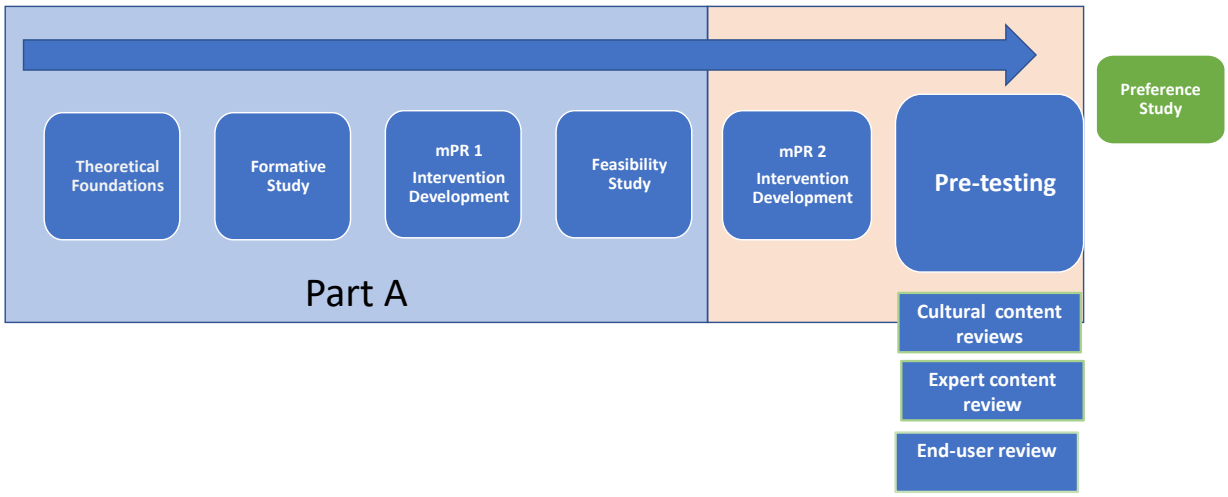


4.6 Pre-testing mPR V2

The final step in the development process of mPR V2 involved pre-testing of the intervention prior to evaluation in a clinical trial. This testing phase involved a review of the content by clinical experts, cultural experts, and consumers as shown in Figure 17.

Figure 17

mPR Development Framework; highlighting the steps undertaken to pre-test mPR



Note. Figure adapted from mHealth Development and Evaluation Framework (Whittaker et al., 2012)

4.6.1 Expert Content Review

Aims

The purpose of the content review was to ensure that the SMS messages and information contained within the mPR V2 were clinically and factually correct.

Methods

The content of mPR V2 was reviewed by a range of clinical experts, including a dietician, occupational therapist, health psychologist, respiratory nurse practitioner, and physiotherapist. The clinical experts were asked to review the mPR V2 content including text messages, the mPR-app and the mPR paper manual. The following key questions guided the review.

1. Is the information factually correct?
2. Is anything is missing from the information provided?
3. Any recommended changes?

Implications

Clinician feedback was collated by the candidate, and minor amendments were made to the relevant content of the SMS and tips and tools.

4.6.2 Cultural Content Review

Aims

To ensure the mPR programme was culturally appropriate.

Methods

Mixes of virtual and in-person semi-structured interviews were conducted with Māori living with a CRD (tangata whaiora) and their wider whānau support members. Participants were recruited through local community networks and were invited to participate in the interviews. All participants provided written informed consent prior to the interview. The interviews and analysis were completed by a member of the collaborative research team (TT) who was experienced in Kaupapa Māori methodology (Jackson, 2015).

During the interviews, the participants reviewed mPR content including text messages, the mPR V2 and the mPR paper manual. The following key questions guided the interview.

1. What do you think about the look and feel of the mPR-app?
2. Is a Te Reo version of the app and SMS programme a “must-have” for a programme delivering support for Māori?
3. Do you have any further feedback or comments on the mPR content?

The data were analysed and grouped into themes. The key findings were reviewed for accuracy by two participants.

Results

Participants (n=8) felt the programme did not need to be fully provided in Te Reo but rather include greetings and mana enhancing (strength based) words in mPR V2 (which is primarily in the English language). It was considered that this would not only improve responsiveness for Māori participants but also a sense of belonging. Participants expressed the importance of diversity in the people demonstrating the exercises and including Māori participants in the mPR V2 videos would ensure cultural

relatability. The participants also expressed value in including the wider whānau in doing home-based exercises. A summary of the recommendations and the rationale for these suggestions can be seen in Table 22.

Table 22

Summary of recommendations from tangata whenua

Component	Recommendation	Rationale
mPR app General	More use of Te Reo within current version	More whānau Māori are learning Te Reo so this may improve responsiveness
	Mana enhancing language	Provides a positive and encouraging experience for whanau
	Include more information, resources and decision support based on real-time symptomology	Provides personalised advice to the user based on their symptoms
Action plan	Include Māori representation in people demonstrating exercises in videos	Better cultural representation may improve responsiveness
Exercise video page	Include exercises at home in everyday environments, using at-home equipment	More realistic representation of at-home exercises
Breathing and relaxing	Include audio/visual clips centre around Te Ao Māori views of wellbeing	Acknowledges the interconnectedness of te taha wairua (spirituality), hinengaro (mental health) and tinana (physical health) on overall wellbeing
	Include Te Ao Māori concepts and natural sounds (i.e. water forests and birds)	Improves responsiveness by acknowledging the interconnectedness Māori have with the whenua (land), moana (oceans), awa (rivers) and ngahere (forest).
	Include information that can display what may happen if an individual hits a particular target (I.e., health benefits)	Rewards based system may better motivate individuals to adhere to their exercise prescription
Progress page	Include smoking cessation in' tips and tools' module	Recognises the impact of smoking can have on health. Creates opportunities for smoking cessation by provide information and resources
Resource page	Provide easy to view summary for whānau members progress on the programme	Gives the whānau member visibility over progress
Whānau support page	Mana enhancing encouragement. Acknowledge the longevity of caring for someone with a chronic illness	Provides positive encouragement to whānau members

Implications

Modifications were made based on this feedback to ensure cultural safety and to enhance a sense of belonging for Māori participants. Models of different age, disease severity and ethnicity were included in the exercise videos. Further Te Reo words were included in mPR V2 along with a relaxation session utilising Te Ao Māori concepts and natural sounds. One concept which was not incorporated due to time and logistical constraints was the addition of patient stories. It was agreed this would be beneficial and will be explored for future iterations.

4.6.3 End-user review

The purpose of end-user testing was to identify any areas of confusion or ambiguity for participants and to identify opportunities to improve the end user's experience.

Aim

To investigate the usability of mPR V2 through observation and investigation of end-user behaviour.

Study Questions

1. Can end-users navigate the mPR V2 appropriately?
2. Are there any barriers to use or areas of confusion?
3. Do end-users encounter any usability issues?

Methods

The study used a mixed method, observational study design. Ethics was approved by amendment to HDEC number 19/NTZ/74/AM04 on 12 January 2021. Participants attending PR at Counties Manukau Health (CMH) were invited to participate, and written informed consent gained.

The study used three methods of data collection.

Think aloud

The participants were invited to interact with the mPR V2 and to verbalise their thoughts and impressions on working through the app (Charters, 2003). Participants

were instructed to look through all mPR V2 with some prompts from the investigator as required to illicit comments regarding usability.

Tasks

Participants were given several tasks, such as inputting the number of repetitions completed, pausing the exercise prescription, finding alternative exercises, watching a 'Tips and Tools' video, and completing the exercise question at the end of a sample week.

Semi-structured interviews

After the participants had explored the app, the investigator interviewed the individual participant following a semi-structured interview guide, with prompts elicited from the observation. The interviews were audio recorded and transcribed verbatim by SC.

Results

Five male participants were included in the study, with a mean age of 68 (56 -83 years). Participants were given the option of a device to view the mPR-app; three participants chose an iPad, and two a laptop. All participants used a device regularly and were familiar with apps. A summary of data collected can be found in Appendix O.

General feedback

All participants asked if they could have the mPR V2 after testing in the belief it would be beneficial. One participant reported that he would like to show his family so they could understand more about his health condition.

> "I think the layout is clear and very simple"

> "Good for People who are not tech savvy."

Implications:

All participants (n=5) interviewed provided positive feedback regarding the mPR V2 and felt it was easy to navigate. They all mentioned they would use it if it was available, and two participants mentioned it would be more convenient than travelling to a centre-based programme for PR.

In this round of usability testing, the logging-on process was not assessed. All participants reported that the mPR-app was generally easy to navigate and was clear and straightforward. Three components received navigation feedback: the arrows to the next exercise, returning to the home page after clicking on a link and the menu section. Two participants reported it would be beneficial to have the other page headings on the menu bar (tips and tools, my progress, and I feel unwell).

No barriers to using the app were identified. Participants reported feedback on preference and ease of reading regarding colour choice and font size, which would be helpful feedback for future iterations.

4.7 Synthesis and next steps

This chapter has outlined the process taken to develop the content for mPR V2 using an adapted version of the mHealth development and evaluation framework. Both mPR V1 and mPR V2 were founded on theoretical underpinnings and grounded in evidence-based practice.

Chapter 5 Protocol for a preference clinical trial of centre-based and mPR delivered rehabilitation in chronic respiratory disease

5.1 Prelude to the chapter

The aim of this chapter is to describe the study protocol for a preference-based study to evaluate the mPR V2 programme.

This chapter involves the preparation required to address objective 4 of the thesis

> *Identify patient preference for delivery of PR and to ascertain if allowing participants to choose their delivery method may improve the rate of attendance at PR.*

5.1.1 Why was this work needed?

Protocols are an important part of research planning and outline the rationale for the any given study, along with a clear description of the methodology, outcomes and data analysis to be undertaken during the study. Additionally, protocols ensure the analysis and results remain consistent with the proposal.

5.1.2 What was undertaken

The study protocol, along with all preparatory processes were undertaken. This involved the protocol preparation, ethical approval, trial registration and training of research team. Part way through the trial the NZ experienced a national lockdown in response to COVID-19 pandemic. This resulted in several unavoidable protocol amendments which are also described in this chapter.

5.1.3 Supporting Documents

Supporting documents for this chapter can be found in the Appendices and include a copy of the data management plan, ethical approval letters, participant information sheet and consent form, data collections forms and a copy of training manual provided to the research team.

5.2 Introduction

Alternative methods of delivering rehabilitation, such as mHealth, may be able to increase the reach of PR and allow more people the opportunity to access this intervention. A recent Cochrane review has reported telerehabilitation is likely to be as effective and safe as centre-based PR (Cox, McDonald, Hill, et al., 2018), however, the scoping review in Chapter 3 has shown studies have found recruitment challenging, with large numbers of screened patients being excluded or declining participation. The scoping review also revealed people living with a CRD believe telerehabilitation would be convenient and reduce the burden of attending a centre-based programme but perceive telerehabilitation to be technically challenging and lacking personal contact. To date, little is known about the patient preference for delivery of PR when compared with centre-based, and who would be best suited to delivery models. We have developed a web-based application for PR developed specifically for the NZ context, mPR V2 - herein referred to as mPR - which is designed to be delivered on a mobile phone, with no costs involved, and requires minimal digital skill.

It is likely that some people would rather attend the in-person group and some would rather receive an mHealth programme. Previous studies have shown patient preference a barrier to recruiting to telerehabilitation trials (Cox, McDonald, Alison, et al., 2018; Hansen et al., 2020; Holland et al., 2017). There are participants who may not physically be able to attend in-person (due to transport, work, or illness) and if randomised to this arm they would be unlikely to attend or complete, affecting the results. The fact that people have preferences mean that if they are randomised to the intervention they did not want, they may be less satisfied and less likely to complete.

We are interested in a pragmatic approach to exploring mPRand envisage that if this preference based trial is successful, mPR could be offered to people in this way and as an alternative to existing standard PR programmes. Therefore, information on patient preferences (how many choose which version) is important information for funders and service developers prior to deciding to implement mPR. To determine this, the study will utilise patient preference methodology. According to Kowalski three criteria to be met for a preference based trial are as follows (Kowalski & Mrdjenovich, 2013);

1. Two programmes are to be compared
2. Blinding is difficult or impossible
3. At least some people are likely to have preference to which programme they receive

The importance of patient preference when translating interventions into real practise drove the choice of methodology.

5.3 Study Objective

This study aims to assess the attendance and completion of PR when patients are given the choice of two different delivery models, mPR or centre-based PR. Additionally; we wish to determine if the mPR programme is able to achieve improvements in clinical outcomes which are not inferior to those achieved with centre-based PR.

Specific study objectives are to investigate the following when participants are given a choice of attending centre-based or receiving mPR:

1. Patient preference for different model of PR delivery
2. The attendance and completion rates of both models of PR
3. Whether mPR achieve improvements in exercise capacity which are not inferior to centre-based PR
4. Whether mPR achieve improvements in health-related quality of life which are not inferior to centre-based PR
5. Patient satisfaction from both delivery models of PR
6. Participant feedback on PR delivered via mPR

5.4 Methods

5.4.1 Study Design

A parallel non-randomised preference trial. Following consent, participants can opt to receive either centre-based PR or mPR delivered PR.

5.4.2 Participants

All participants referred to PR at three metropolitan hospitals in Auckland will be screened for inclusion and invited to participate.

Inclusion criteria

1. Aged 18 years or older
2. Have a CRD e.g., COPD
3. Eligible for PR (according to the recruitment site's existing protocols)
4. Able to read and understand English
5. Able to provide informed consent
6. Own or have regular access to a mobile phone (mPR group only)

Exclusion criteria

1. Not available for the duration of the study
2. Completed PR within previous year

Withdrawal criteria

Participants can withdraw from either arm of the intervention at any time. Their decision to withdraw will not affect their usual care. Participants can stop the mPR programme and any of its components at any time by free texting back STOP to the mPR short code, uninstalling the app and/or ceasing wearing the sensor. As their feedback and the reason for wanting to stop the programme is vital to our understanding of completion of PR, these participants will still be contacted and asked if they would be willing to complete a follow up assessment and interview.

Participants from either group who decline to complete the follow up assessment will be included as lost to follow up and their data will be included in the analysis of the group to which they were allocated. Clinicians will be able to stop the programme on behalf of participants if deemed clinically inappropriate. If a participant in the mPR group wishes to attend a centre-based programme, they will be given the opportunity to attend on completion of their mPR component of the study.

5.4.3 Sample size calculation

To determine the required sample size, a two-sample proportion test for non-inferiority was completed based on a completion rate of 60% for the centre-based PR

with a non-inferiority margin of 30% at 80% statistical power. The non-inferiority null hypothesis in terms of Odds ratio was: Odds of completion in centre-based PR/Odds of completion in mPR ≥ 3.5 (equivalent to Cohens'd=0.5). Fifty participants are required in the smallest group to detect a difference in attendance between groups.

5.4.4 Procedures

Recruitment

Recruitment will be conducted through three collaborating metropolitan hospitals PR services in Auckland, NZ (Counties Manukau Health, Waitemata and Northshore).

Potential eligible participants will be identified by senior PR physiotherapist at one of the recruitment sites. They will be given a Patient Information Sheet (PIS) and Consent Form (CF), see Appendix R. The senior PR physiotherapist will discuss the programme with the participant and answer any questions they may have. The participant will have the option of contacting a member of the project team to answer any further questions. Participants will be encouraged to discuss their participation with whānau, family, and friends. If the potential participant indicates that they would like to take part in the study the clinician will confirm eligibility and obtain informed consent.

Recruiting physiotherapists will keep note of the number of potential participants who decline to participate in the study. Recruitment will be monitored by (SC) on a regular basis to ensure that the recruitment process is effective and that recruitment targets will be met within timelines where possible.

Pulmonary Rehabilitation Intervention

All participants in both groups will attend a standard centre-based assessment at the site where they are recruited as per best practise guidelines (Alison et al., 2017). Both groups will receive an eight-week intervention and then return to the same centre for a follow up assessment.

Group A: Centre-based Group

Participants who opt for the centre-based intervention will attend the centre two days per week for eight weeks. The intervention will include one hour of supervised exercise training in a group setting (8 – 14 participants) delivered by a physiotherapist and respiratory nurse and/or health care assistant. Exercise prescription includes aerobic,

resistance and balance exercises individually prescribed and completed in a circuit programme. Intensity of exercise is prescribed based on the modified BORG scale of breathlessness with all participants encouraged to progress exercise to maintain a breathlessness score of 3 - 4. Participants will be provided with a home-based exercise programme, which they are asked to complete three times per week and record in the provided activity diary. The number of sessions attended, the number of completed exercise circuits at the centre-based site, and the number of exercises completed in the activity diary will be monitored. In addition, participants will be invited to attend a 30-minute group education session with focus on self-management education, which occurs after every exercise session. Participants will be offered the opportunity to make up classes that may have been missed by extending the duration of PR up to 12 weeks if required. The centre-based PR intervention follows standard clinical practise (Alison et al., 2017).

Group B: mPR Group

To qualify for the mPR-app participants must own or have regular access to a mobile device and have regular access to the internet on the device (mobile data or Wi-Fi). Participants who opt for the mPR intervention will receive a technology delivered PR programme with content mapped from standard PR programmes and based on best practise guidelines (Alison et al., 2017). In addition to mPR-app, each participant enrolled in the mPR programme will receive a personally tailored package of text messages over the 8-week period. The programme consists of different modules to allow content to be tailored to individual clinical characteristics, preferences, and demographics. All participants receive a core programme. In addition, if they are a smoker, they receive a smoking cessation module and if they experience retained or excessive respiratory secretions, they receive the secretion clearance module.

The programme includes a core component of individually tailored exercise prescription consisting of aerobic, resistance and balance exercises. Information regarding the safe and effective technique of each exercise will be provided in written and video format. Exercise prescription is based on participants initial assessment scores (6-minute walk test distance and dyspnoea score mMRC) with participants being stratified to four different exercise levels by the recruiting clinician (see Table 21, Chapter 4). Participants are encouraged to work at an intensity equivalent of 3-4 on

the modified BORG scale. Information regarding the BORG scale will be provided in the mPR-app and in a paper manual for participants unable to access the mPR-app. The programme is adaptive to patient's current health state in several ways: offering alternative exercises if a participant is unable to complete the prescribed activity, allowing participants to pause the programme if they are unwell, and allowing participants to determine if they are ready to progress their exercise programme.

Participants can self-monitor their progress in the mPR-app which displays the number of exercises completed each day. The programme has been designed to monitor adherence to exercise by 2-way messaging. Each week on day 7, a message will be sent asking the participant how many times they have completed their exercises that week, and participants are asked to reply with the number.

Where appropriate, participants will be asked if they would like to wear an activity-based sensor for the eight-week period. The mPR-sensor used in this component of the study will be a commercially available Fitbit or Withing smartwatch, which monitors step count. Participants who already use a sensor can integrate the data with their own sensor to the mPR-app. Participants will be asked to wear the mPR-sensor as they wish over the eight-week period and will be shown how to use the accompanying app at registration. Daily step count and weekly average step count data will be displayed on the 'My Progress page' of the mPR-app in those using a sensor. Step count data from the sensor will be accessed at the end of the study as well as data on how the sensor was used and how often.

Participants will be offered an mPR handbook which is paper manual designed to provide additional support on the mPR programme if required. The handbook has two sections, the first describing the mPR programme including pictures and descriptions of the exercises, and the second part provides instructions on how to access and navigate the mPR-app.

The mPR programme has been tested in a feasibility study (Whittaker et al., 2021) which found 85% of participants reporting mPR had an impact on how they managed their condition and helped them to change their behaviours.

5.4.5 Outcome measures

All participants will complete a centre-based baseline and follow-up assessment appointment. The baseline assessment is completed at first visit, prior to commencement of the intervention. The follow-up assessment is completed at end intervention (within two weeks of completion).

Blinding

Due to the nature of the intervention, blinding of participants is not possible. The recruiting physiotherapist will complete the standard PR assessment and an independent physiotherapist will undertake baseline and follow up outcome measures. The following data will be collected:

Demographics and Clinical characteristics

Participant's demographic and clinical information will be collected at baseline assessment (see Appendix T) by the recruiting physiotherapist. The data were collected from subjective assessment and hospital records. The data will be entered into REDCap software.

Primary Outcome

Attendance and completion rates at the different delivery methods of PR will be assessed by the following:

Group A Centre based – percentage of classes attended out of the 16 offered.

Group B mPR – a proxy measure of attendance will be used by asking participants to respond to two text messages per week:

1. *How many times did you complete your exercise programme this week?*

2. *Are you ready to progress your exercise programme?*

The percentage of responses out of the total 16 text messages will be considered their rate of attendance for the mPR group. An a priori definition of pulmonary rehabilitation completion will be attending a minimum of 70% of the sessions (Williams et al., 2014).

Intervention preference

Patient preference will be assessed by their choice of intervention at recruitment.

Secondary Outcomes

The following outcome measures will be completed by the blinded physiotherapist at baseline (exercise capacity, symptom score, HRQoL, dyspnoea and activity levels) and at follow up (exercise capacity, symptom score, HRQoL, dyspnoea, activity levels, adherence and satisfaction), see Figure 17 and 18.

Exercise Capacity

Exercise capacity will be measured by change in distance walked on 6-min walk test (6WMT) and one minute sit to stand (1-min STS) scores from baseline to follow up (end intervention). The 6MWT has been found to be a valid and reliable measure of exercise capacity if two tests are conducted to allow for learning effect (Holland et al., 2014). The 6MWT has been shown to be responsive to change following PR for people living with a chronic respiratory condition (Holland et al., 2014). Two tests will be completed at the baseline assessment.

The 1-min STS has been shown to be valid and reliable measure of exercise capacity in people with COPD (Crook et al., 2017). The test has also been found to be responsive to change following PR with a minimal important clinical difference found to be 3 repetitions (Crook et al., 2017).

Symptom Score

Changes in participant's symptoms will be monitored by the COPD assessment test (CAT) tool at baseline and follow up. The CAT tool is valid and reliable assessment tool for health status in people with chronic respiratory conditions (Tsiligianni et al., 2012) (Lee & Elkin, 2012; Suzuki et al., 2019). Permission to use the CAT in this study was received from Mapi Research Trusts (MRT).

Health related quality of life

Participant's health related quality of life (HRQoL) will be assessed with the EQ-5D tool at baseline and follow up. Permission to use the EQ-5D was received from EuroQol (#41477), for this study. The EQ-5D has been shown to be a valid and reliable measure of HRQoL in people living with CRD (Bae et al., 2020)and has shown to have moderate

to strong correlation with disease specific measures of HRQoL in COPD (Nolan et al., 2016; Pickard et al., 2007). The EQ-5D has been shown to be responsive to PR (Nolan et al., 2016), with a minimal important clinical difference in the VAS shown to be 7.0 (Nolan et al., 2016).

Dyspnoea

Participants dyspnoea will be measured using the modified medical research council scale (mMRC) (Bestall et al., 1999).

Physical Activity

Participant's level of physical inactivity will be indirectly measured with the sedentary behaviour questionnaire (SBQ). The SBQ is designed to assess the amount of time spent in nine different sitting behaviours and examines a weekday and weekend day. This self-reported measure of sedentary behaviour has been shown to be a valid and reliable measure of sedentary behaviour in adults (Rosenberg et al., 2010).

Participant satisfaction

All participants will be asked to complete a survey on their satisfaction with PR at the end of the intervention (see Appendix T). Participants can complete the survey in paper or electronic format. Both versions will be requested to be completed at the time of the follow up assessment. The satisfaction survey data will be de-identified.

Follow up interview

A purposefully selected sample of participants will be invited to complete a follow up interview. To ensure diversity of participants a sampling frame has been drawn up and can be seen in Appendix Z. Participants will be invited to participate in this follow-up interview at the follow-up assessment. The interviews will follow a semi-structured format (see Appendix AA). Participants will be asked about their experiences and opinions of the mPR programme. All interviews will be completed by the principal investigator (SC), who will be involved with recruitment to the study but not delivering the intervention. Interviews will be conducted at the participants PR site or remotely via telephone or videoconferencing. The interview will take approximately 30 – 45 minutes to complete. The follow up interviews will be audio recorded and transcribed verbatim. All potentially identifiable information will be redacted from the transcript.

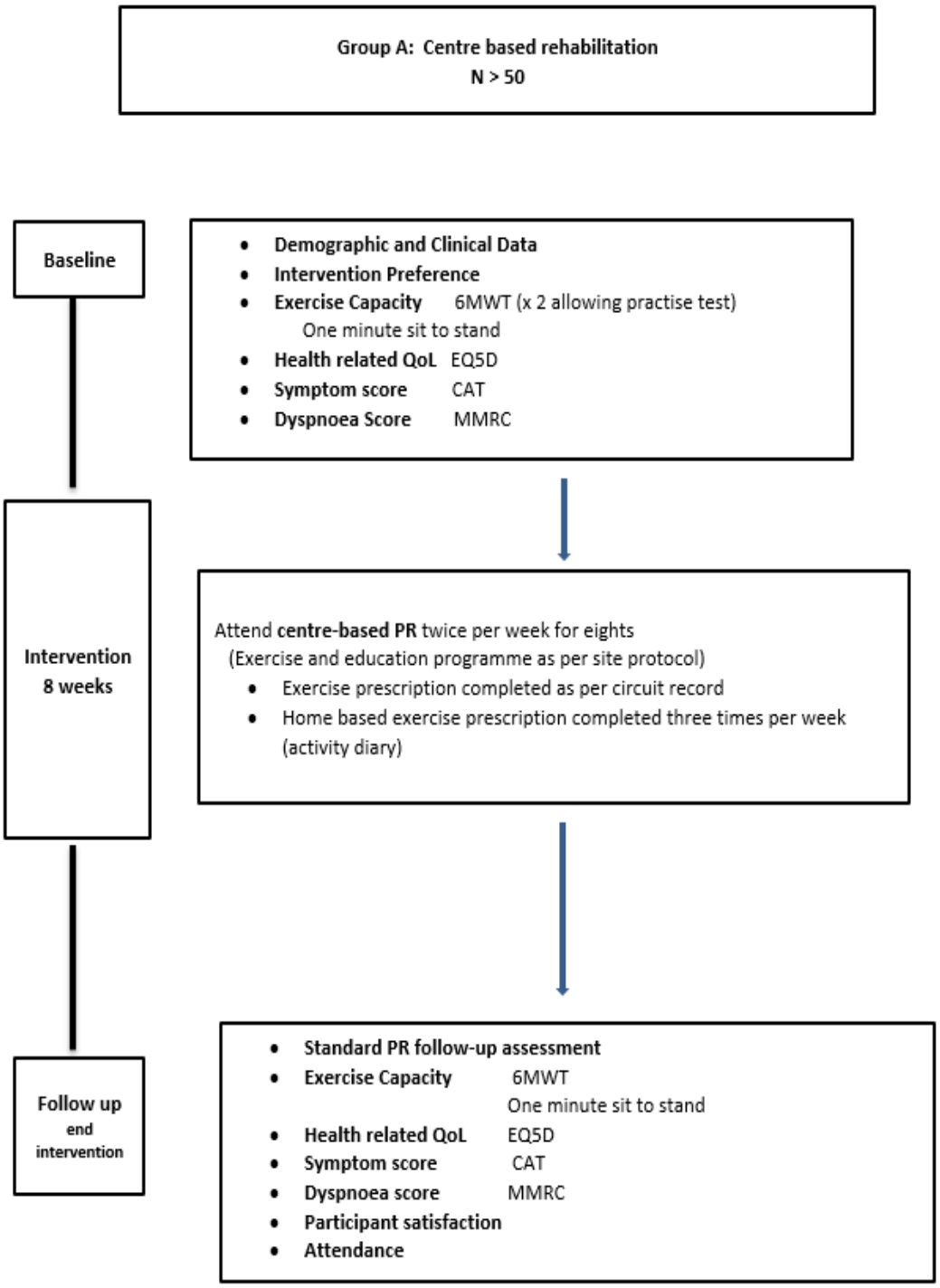
Following completion of re-assessment all participants will be offered a koha (gift) as appreciation of their time.

Study Flow Diagrams

The participant flow through the study is shown in Figure 18 for centre-based participants and Figure 19 for mPR participants.

Figure 18

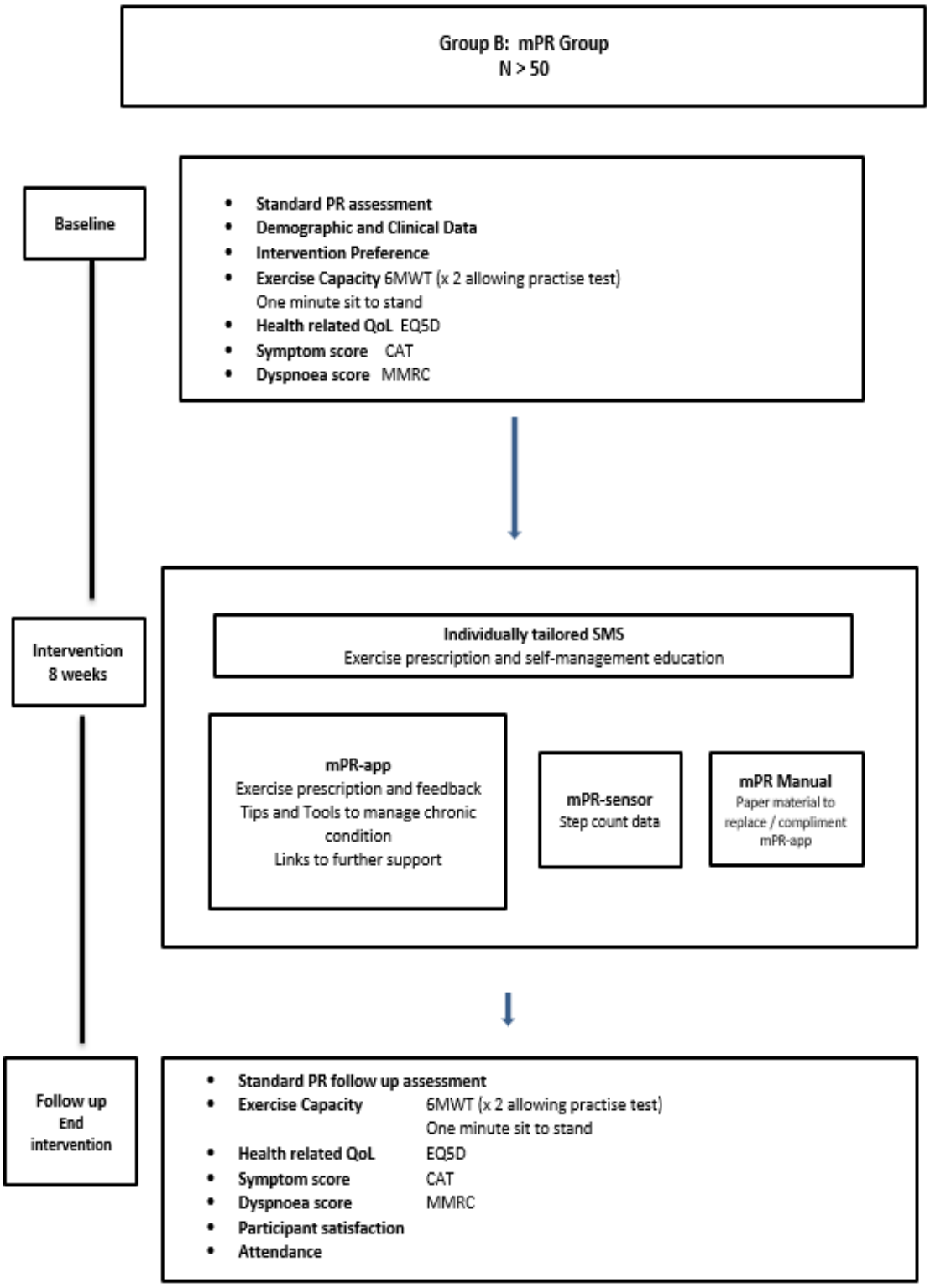
Centre-based participants flow through the preference-based PR study



Note. 6MWT = six-minute walk test, EQ5D = EuroQol, CAT = COPD assessment test, mMRC = modified medical research council.

Figure 19

mPR participants flow through the study preference-based PR study



Note. 6MWT = six-minute walk test, EQ5D = EuroQol, CAT = COPD assessment test, mMRC = modified medical research council.

Data analysis

Quantitative data analysis

All quantitative data will be entered into REDCap electronic data capture tools hosted by University of Auckland (Harris et al., 2009) and downloaded to IBM SPSS Statistics (Version 26) for data analysis. An intention to treat analysis will be conducted and p-values of <0.5 considered significant. Patient preference will be calculated as percentages. Demographic and clinical characteristics will be reported with simple descriptive statistics and between-group comparisons will be analysed with independent sample t-tests and chi-square tests. Attendance data will be calculated as percentage and attendance at >70% sessions considered as completion of the intervention. Logistic regression will be used to determine the odds of completing each intervention and a multiple logistic regression to identify any predictors of completion.

The secondary outcome measures will be analysed using analysis of co-variance to determine any between group differences.

Qualitative data analysis

Interview transcripts will be transcribed verbatim using NVivo qualitative data transcription software, QSR International Pty Ltd (2020). The transcripts will be checked for accuracy and any identifiable data removed. The qualitative data will be analysed using thematic analysis. The transcripts will be read and undergo familiarisation before coding of data. Themes will be derived from the coded data. Quotes will be used to substantiate themes.

5.4.6 Ethics and Trial registrations

Ethical approval has been received from Health and Disability Ethics committee (21/NTB/54) and Auckland University of Technology Ethics Committee (AUTEC) 21/113. The trial is registered with Australian and New Zealand clinical trial registry (ACTRN12621000365864p). The study received locality approval at Counties Manukau Health (1396) and Waitematā District Health Board (RM14968).

5.4.7 Safety and adverse events

If an adverse event (AE) was to occur onsite or is reported, the researcher will record the AE on the adverse events form and a meeting of the project management team

will be called to discuss the AE. The outcome of this meeting will be a) minor AE – monitor with subsequent participants b) major AE – halt data collection until modifications have been made, or c) serious AE – halt data collection and investigate AE, inform HDEC.

5.4.8 Ownership of data

Individual study data will remain the property of individual participants. AUT University has the responsibility for storage, protection, and retrieval of study data. Data will be stored securely on a password protected data stick within a locked cabinet, located in a locked office at Middlemore Hospital until all data collection is completed and then stored at AUT University North Campus for 10 years, accessible only to the research team and after this time will be safely destroyed.

5.4.9 Data management

All participants will be given a unique identification code. The NHI (patient hospital identification index) and code will be stored on a password protected memory stick. The de-identified data will be stored on a purpose-built online database using REDCap software, with password protection and access restricted to the research team only. No identifying information will be stored on the online database.

5.4.10 Protocol Amendments

A summary of protocol amendments can be seen in Table 23. A major protocol amendment occurred partway through the trial when national restrictions due to COVID-19 pandemic forced closure of all centre-based services. This meant recruitment had to stop short of the target sample size. It also meant all centre-based participants had to pivot to telerehabilitation options. These key changes can be seen in the CONSORT for extenuating circumstances (Orkin et al., 2021) in Appendix X.

Table 23

Protocol Amendments

Section heading	Amendment
Recruitment	Patient invitation to study moved from telephone call to invitation completed in-person at initial PR assessment clinic.
Primary Outcome	Centre-based stopped due to COVID-19 – primary outcome amended to percentage of classes offered, previously percentage of 16 classes. Telephone calls offered once weekly or zoom classes twice weekly. The intervention duration was 8 weeks for both groups.
Intervention	Centre-based PR When face-to-face was stopped all services pivoted to telerehabilitation. Participants were given the option of individual telephone calls (once per week) or group video-conferencing classes (twice weekly).
Sample size	Recruitment had to stop when all face-to-face stopped. Recruitment stopped at n =36 in the smallest group (target n = 50)
Outcome measures	Return to centre for follow-up assessment – occurred for 5 participants, remainder forced to occur over the phone 6 MWT – only able to be completed at baseline 1 min STS – only able to be completed at baseline EQ5D, SBQ and CAT completed over the phone rather than in-person

Note. 6MWT = six-minute walk test, 1 min STS = one minute sit to stand, EQ5D = EuroQol % dimension, SBQ= sedentary behaviour questionnaire, CAT = COPD assessment test, PR = Pulmonary Rehabilitation

Chapter 6 The impact of patient preference on attendance and completion rates at centre-based and mHealth pulmonary rehabilitation: A non-inferiority pragmatic clinical trial

6.1 Prelude to manuscript

The following chapter is designed to address objective 4 of the thesis:

> *The current study aims to identify patient preference for this mode of delivery of PR and to ascertain if allowing participants to choose their delivery method this may improve the rate of attendance PR.*

6.1.1 Why was the study needed?

The reach of current PR services in NZ is suboptimal with low rates of access, uptake and completion (Candy et al., 2020a; Levack et al., 2012). The overarching goal is to develop an alternative model for delivering PR which can increase the reach of services. To evaluate if mPR can achieve this goal a preference-based study was required.

6.1.2 What was undertaken?

To understand the patient preference for different delivery methods, all patients who attended the PR clinics at three hospitals in Auckland, were offered the opportunity to be part of the study. Participants were given the option of attending the standard PR programme (centre-based) or to participate in our mHealth PR programme (mPR). The assessment and follow-up were the same for both programmes. Both programmes were 8 weeks in duration and involved exercise and self-management education. Participant's attendance with the programme was recorded along with information on preference and health outcomes.

6.1.3 Publication citations

Candy, S., Reeve, J., Dobson, R., Whittaker, R., Garrett, J., Warren, J., ... & Taylor, D. (2023). The Impact of Patient Preference on Attendance and Completion Rates at Centre-Based and mHealth Pulmonary Rehabilitation: A Non-Inferiority Pragmatic Clinical Trial. *International Journal of Chronic Obstructive Pulmonary Disease*, 1419-1429.

https://doi.org/10.2147/COPD.S408423

Contribution by the candidate

The candidate contributed to the overall study design. She was responsible for, and carried out, the study procedures with support from her supervisors and Dr Rosie Dobson and Professor Robyn Whittaker. She cleaned the data and analysed the baseline data. Analysis of primary and secondary outcomes was competed by co-author Usman Rashid. The candidate wrote the manuscript with contributions from all authors.

Supporting Documents

The following supporting documents can be found in Appendices: Consort checklist for pragmatic trials, Consort checklist for COVID-19 impacts and TIDieR checklist.

The COVID-19 restrictions were in place from 17 August to 2 December 2020.

6.2 Abstract

Background and objective

Pulmonary rehabilitation (PR) is a vital component in the management of chronic respiratory disorders (CRDs) although uptake, attendance and completion are poor. Differing models of delivering PR are emerging in an attempt to increase the uptake and completion of this intervention. This study aimed to evaluate participant rate of attendance and completion of PR when participants are given a preference regarding model of delivery (centre-based and mHealth (mPR)). Secondary aims were to evaluate the factors affecting patient preference for model of delivery and determine whether mPR is non-inferior to centre-based PR in health outcomes.

Methods

A multi-centre non-inferiority preference-based clinical trial based in Auckland, New Zealand. Participants with a CRD referred for PR were offered the choice of centre-based or web-based PR (mPR). The primary outcome was completion rate of chosen intervention..

Results

105 participants were recruited to the study with 67 (64%) opting for centre-based and 38 (36%) preferring mPR. The odds of completing the PR programme were higher in the centre-based group compared to mPR (odds ratio 1.90 95% CI [0.83 – 4.35]). Participants opting for mPR were significantly younger (p=0.002) and significantly more likely to be working (p=0.0001). Results showed mPR was not inferior to centre-based regarding changes in symptom scores (CAT) or time spent in sedentary behaviour (SBQ). When services were forced to transition to telehealth services during COVID-19 restrictions the attendance and completion rates were highest with telephone calls and video-conferencing compared to mPR – suggesting synchronous interactions with clinicians may facilitate the best attendance and completion rates.

Conclusion

When offered the choice of PR delivery method, the majority of participants preferred centre-based PR and this facilitated the best completion rates. mPR was the preferred choice for younger, working participants suggesting mPR may offer a viable alternative

to centre-based PR programmes for some participants, especially younger employed participants.

6.3 Introduction

Chronic respiratory disorders (CRDs) contribute 7% of the global burden of disease, and are the third leading cause of death worldwide (Maio et al., 2016). People with CRD experience considerable symptom burden including shortness of breath, fatigue, and reduced health related quality of life (HRQoL). Pulmonary rehabilitation (PR) is an evidence-based, key intervention in the management of people with CRD, and includes a structured programme of exercise and self-management education (Martijn A. Spruit et al., 2013). It is usually delivered in group sessions twice weekly over eight-weeks (Alison et al., 2017). Systematic reviews of PR have demonstrated reductions in breathlessness, reduced hospital admissions for acute exacerbations and improved HRQoL (McCarthy et al., 2015; Puhan et al., 2016). Clinical guidelines strongly recommend referral to PR for all patients with COPD and increasing evidence supporting PR for other CRDs (Dowman et al., 2021; Pasteur et al., 2010). Despite this, up to 50% of people referred do not attend and of those attending, 10-32% fail to complete PR (Keating et al., 2011). Known barriers to attendance and completion include travel distance, transport, illness, and lack of perceived benefit (Keating et al., 2011).

Mobile health (mHealth), the delivery of healthcare interventions through mobile devices (phones, tablets, and computers), is increasingly considered an option to support the management of chronic health conditions (Dobson et al., 2018; Pfaeffli Dale et al., 2016). An mHealth PR programme (mPR) was developed in 2020 for use in Aotearoa New Zealand (NZ) context by our team of public health and mHealth experts, physiotherapists, respiratory physicians, psychologists, respiratory nurse specialists, cultural experts, and ongoing input from end users (see Chapter 4) (Dobson et al., 2019; Whittaker et al., 2021). The feasibility of this programme has been demonstrated for people living with a CRD in NZ.

Patients have preferences for how they receive rehabilitation programmes (Chaplin et al., 2017; Holland et al., 2017) however an important limitation in PR clinical trials to date is that they do not account for patient preferences for mode of delivery (Chaplin

et al., 2017; Cox, McDonald, Alison, et al., 2018; Hansen et al., 2020; Holland et al., 2017) . Several home-based trials of PR have reported low uptake due to participants' preference for centre-based PR (Chaplin et al., 2017; Cox, McDonald, Alison, et al., 2018; Hansen et al., 2020; Holland et al., 2017). The primary aim of this study was to evaluate attendance and completion rates when PR was delivered via two different delivery models (centre-based and mPR). Secondary aims were to evaluate patient preferences for model of delivery and to determine if mPR could achieve improvements in clinical outcomes that were not inferior to centre-based PR when patients chose mPR as their preferred mode of delivery.

6.4 Methods

6.4.1 Study design

A parallel non-randomised preference-based non-inferiority clinical trial was conducted at three tertiary hospitals in Auckland, NZ from June to November 2021. The trial was registered with the Australian New Zealand Clinical Trials Registry (ACTRN12621000365864p) and received ethical approval from the Health and Disability Ethics Committee (21/NTB/54) and met the principles of the Declaration of Helsinki.

6.4.2 Participants

Patients who attended PR clinics at the participating hospitals were invited to take part in the study. Eligibility criteria were age ≥18 years, physician diagnosed CRD, able to read and understand English, and participants should not have completed PR within the last year. The mPR group required access to a standard mobile phone capable, at a minimum, of sending and receiving text messages.

6.4.3 Procedures

At the initial PR appointment, the study was explained, and choices of delivery described. If participants gave written consent, they were offered the choice of intervention delivery model. Baseline assessment was then completed by a clinician blinded to patient preference. Post intervention assessments were completed within two weeks of intervention end by the attending PR team who were not blinded to group allocation.

6.4.4 Interventions:

All participants in both groups attended a standard centre-based PR assessment based on best practise guidelines, which included a measure of exercise capacity (6 minute walk test), HRQoL (EQ5D), health status (CAT test) and dyspnoea score (mMRC). All participants received an eight-week PR programme, consisting of exercise, education and behaviour change interventions. The exercise programme was prescribed based on assessment findings and included aerobic, resistance and balance exercises. Particiants were informed they were to exercise five times per week regardless of group allocation.

Centre-based PR

This followed best practise guidelines which was standard care at all study sites (Alison et al., 2017). Participants received face-to-face group exercises twice a week supervised by senior PR physiotherapist, and self-management education delivered by a member of the PR team. Participants were given a home-based exercise programme to complete on a further three days per week. Further intervention details are described in TIDiER checklist in Appendix Y.

Mobile Pulmonary Rehabilitation (mPR)

The mPR was based on standard PR programmes and met with best practise guidelines, including a patient-tailored intervention based on assessment findngs. The multicomponent intervention was delivered to participants through text messages (SMS) with or without an optional web-based app and wearable sensor (Fitbit or Withing). Participants were also provided with a paper manual which included detailed instructions on how to safely complete each of the prescribed exercises. The exercise component of the programme was scheduled for five days per week for the 8-week intervention and was progressed with weekly increases in duration of aerobic exercises and numbers of repetitions of resistance exercises. (See TIDiER checklist in Appendix Y).

Impact of COVID-19 restrictions

During the study, national lockdown restrictions were imposed due to the COVID-19 pandemic and centre-based services and face-to-face research and recruitment were required to cease. All participants allocated to the mPR arm of the study continued as

per protocol and the following protocol change was therefore necessary to be implemented for those in the centre-based PR arm of the study. All participants in the centre-based group during the onset of restrictions were offered alternative home-based options which comprised, either weekly telephone calls or twice weekly video-conference classes (VC). All interventions were interpersonal and synchronous to mimic being as close to centre-based PR as possible. All participants in centre-based group attended a minimum of one in-person session prior to COVID-19 restrictions. These interventions continued until participants were scheduled to complete their 8-week PR programme.

6.4.5 Outcomes

The primary outcome was attendance and completion which was recorded as a percentage of the number of sessions offered. Completion was defined as attendance ≥70% (Williams et al., 2014).

1. For the centre-based group attendance was initially two sessions per week. However, modifications due to COVID-19 restrictions meant some centre-based participants had to pivot to receiving weekly telephone calls or twice weekly VC's.
2. For the mPR group a proxy measure of attendance was used based on participants replying to two SMS per week. The first asked *how many times participants had completed their programme* and then second if *participants were ready to progress their exercise programme*.

This measure of attendance was chosen as it was achievable for all participant regardless of device used and involved minimal participant burden.

Secondary outcomes were patient preference (centre-based or mPR), engagement with mPR (measured using system recorded data, e.g. app page views, SMS sent/received) and clinical outcomes: HRQoL (EQ5D-VAS) (Rabin & Charro, 2001), symptom score (COPD assessment test (CAT)) (Tsiligianni et al., 2012), dyspnoea (Modified Medical Research Scale (mMRC)) (Launois et al., 2012) and time in sedentary activities (sedentary behaviour questionnaire (SBQ)).

6.4.6 Statistical Analysis

A two-sample proportion test for non-inferiority was used to determine the required sample size to detect a difference between the attendance and completion at centre-based and mPR. We used a completion rate of 60% for the centre-based PR group based on previous research findings (Candy et al., 2020b). Calculations were based on a non-inferiority margin of 30% between the groups. Using a statistical power of 80% te two-sample proportion test determined 50 participants would be required in the smallest group. .

The non-inferiority null hypothesis in terms of odds ratio was: Odds of completion in centre-based PR/Odds of completion in mPR ≥ 3.5 (equivalent to Cohens' d=0.5 (Wang & Zhang, 2012)).Data were analysed using IBM SPSS Statistics (Version 26) and R environment for statistical computing (Team, 2013) . All participants were included in an intention to treat analysis regardless of number of sessions attended. As the proportion of missing values was <5% no imputations were used for missing data. Between-group comparisons were analysed with independent sample t-tests and chi-square tests. In the primary model used to evaluate odds ratios, logistic regression was used with the dependent variable of group. The secondary model to detect predictor variables used multivariate logistic regression with dependent variables group choice and completion of PR. An analysis of co-variance was used to determine between-group differences after controlling for baseline values. For both primary and secondary outcomes, one sided non-inferiority null hypothesis tests were conducted with a non-inferiority margin equivalent to Cohen's d=0.5. These non-inferiority tests evaluated whether the differences between centre-based and mPR were smaller than a medium effect size as this corresponds to a clinically meaningful difference (Sedaghat, 2019). These tests evaluated whether the differences between the two interventions were smaller than clinically meaningful differences. Statistical significance level was set at 0.05 and 0.025 for the two-sided and one-sided hypothesis tests respectively.

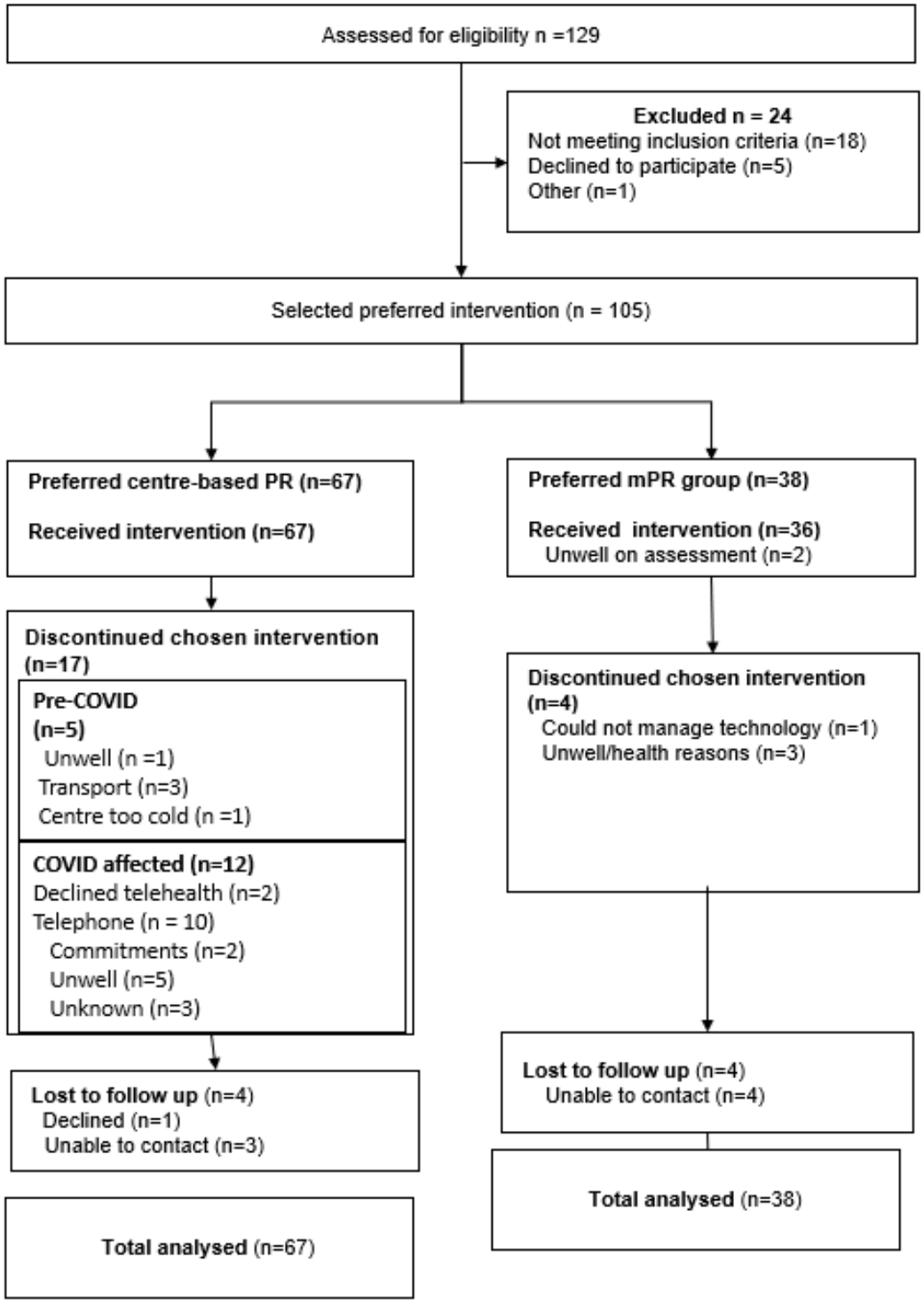
6.5 Results

A total of 129 participants were screened for eligibility and 105 recruited. Participants were asked their preference for delivery of PR; 67/105 (64%) selected centre-based and 38/105 (36%) mPR. Follow-up assessment was completed for 95/105 (90%)

participants; 63/67 (94%) from the centre-based group, and 32/38 (84%) from mPR. Flow of participants through the study can be seen in Figure 20.

Figure 20

Study Flow Diagram through the preference-based study



Note. VC = video conference

The demographic and clinical characteristics of participants at baseline can be seen in Table 24. Those who chose mPR were significantly younger (p=0.002) and more likely to be working (p=0.0001).

Table 24

Baseline characteristics of participants by preferred intervention. Data are number (%) of participants unless stated otherwise.

Characteristic	Centre (n = 67)		mPR (n = 38)		P value	
Gender: Female/Male	41/26		26/12		χ^2=0.548	(p=0.459)
Age (years), mean (SD; range)	71(9; 49-88)		64 (11; 34-82)		t=3.16	(p=0.002)
Ethnicity						
Māori	13	(19%)	6	(16%)	χ^2=0.214	(p=0.644)
Pacific peoples	6	(9%)	7	(18%)	χ^2=2.003	(p=0.157)
European/Other[1]	48	(72%)	25	(66%)	χ^2=0.392	(p=0.531)
Primary condition						
COPD	42	(63%)	22	(58%)	χ^2 =0.234	(p=0.629)
Bronchiectasis	12	(18%)	5	(13%)	χ^2=0.404	(p=0.525)
Interstitial Lung disease	6	(9%)	3	(8%)	χ^2=0.035	(p=0.852)
Other*	9	(13%)	8	(20%)	χ^2=1.038	(p=0.308)
Smoking status						
Current smoker	10	(15%)	6	(16%)	χ^2=0.656	(p=0.720)
Ex-smoker	42	(63%)	21	(55%)		
Never smoked	15	(22%)	11	(29%)		
Employment status						
Employed	6	(9)	21	(58)	$\chi^{2=}$28.5	(p=0.000)
Not working	59	(91)	15	(42)		
Highest education level						
Trade or below	42	(63%)	15	(40%)	χ^2=5.747	(p=0.057)
Diploma and above	20	(30%)	20	(52%)		
Not stated	4	(6%)	2	(5%)		
6-min. walk test (metres), mean (SD)	380	(105)	386	(124)	t=-2.72	(p=0.185)
1-min. sit to stand, (reps) mean (SD)	17.0	(5.6)	18	(6.8)	t=-1.314	(p=0.108
mMRC (median, IQR)	2.1	(0.9)	2.0	(1.1)	t=0.648	(p=0.606)
CAT total, mean (SD)	18.27	(7.6)	18.8	(7.6)	t=-0.396	(p=0.931)
EQ5D VAS %, mean (SD)	62.35	(22.7)	64.08	(20.7)	t=-2.045	(p=0.043)
SBQ total time (hrs/wk), mean (SD)	57.1	(27.2)	69.6	(27.6)	t=-2.045	(p=0.881)

Note: mMRC= modified medical research council, CAT = COPD assessment test, EQ5D VAS = EQ5D visual analogue scale, SBQ = sedentary behaviour questionnaire

* Other = Asthma (n=6), post-surgery (n=2), alveolar proteinosis (n=1), OSA (n=8)

Due to a national COVID-19 lockdown, the planned face-to-face follow-up assessment was able to be completed for only three (4%) centre-based and two (6%) mPR participants. The remaining participants completed the follow-up assessment over the

telephone. The face-to-face elements that were unable to be completed were the 6-minute walk test and one minute sit to stand test. Elements which were able to be assessed over the phone for the remaining participants were CAT, EQ5D, SBQ and mMRC.

6.5.1 Primary Outcome

The overall proportion of participants who completed ≥70% of the available sessions was 67%; 50/67 (75%) in centre-based, and 20/38 (53%) in mPR. Logistic regression showed the likelihood of completing PR was nearly twice as high if participants were enrolled in centre-based compared to mPR (odds ratio 1.90 95% CI [0.83 – 4.35]). We were unable to reject the non-inferiority null hypothesis (H_0: Odds ratio ≥ 3.5, z-value = -1.446, p-value = 0.074), and thus we cannot confirm whether mPR is able to achieve a completion rate which is not lower than centre-based. A secondary model using multi-variate logistic regression assessed the impact of a set of predictor variables on the odds of participants completing PR (Table 25) did not identify any significant predictors of completion. No multicollinearity existed between variables.

Table 25

Multivariate Logistic Regression

Variable	**Level**	**Odds ratio**		**H_0: Odds ratio=1, p-value**
Choice	Centre	1.744	(0.37 – 8.2)	0.483
Age	Per year increase	1.047	(0.96-1.14)	0.28
Gender	Female	1.17	(0.334-4.08)	0.809
Ethnicity	Non-Māori/ non-Pacific	0.572	(0.145-2.27)	0.427
Employment	Working	0.389	(0.77 – 1.97)	0.255
Education	Trade or lower	0.536	(0.4-6.0)	0.632
	Not stated	1.7	(0.116-26.7)	0.682
Exercise tolerance (6MWT)	Metre	1.0	(0.995-1.0)	0.369
mMRC		1.0	(0.545-2.0)	0.896

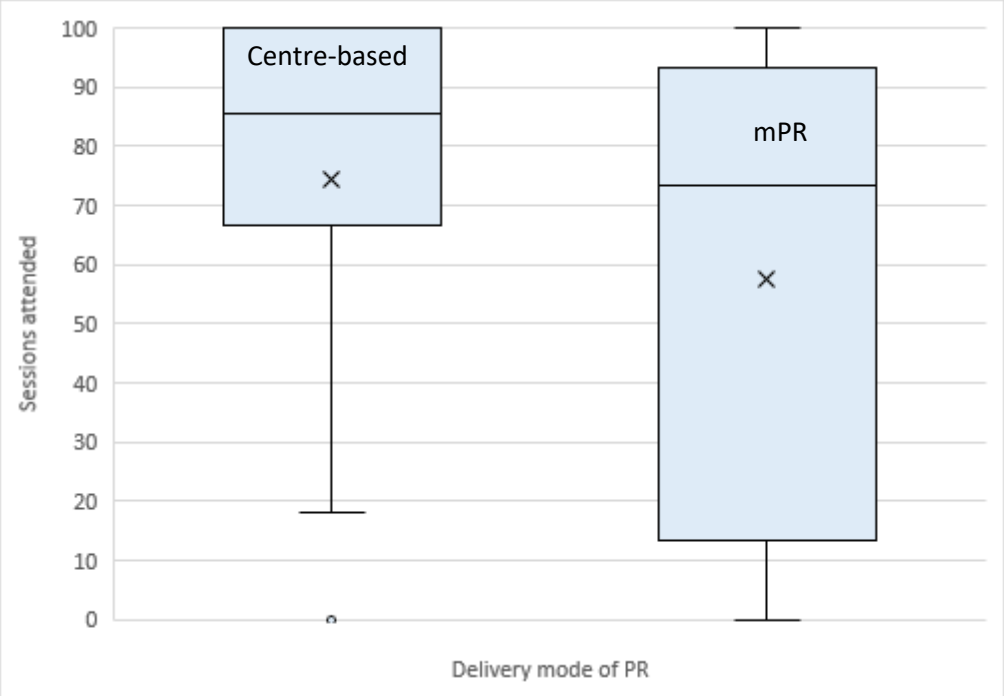
Note: 6MWT= six-minute walk test, mMRC – modified medical research council

In the centre-based group, 13/67 (19%) participants reached the end of the intervention period prior to COVID-19 restrictions (pre-COVID-19 group). When restrictions were implemented 54/67 (81%) participants were affected, with two

participants declining telehealth. The remaining 52/67 (78%) were subsequently given the choice of telephone calls or VC classes, with 41/52 (78%) opting for telephone and 11/52 (21%) VC. Attendance rates for both groups are shown in Figure 21.

Figure 21

Box and Whisker plot showing attendance rates at Pulmonary Rehabilitation



Key:
X = mean
• = outlier
Outlier < Q1-1.5*IQR

Of the 38 participants in the mPR group, 3/38 (8%) opted to receive SMS only, 8/38 (21%) mPR-app and SMS, and the remaining 25/38 (66%) mPR-app, sensor, and SMS and 2/38 (5%) did not receive the intervention. According to our *a priori* definition the completion rate for the mPR group was 53%.

6.5.2 Engagement in mPR

The mPR app dashboard was viewed by participants a total of 8,593 times during the study period and videos were opened 1,038 times. A total of 3932 SMS were sent to participants (mean per participant = 109.22, range 14-169). Of those who started mPR 33/38 (87%) engaged to some degree (responded to SMS, accessed the app). Of those registered to use the app, 25/33 (76%) were still accessing it in week 8, with 63% responding to SMS questions at week 8.

6.5.3 Secondary outcomes

Centre-based participants demonstrated improvements in dyspnoea, symptom scores and HRQoL, with no change in time spent in sedentary behaviour (SBQ) (Table 26). mPR participants showed improvement in symptom scores and reduced time in sedentary behaviour but did not show improvements in dyspnoea or HRQoL. Statistical analysis showed mPR was not inferior to centre-based PR in terms of changes in health status (CAT) or time spent in sedentary behaviour (SBQ), and thus we could reject the non-inferiority null hypothesis for these outcomes, but we were unable to exclude non inferiority for dyspnoea (mMRC) or HRQoL (EQ5D).

Table 26

Outcome measures taken at baseline and follow up assessments, mean (standard deviation)

Outcome	Baseline		Follow up		Within group difference		Baseline adjusted between group mean difference (MD), 95% CI		H_0: MD ≥ 0.5 Cohen's d t-value[df], p-value		
	Centre	mPR	Centre	mPR	Centre	mPR					
CAT	18.2 (7)	18.9 (8)	15.0 (8)	15.1 (7)	2.5 (6.6)	3.2 (6.8)	0.71	[-1.98, 3.4]	H_0: MD ≤	-3.6	t[90]= -3.183, 0.001
mMRC	2.1 (0.9)	2.0 (1.1)	1.8 (0.9)	2.2 (0.9)	0.30 (1.1)	-.28 (1.1)	-0.473	[-0.84, -0.107]	H_0: MD ≤	-0.52	t[89]= 0.254, <0.399
SBQ	57.6 (27)	69.6 (27)	54.9 (25)	59.8 (19)	1.7 (25)	6.8 (23)	-0.321	[-9.1, 8.45]	H_0: MD ≤	-13.9	t[91]= -3.074, <0.0014
EQ5D-VAS	63 (23)	65 (21)	70 (19)	64 (21)	7.25 (25)	-1.9 (22)	7.35	[-0.952, 15.6]	H_0: MD ≥	11.1	t[91]= -0.899, 0.1855

Note. CAT = COPD assessment test, mMRC= modified medical research council scale, SBQ= sedentary behaviour questionnaire, EQ5D-VAS = EuroQol 5 dimension visual analogue scale. MD = mean difference and is defined as Centre based – mPR

One adverse event was reported; a participant in the mPR group fell whilst walking, injuring her shoulder and was unable to complete the intervention but participated in the follow-up assessment. No other adverse events were reported.

6.6 Discussion

This trial provides information regarding attendance and completion rates of PR when participants are given choice in delivery model. The likelihood of completing PR was nearly twice as high if participants were enrolled in centre-based compared to mPR, even if this centre-based model were forced to transition to a telephone/VC model. Despite this being almost twice as likely to complete in the centre-based group, this was not statistically significant and thus we cannot confirm whether mPR can achieve the same completion rate as centre-based PR. Our centre-based completion rate is similar to a National UK audit rate (Steiner et al., 2015a) and higher than a previous NZ audit at our centre where completion rates were 61% (Candy et al., 2020a). We believe the forced transition of the centre-based group to telerehabilitation due to COVID-19 restrictions may be a contributor to this higher completion rate of the centre-based group in our study. Previous home-based PR trials using telephone calls and VC have shown higher completion rates than centre-based PR (Holland et al., 2017; Tsai et al., 2017) and it has been suggested it is easier to 'attend' a telephone call than travel to a centre (Holland et al., 2017). We also believe this to be especially the case in our study, when the national COVID-19 restrictions required people to stay at home thus making them more available to answer calls. This study has shown whilst 64% of participants preferred centre-based PR, when forced to transition to telerehabilitation models (telephone and VC), the attendance and completion rates improved for this group indicating that once the therapeutic relationship had been established, participants were able to successfully transfer to remotely delivered PR and maintain this relationship at a distance.

Whilst the completion rate of mPR in this study was lower than that of centre-based (53% v 75%), several factors may have influenced this. The study was underpowered to determine non inferiority due to recruitment stopping when national COVID-19 restrictions forced the closure of face-to-face services. The required sample size of 50 in the smallest group was not achieved with only 38 participants is the mPR group. We used a proxy measure of attendance to determine completion rates in the mPR group

requiring participants to respond to two messages per week for 8-weeks. This may have underestimated the true completion rate of mPR as our analysis showed participants were more likely to answer general questions regarding progression of their exercise programme than the more specific question regarding frequency count of completed exercises. It is inherently difficult to measure engagement with digital health interventions (Danaher et al., 2006; Yeager & Benight, 2018) and we are reliant on either subjective reports or system measures, such as participants logins, which indicate usage but do not provide information on fidelity to the intervention. In this study we needed a measure of attendance which could accommodate the different levels of engagement participants had with the interventiojn, as some participants received mPR via SMS alone and others using mPR-app. Whilst we appreciate the limitations with this outcome measure, we are yet to determine accurate measures of attendance and fidelity with remotely delivered interventions and this needs ongoing consideration.

Previous studies investigating web-based programmes have shown a gradual decline in usage over time of the intervention (Bourne et al., 2017; Chaplin et al., 2017) , however this was not seen in our study. Based on responses to the two questions aimed at ascertaining attendance there were fewer responses in the first week suggesting technical or digital challenges may have been a factor. Several authors have stressed the importance of training participants in the use of technology (Alwashmi et al., 2020a; Vorrink et al., 2017) and the inclusion of technical support to facilitate this should be considered in any future work. Our mPR programme was designed to be asynchronous, 'stand-alone' intervention with no scheduled clinician interactions and whilst participants were advised they could contact a clinician through the mPR 'contact us' page, only four participants did so. It is possible that adding regular contact points would establish a therapeutic relationship with the clinician and have the potential to enhance outcomes, as found in a trial of home-based PR with health coaching, where high patient adherence and satisfaction was attributed to the interactions with the physiotherapist (Benzo et al., 2018). Interestingly The American Thoracic Society suggests that (Holland et al., 2021) regular contact between health care professionals and the patients was desirable rather than essential.

Our results show that whilst two-thirds of participants preferred centre-based PR, one-third of participants preferred mPR, and that in patients who are younger, employed and living in rural locations mPR offers a useful alternative. Whilst there is limited data available on the uptake and completion of telerehabilitation in real-world settings, an implementation study reported 36% of participants opted for home-based PR with telephone support after declining centre-based (Bondarenko et al., 2021) and our study supports this finding. It is likely as our population ages and digital confidence grows, the portion of participants opting for telerehabilitation options may also increase.

The improvements in clinical outcomes observed in both groups were lower than expected with significant improvements seen only for health status scores (CAT). Whilst the centre-based group showed improvements in HRQoL, the mPR group did not. A meta-analysis of centre-based PR trials has shown improvements in HRQoL (Lacasse et al., 2007), with a recent Cochrane review showing equivalence in outcomes between telerehabilitation and centre-based PR. (Cox et al., 2021) However, our trial along with other pragmatic trials have failed to show improvements in HRQoL (Hansen et al., 2020; Holland et al., 2017). Our study occurred during a pandemic when people living with a CRD felt particularly vulnerable which may have impacted on their feelings of anxiety, perceived health status and respiratory status. In people living with CRD in the UK undergoing COVID-19 restrictions, reductions in physical activity levels and HRQoL were observed (Hume et al., 2020) , and it is likely that similar impacts may have occurred for participants in this study.

A major limitation of this study was our inability to measure changes in exercise capacity due to the restrictions in face-to-face contact which were imposed by the COVID-19 pandemic. Additionally, the inability to recruit to the target sample size due to COVID restrictions impacted the statistical power and thus our ability to clearly demonstrate non inferiority between centre-based and mPR. An advantage of the pragmatic trial design of this study was the broad inclusion criteria reflecting clinical practise and resulting in low rate of participant declining participation.

6.7 Conclusion

This trial has shown that whilst centre-based PR remained the preferred method of delivery for the majority of patients, mPR was preferred by 36% of participants referred for PR and appealed to younger participants who are working and may have found attendance at centre-based programmes challenging. Attendance and completion rates were highest in the group who started centre-based and transitioned to telerehabilitation via telephone and videoconferencing during the COVID-19 pandemic, suggesting the opportunity to develop a therapeutic relationship with clinicians prior to remotely delivered PR may be important.

Acknowledgements:

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Chapter 7 The participant experience of mobile technology delivered pulmonary rehabilitation

7.1 Prelude to manuscript

The following chapter is designed to address objective 5 of the thesis:

> *To evaluate end-user experiences of the NZ purpose designed mHealth intervention (mPR).*

7.1.1 Why was the study needed?

Capturing the patient experience is important when developing an alternative method for delivering PR to ensure the intervention is patient centred. These personal stories can provide us with critical insights into how an intervention is accepted and which components can enhance or obstruct engagement. This was particularly important in this study as the national COVID-19 restriction occurred through the study period making for unprecedented times.

The aims of this study were to (1) evaluate the satisfaction, usability, and usefulness of mPR by comparing this to centre-based PR and (2) to identify factors which impact participation in mPR.

7.1.2 What was undertaken?

A mixed methods design was used incorporating quantitative and qualitative data. Two data collections tools were used: a participant feedback questionnaire and semi structured interviews.

The feedback questionnaire was completed by all participants included in the preference trial (n= 32). The interview was completed with a purposeful sample of participants from the mPR group (n=17).

7.1.3 Publication citations

The manuscript will be submitted to Respiratory Care following publication of the preference study manuscript.

7.1.4 Contribution by the candidate

The candidate contributed to the overall study design. She was responsible for, and carried out, the study procedures with support from PhD supervisors, Dr Rosie Dobson and Prof Robyn Whittaker. She analysed the data with assistance from PhD supervisors and wrote the manuscript with contributions from all authors.

7.1.5 Supporting Documents

The following supporting documents are included in the Appendices: semi structured question guide, sampling framework and sample of coding manuscripts and COREQ.

7.2 Abstract

Background

The efficacy of Pulmonary Rehabilitation (PR) in the management of chronic respiratory disorders is clearly established. To address issues of poor uptake and completion in traditional centre-based PR programmes, new models of PR delivery are being developed. One model is PR delivered via mobile technologies (mHealth). Understanding the end-user experience with these alternative models is important to ensure they are patient-centred and have high levels of engagement. A preference based clinical trial was conducted in NZ to assess the attendance, completion, and preferences of people between mHealth (mPR) and centre-based PR. During this trial an evaluation of user experiences with mPR was conducted.

Aims

To evaluate the satisfaction, usability, and usefulness of mPR for participants who elected to undergo their PR via mobile technology and to identify factors which impacted their participation in mPR.

Method

This study was nested in a preference-based trial evaluating participant rate of attendance, completion, and preference for different delivery methods for PR (centre-based or mPR). The current study used a mixed methods design utilising quantitative and qualitative data from participants who chose to undertake PR via mPR. On completion of the mPR intervention a feedback questionnaire was administered to all mPR participants who completed follow-up assessments (n= 32) to evaluate their experiences of undertaking mPR. A purposeful sample of these participants (n = 17) completed qualitative semi-structured interviews to explore more in-depth patient experiences with the mPR programme.

Findings

Participants undertaking PR via mPR reported high satisfaction with mPR and considered it useful, inclusive, and easy to use. Follow-up interviews found engagement with mPR was enhanced by personal convenience, feeling supported and the feedback provided through mPR. Health concerns, logistics and COVID-19 restrictions implemented during the study impacted participation for some.

Key words
Chronic respiratory disorder, mHealth, patient perspective, pulmonary rehabilitation, telerehabilitation.

7.3 Introduction

Pulmonary rehabilitation (PR) is a highly effective intervention with clearly proven benefits in the management of CRD (McCarthy et al., 2015). The Cochrane Collaboration recommends no further trials of effectiveness are required as the outcomes are conclusive (McCarthy et al., 2015). Despite known efficacy of PR, attendance and completion of PR programmes remains a problem (Candy et al., 2020a; Levack et al., 2012; Moscovice et al., 2019; Rochester et al., 2015). The reasons for this are multifactorial but include patient related factors and service organisational factors (Cox et al., 2017; Keating et al., 2011; Lahham & Holland, 2021).

Telerehabilitation is the delivery of rehabilitation services at a distance through the use of technology (Cox, McDonald, Hill, et al., 2018) and provides an opportunity to overcome many of the barriers to attending centre-based PR, providing alternative options which may increase the access, uptake, and completion of PR. To date, several models of telerehabilitation have been trialled including telephone, video teleconferencing, and mobile technology (Bourne et al., 2017; Holland et al., 2017; Tsai et al., 2017). A recent systematic review has shown telerehabilitation interventions in PR are safe and likely to be equivalent in outcomes to centre-based models, however the small number of studies and large variation in study methods used makes this conclusion guarded (Cox et al., 2021). Furthermore, the studies included in Cox et al's systematic review showed challenges in recruiting to telerehabilitation trials suggesting telerehabilitation may not be the preferred modality for PR, with between 39% and 80% of patients across studies declining due to a stated preference for centre-based (Cox, McDonald, Alison, et al., 2018; Holland et al., 2017), or concerns around technological challenges (Simonÿ et al., 2019; Tsai et al., 2017).

Several qualitative studies have explored the patient perception of partaking in telerehabilitation, and this has informed our understanding of some the barriers for participants, including device access, digital competency, internet access, illness duration and lack of peer support (Alwashmi et al., 2020b; Dobson et al., 2019; Inskip

et al., 2018; Lahham et al., 2018b; Tsai et al., 2016). These identified barriers raise concern that these new delivery modalities may create different barriers to participation than those with centre-based PR, potentially furthering inequities rather than increasing access for all participants.

In an attempt to increase the reach of PR in NZ, we developed an mHealth PR programme (mPR), which is an individually tailored and theoretically based PR intervention delivered via mHealth. The mPR programme has been designed to allow participation for everyone regardless of level of digital access or digital literacy. The essential components of PR are delivered through an individualised mPR-app and personally tailored text messaging. The content of mPR was mapped from standard PR programmes and based on best practise guidelines (Alison et al., 2017) and is described in Chapter 4. The programme includes exercise prescription consisting of aerobic, resistance and balance exercises, and strategies to support self-management behaviour change such as daily text messaging and tips and tools modules.

The patient preference for and attendance at mPR or centre-based PR was assessed in a preference based clinical trial, an overview of the participant flow through the trial can be seen in Figure 22. Although the trial investigated the impact of the choice of modality on attendance, completion, and health outcomes (Chapter 6), understanding participant experiences with interventions is crucial to assist in their evaluation and to inform improvement.

This study presents an evaluation of participant experiences with the mPR programme. The aims of this study were to

1. evaluate the satisfaction, usability, and usefulness of our mPR programme from the participant's perspective and
2. to identify factors which were reported by participants as impacting on their participation in mPR.

7.4 Methods

The study was nested in a preference-based clinical study aiming to compare the attendance and completion of PR when participants had the choice of how they received their intervention (centre-based or via mPR), at three tertiary hospitals in

Auckland, New Zealand. This nested mixed methods study had two parts - a feedback questionnaire and semi-structured interviews. Ethical approval for this study was granted by the HDEC 21/NTB/54 and the study was registered with Australian New Zealand Clinical Trials Registry (ACTRN12621000365864p).

7.4.1 Mixed method approach

The study used an integrated mixed methods design (Creswell & Creswell, 2017; Giddings & Grant, 2006), where qualitative data were analysed following quantitative questionnaire analysis, to increase interpretability and allow greater understanding of the user experience (Greene et al., 1989). All participants enrolled in the mPR group were asked to complete a post intervention feedback questionnaire at the time of the post-intervention assessment (8-weeks). A purposive sample of participants from the mPR group was asked to undertake a semi-structured interview which, due to COVID-19 restrictions, was completed over the telephone.

Questionnaire

The feedback questionnaire was designed based on a pre-existing and currently utilised questionnaire at a centre-based PR programme at one of the recruiting sites in the study. Additional questions were included regarding the technology component. The questionnaire included closed and open ended questions, and included 16 general feedback and 12 mPR related questions which were piloted in an earlier feasibility study (Whittaker et al., 2021) (see Appendix T). The questionnaire data were collected and managed using REDCap electronic data capture (v8.5.0). Participants were informed they may complete the questionnaire via an online link, paper format, or over the telephone.

Semi-structured Interviews

The semi structured interviews were conducted with a purposive sample of mPR participants and used open ended questions, focusing of the participant's experiences with the intervention. Due to COVID-19 restrictions, it was necessary that all the interviews were completed over the telephone. All interviews were completed by the primary researcher (SC). The interviewer was a female physiotherapist with >15 years' experience delivering PR. The interviewer was involved in recruitment to the study but not the delivery of the intervention. The interviews ranged from 20 – 50 minutes in

duration and were completed within four weeks of intervention completion. Interviews were audio-recorded and transcribed verbatim using NVivo transcription (version 12), which were reviewed against the audio recordings to ensure accuracy. Any information that identified an individual was removed from the transcripts.

Recruitment

Participants were recruited for the semi-structured interviews based on a sampling framework developed by the authors to ensure diversity and representation of participants, including known barriers to attending PR (see Appendix Z). Younger people, those with lower exercise tolerance, current smokers, and people of Māori (indigenous population of NZ) and Pacific Island ethnicity have been shown to be less likely to participate in PR programmes (Candy et al., 2020a) and it was considered important to include these participants in the interviews to better understand their experiences.

Data analysis

All data provided in the questionnaire was de-identified and analysed by aggregation. Categorical data were reported through counts and percentages. The qualitative data from the questionnaire was analysed using inductive thematic analysis emphasising semantic themes and illustrated using participant quotes (Clarke et al., 2015).

All interview transcripts were de-identified and initially analysed through familiarisation, exploration, and complete coding by SC. The transcripts were read and re-read to allow for familiarisation with the data before exploring the data for codes. Complete coding was undertaken by systematically working through the data and extracting data relevant to the research aims (see Appendix BB). The codes were then reviewed and revised as necessary by DT and JR. Patterns in the data were identified and themes were developed through the process of thematic analysis (Clarke et al., 2015). Participant quotes are used to explain and substantiate each theme.

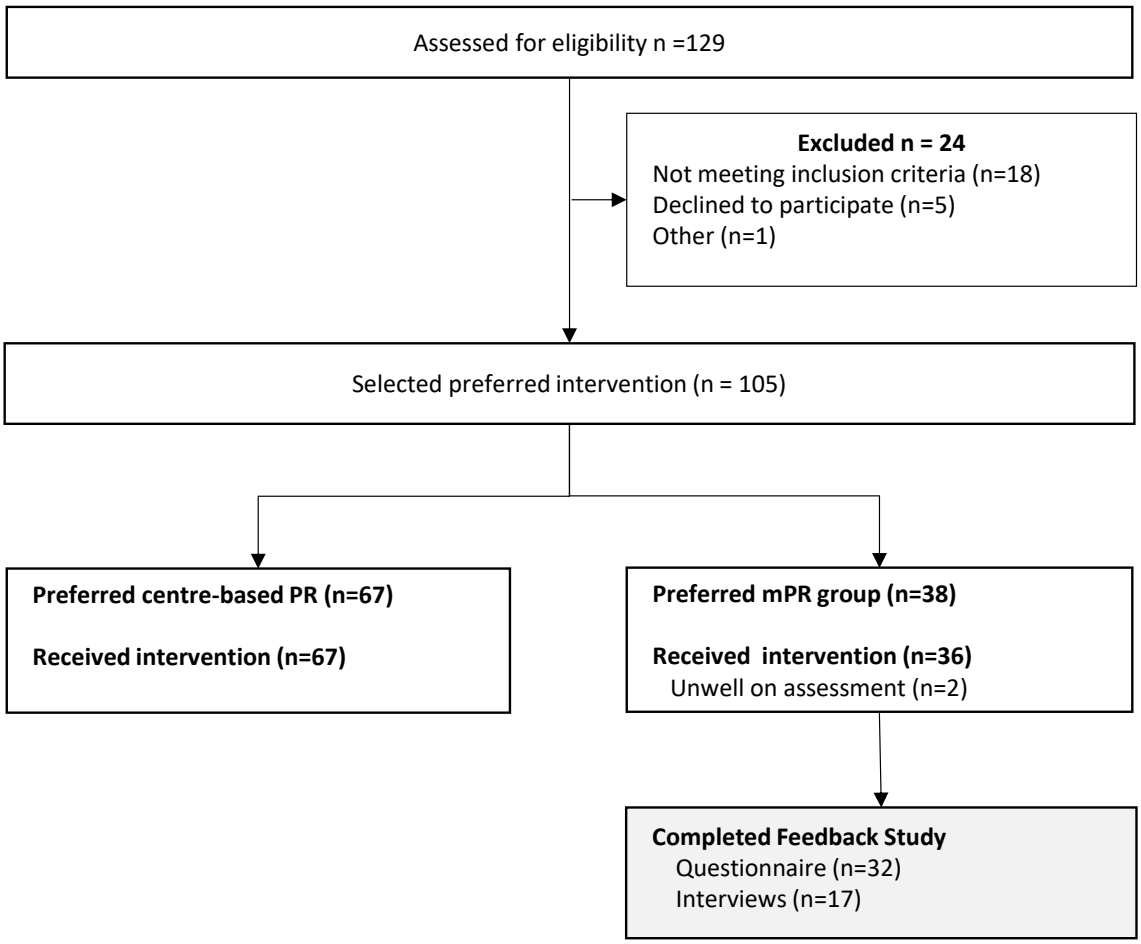
Finally, the analysed data from the questionnaire and interviews were woven together to form a broader insight. The quantitative results were integrated with the findings from the qualitative analysis to provide comprehensive evaluation of patient experiences with mPR. All quotes contained here arose directly from the interviews.

7.5 Results

The flow diagram for the preference trial in which this study was nested can be seen in Figure 22. Of the 129 participants who attended PR clinics and were assessed for eligibility, 105/129 (81%) provided consent to be part of the preference trial, with 67 (64%) choosing centre-based PR and 38 (36%) opting for mPR.

Figure 22

Study flow diagram for end-user experience study



Of the 38 participants who chose mPR: 5% (2/38) were not eligible following baseline assessment, 84% (32/38) completed the questionnaire, with 10% (4/83) lost to follow up and 17 were selected to complete the semi-structured interview. The data collection for the questionnaire and semi-structured interviews occurred between August and December 2021. The demographic characteristics of the participants who chose mPR along with the subgroups of the questionnaire and interview participants can be seen in Table 27.

Table 27

Participant Characteristics

Characteristic	mPR Group (n = 38)	Questionnaire (n=32)	Interview Group (n = 17)
Age, years (mean, SD)	64 (11)	66 (11)	68 (13)
Male/female, n	42/26	39/23	7/10
Ethnicity, n (%)			
NZ European/Other	25 (66%)	22 (69%)	10 (59%)
Māori	6 (16%)	4 (12%)	2 (12%)
Pacific	7 (18%)	6 (19%)	5 (29%)
Smoking status			
Current	6 (16%)	4 (12%)	1 (6%)
Ex-smoker / never smoker	32 (84%)	28 (87%)	16 (94%)
Living situation			
Alone	8 (21%)	7 (22%)	5 (29%)
With family	30 (79%)	25 (78%)	12 (71%)
Working			
Working	21 (55%)	17 (53%)	7 (41%)
Not working	15 (39%)	13 (41%)	10 (59%)
Not stated	2 (5%)	2 (6%)	0 (0%)
Diagnosis			
COPD	22 (58%)	18 (56%)	9 (53%)
Bronchiectasis	5 (13%)	4 (12%)	3 (18%)
Interstitial Lung Disease	3 (8%)	3 (9%)	2 (12%)
Asthma	6 (16%)	5 (16%)	2 (12%)
Other	2 (5%)	2 (6%)	1 (6%)

Note. COPD = Chronic Obstructive Pulmonary Disease

* Other = (post-surgery n=2, protein alveolitis n=1, asthma n=1),

7.5.1 Usefulness of mPR

Of the 32 participants that completed the questionnaire, 31 (97%) reported they found the mPR programme to be 'useful'. When asked to rate how useful the programme was on a Likert scale from 0 (not useful) to 5 (extremely useful) participants gave a median rating of 4.2 (IQR 1). Participants were asked their general thoughts about the programme and the majority (27/32) described their experience with mPR to be positive.

> "I couldn't be happier… I feel better now than I have for years…, I thought I was going to end up bed ridden and doing those exercises

> every day …it really made me feel good and I would recommend it …. I feel so much better, every morning I open the app, it's a real incentive" (female 74yrs)

> "I thought it was well organised and has benefited me. It gave more me confidence and made me feel more capable of doing things. I was wary to attempt things in case I couldn't manage but I can cope better now. I felt I was doing something to help myself and it motivated me to go for a walk." (female 71yrs)

Six percent (2/32) of participants described the programme negatively, one of whom had an exacerbation which required hospitalisation limiting participation and the other was unable to access the mPR app due to technical difficulties.

7.5.2 Factors impacting engagement with mPR

Analysis of both the questionnaire and interview data identified themes related to engagement with mPR which were grouped into two main categories: enablers and barriers. Additional to these themes were influential factors which impacted participation differently across the participants, being an enabler for some and a barrier for others.

Enablers

Several enablers which enhanced participation with the mPR intervention emerged from the data and are discussed below.

Usability

Data were collected on the usability of mPR through the questionnaire (n=32). Participants were asked to rate on a Likert scale how easy it was to interact with the mPR programme. On a scale of 0 = very difficult to 5= very easy, participants reported the programme to be very easy to use (median = 4.8 (range 3 -5)); and on a scale of 0=did not like to 5=liked very much, that they liked the look and feel of the mPR interface (median = 4.6 (range 3 -5)). The data from the qualitative interviews (n=17) supported the usability of mPR as an enabler to participation. Comments included:

> "The app was intuitive … it was easy to follow instructions …I liked the videos and checking I was doing the exercises correctly" (female 60yrs)

> "It was a good app… it did what it needed with nothing extra that was not needed" (male 80yrs)

The video exercise demonstrations and the alternative exercise options found in the mPR app were reported as being particularly useful and helpful for ensuring participants were performing the exercises correctly.

> "Saw the model showing the exercises who was on oxygen … thought that was cool … made it so real… having someone that was actually doing it made it a lot more meaningful " (female 60yrs)

> "Yes, I think it was very easy to use because what it would do is, here is your exercises and there was a reminder on how to do them "(female 82yrs)

Interview data did reveal technical challenges for one participant which hindered their ability to interact with the intervention. This resulted in the participant not receiving a progression of their exercise programme.

> "Could not get the app to work and did not really want to learn and so just went with the exercises and SMS" (female 75yrs)

Convenience

A key theme was the convenience of mPR due to the flexibility offered by the programme. Being able to fit the programme around their needs and preferences was highly valued by participants, who reported attending a centre-based programme was impossible because of work or other commitments. Participants believed mPR offered them an otherwise unachievable opportunity.

> "Being able to do exercise in own time when suits…. Break up the exercises rather than doing all at once to fit in with own timetable" (male 72yrs)

> "The joy of the app is that you can do it in your own time. All the ones I can't do at work; I do at home before I go to work" (female 57yrs)

Support

A total of 29 of the 32 participants felt that success with mPR was attributed to the support participants felt they had throughout the intervention. This support came in different forms. For some it was being able to complete the programme with a family member.

> "I do the exercise with my wife. She does the counting for me .." (male 35yrs)

> "I like being able to do at home when it suits me and to do all the exercises with my husband – he used heavier weights than I did". (female 71yrs)

Other participants felt supported by the reminders they received in the daily text messages.

> "The messages helped me keep my mind on the job, when I got a message it reminded me to do my exercise" (female 57yrs)

> "it was like you had a buddy" (female 59yrs)

Personal contact

Participants had differing views on whether there should be personal contact points from health professionals within the mPR programme. Some participants reported not requiring personal contact and reported enjoying the flexibility of completing the programme in their own schedule. Others reported preferring more input from a health care professional.

> "I did not need anyone to contact me I was happy with doing it on my own" (female 71yrs)

> "More personal interaction… more interaction from someone would either give incentive for doing it or why have you not done it" (male 72yrs)

Knowledge of Performance

Participants reported the increased self-awareness of their performance provided through mPR was a source of motivation. The features of mPR which were reported as promoting the most self-awareness included the wearable sensor, the 'my-progress' page, and the daily SMS. These were reported as helping to drive behaviour change, particularly regular exercise habits.

> "I am quite visual, and it is nice to see what I have done and the sit to stand was good to see I have made an improvement and that makes me want to do better" (female 60yrs)

> "Replying to the text messages was fine as then I knew I had achieved something that week" (female 59yrs)

Barriers

Two themes emerged from the data relating to factors impeding engagement with mPR, and these could be grouped as relating to logistical challenges or health related factors.

Logistical challenges

Bad weather (restricting outdoor walking), a lack of physical space at home, and fitting the programme into an already busy schedule impacted participation for some who were working or had family commitments. This problem was exacerbated by the COVID-19 lockdown, resulting in whole households being at home, reducing the time and space available for participants to focus on mPR.

> "Remembering to do it and having the time to do it… pushing myself…" (male 64yrs)

> "Our house is quite small …with COVID and children home there was no space to be able to do the exercises…" (male 43yrs)

Health challenges

Participants reported changes in their health status which impacted their ability to complete the intervention as prescribed or resulted in disengaging completely. The health concerns included an exacerbation of their primary respiratory condition resulting in a hospital admission, an exacerbation of a non-respiratory co-morbidity, and exercise related discomfort.

> "The pain... my arthritic pain made some of them (exercises) challenging…" (female 60yrs)

> "I got sick and then went into hospital… I still felt unwell for quite some time, and now I am on painkillers for back pain all the time and can't do much" (female 68yrs)

Impact of COVID-19

National restrictions associated with COVID-19 occurred during the study period and while some participants were able to continue with the programme uninterrupted, participants experienced challenges which caused one participant to disengage

completely from the mPR programme. Barriers reported during the COVID-19 lockdown included feeling vulnerable when out walking, the difficulty of wearing a mask whilst exercising and problems associated with extended family being at home.

> "It's the walking … going out for walks on the road … I am too frightened of getting the virus … my family said don't go out anywhere you don't need to …. Have been less active than usual" (female 58yrs)

> "Finding it really hard to wear a mask … makes it hard to go out walking" (male 35yrs)

In contrast, other participants appreciated having mPR during the national lockdown as they felt they had a structured programme to work through, and more time available to focus on the programme.

> "I have done the exercises more often, I liked having the programme and structure during COVID-19" (female 71yrs)

> "It was good to have something to focus on during lockdown" (male 80yrs)

7.6 Discussion

This study used a mixed method design to capture the personal experience of participating in mPR and found participants were highly satisfied with the flexibility, convenience, and usability of the programme. A key strength of this study was the inclusion of the majority participants in the follow-up questionnaire. Additionally, the experiences and perceptions were obtained from participants who both successfully completed the programme as well as those who did not complete. This gave insights into factors which make it harder to complete mobile-based PR programme and into the challenges patients face in using technology including in the face of a pandemic.

mPR was designed as an alternative method for delivering PR to overcome barriers faced by participants in attending centre-based programmes, and to attempt to increase the accessibility and inclusiveness of PR. Findings from this study show that the flexibility offered by mPR is a key enabler to allowing people to participate, particularly participants who would not otherwise have the opportunity due to commitments. Most centre-based services offer classes only within working hours, limiting participation for people who cannot attend at the specified times (Candy et al.,

2022). Participants who opted for mPR reported liking being able to fit it in around their schedule, and this echoes the experience of participants enrolled in other home-based models (Lahham et al., 2018b; Tsai et al., 2016). mPR allows flexibility over other delivery methods, such as videoconferencing, by allowing participants autonomy over where and when they complete the prescribed session. Participants in our study were advised to complete the programme on five days of the week and several participants reported that they would break the exercises up and complete over the course of the day rather than completing them all in one session. Further exploration is required to determine the impact of fragmenting individual exercises on building exercise capacity and, ultimately, the effectiveness of PR.

Our mPR included two-way messaging to enable participants to be able to contact health care professionals, although there was no scheduled personal contact with a member of the clinical PR team. Whilst participants were advised they could contact the clinician at any time, patient-initiated interaction seldom occurred, and this mirrors findings from other unsupervised mobile PR programmes (Bourne et al., 2017; Chaplin et al., 2017; Simonÿ et al., 2019). Whilst some participants in our study did not feel they needed personal contact, previous studies have shown that health coaching can enhance the outcomes of tele-rehabilitation programmes (Benzo et al., 2021). Providing regular touch points throughout the intervention, either digitally or in-person may have several benefits. Firstly, participants who are faced with barriers to engaging, such as technology or health concerns, may have the opportunity to overcome these barriers through coaching from a member of the PR team. A known barrier to attending PR is respiratory exacerbations and becoming unwell (Keating et al., 2011), and this was the case for several participants in this study. Increased clinician monitoring and mentoring within the intervention may have been useful to assist participants to navigate these exacerbations and return to PR in a safe and appropriate manner. In addition, health coaching may enhance the outcomes of the intervention through optimising motivation and ensuring participants are engaging appropriately with all aspects of the programme. This would have allowed for early identification and support for the participant who was unable to progress their exercise programme due to challenges responding to the text message.

The need for motivation to engage with PR programmes has been identified in previous studies exploring the patient perceptions toward telerehabilitation (Bairapareddy et al., 2021; Dobson et al., 2019; Inskip et al., 2018). Our study determined key enablers which assisted in aiding motivation for participants, for example feeling supported through the inclusion of family members, and from the daily text messaging. Previous studies have shown daily text messaging increases perceptions of support and this aligns with the findings of this study (Dobson et al., 2018). The benefits of text messaging could be considered alongside other PR delivery methods and may also add value to centre-based or telerehabilitation programmes delivered through telephone or video-conferencing facilities.

Earlier formative work to this study (Chapter 4) highlighted that a lack of peer support may be a barrier to participation in a mobile based PR programme (Dobson et al., 2019), however, the current study showed that participants did not feel this a barrier and that support was received in other ways (e.g. family members, SMS). Other published trials of home-based PR models delivered through telephone calls and video conferencing have reported similar findings (Burkow et al., 2015; Holland et al., 2017), indicating this inclusion of family and friends in the rehabilitation process is an important feature of alternative models of PR.

COVID-19, and associated lockdown restrictions, has a significant impact on the main trial and therefore influenced the results of this study. The interviews revealed that for many participants they felt unsettled and vulnerable at this time because of their respiratory condition and feared they may not survive a COVID-19 infection. Furthermore, the COVID 19 restrictions forced all the interviews to be completed over the telephone which may have limited in-depth discussion around some concepts.

7.7 Conclusion

This study has shown that an mHealth PR programme such as mPR provides a useful, usable, and satisfactory option for people living with CRD and has the potential to increase the reach of PR. This study demonstrated a key feature of mPR is the flexibility this model allows resulting in those who reported not otherwise being able to attend in-person PR and thus having the opportunity to participate in PR. Furthermore, whilst mPR may lack some features of centre-based PR such as the social

support of in-person programmes, our study found the support provided through the engagement of family and friends, along with the text messaging component, seemed to counterbalance this. Future considerations of regular clinician touch points should be explored to determine if these further enhance participation with the intervention and influence its effectiveness.

Chapter 8 Discussion

8.1 Prelude to chapter

Living with a CRD can be distressing for both people living with the condition and their family. PR is an effective treatment which can reduce the symptom burden and improve HRQoL. The efficacy of PR is undisputable. Despite this, the reach of PR is suboptimal with the number of people who are referred, attend or complete PR being low both in NZ and around the world.

The aim of this thesis was to design and evaluate an mHealth application for PR specifically for the NZ context in an attempt to address the low reach of PR in NZ. The key research objectives were:

1. To develop an understanding of current PR practises in NZ and how these might impact uptake and completion.
2. To identify factors which influence patient participation in telerehabilitation
3. To develop the content for a NZ based mHealth PR programme
4. To evaluate the content for a NZ based mHealth PR programme
5. To identify patient preference for delivery of PR via either centre-based or mHealth delivered PR, and ascertain if allowing participants to choose their delivery method improves the rate of attendance at PR.
6. To evaluate end-user experiences of the NZ purpose designed mHealth intervention (mPR).

This chapter aims to:

Integrate findings from this thesis and discuss the implications for clinical practice and research.

8.2 Overview of thesis findings

Despite being highly effective, the reach of PR is poor with access, uptake, and completion rates low around the world (Holland et al., 2021). There are well known reasons which include both patient related factors (including transport and travel, gender, ethnicity, and socioeconomic status) and organisational factors (including location and timing, type of programme and wait times). The stimulus for this thesis

was to improve the reach of PR in NZ. Our research prior to this thesis explored factors which prevented participants from completing PR and identified age, ethnicity, and exercise capacity as independent predictors of non-completion (Candy et al., 2020a). The survey findings in Chapter 2 extended this knowledge by outlining the structure, content, and organisation of PR services in NZ, allowing us to have a clearer understanding of similarities as well as differences across the country. This survey provided baseline information of how PR services currently operate across NZ and how the structure and organisation of services might impact widespread access to PR. Our findings that most PR services offered just one delivery structure - an in-person programme provided within working hours only, highlighted the potential for expanding reach by developing different models of PR. Whilst different models have been evaluated overseas, no such models have been designed, evaluated, or implemented in NZ.

Following COVID-19 restrictions imposed shortly after the closing date for Survey 1, all services ceased face-to-face delivery of PR providing an unprecedented opportunity to explore how services adapted to this sudden change in circumstances. A second survey was administered to the same participants requesting they report any adaptations to their service as a result of the COVID-19 restrictions. The result showed that 59% (16/27) services who responded to this second survey continued to operate a service, albeit modified, during national restrictions, with the majority of respondents providing the services via the telephone. This choice of telephone-based PR was reported as the patient preference and was attributed to low digital access and/-or literacy. Of those who completed the survey, 37% (10/27) intended to keep their telerehabilitation service operating as an ongoing option for participants after resumption of face-to-face services, suggesting that the service providers and patients identified ongoing benefits in providing a telerehabilitation service. This further validated our decision to design an mHealth programme with a NZ focus and to consider the design of the mPR programme.

The objective of the scoping review in Chapter 3 was to source current literature regarding the uptake, perceptions, and experiences of participants to engaging with telerehabilitation models. The information gathered in the literature review would help shape the content development for an mHealth PR programme. Findings from the

scoping review revealed that, digital access and literacy were barriers for many participants who believed that telerehabilitation would be outside their capabilities, and that *perception* is of upmost importance, the way that telerehabilitation is marketed to potential participants, may have a significant impact on the uptake. For instance, some of the perceived barriers to uptake, such as technical challenges, in turn, shown to be minor, and the anticipated lack of support from peers was replaced by a feeling of support from family members and the mPR programme.

Amalgamated findings from the surveys and scoping review highlighted key considerations for the development of telerehabilitation programmes, including:

1. addressing low digital confidence by including options that do not require complex technical skills,
2. using technology which is accessible and familiar to patients, such as mobile phones and text messaging,
3. including technical support to all participants.

The information from Chapters 2 and 3 led to the content development of an mHealth application for PR in NZ. By using the mHealth development framework (Whittaker et al., 2012) we were able to engage with patients and clinicians along the journey and, through an iterative process of testing and modifying, develop an intervention to attempt to meet the needs of our NZ context. The foundation for the first iteration of the mHealth application (mPR V1) was text messaging (SMS), as this had been shown to overcome the challenges of device and data access as well as low digital literacy. The SMS messaging continued to be an important component of the intervention into mPR V2, as SMS provided an ideal opportunity for delivering behaviour change techniques (BCT). Supporting long term behaviour change is a core goal of PR programmes, and BCTs can be useful for helping participants to increase physical activity and exercise (Hanrahan et al., 2021). The clinical benefits achieved from completing PR are often lost over time as patients are unable to maintain exercise habits (Spencer & McKeough, 2019) and by incorporating BCTs into mPR it was hoped this would support sustained changes in behaviour and potentially longer-term clinical improvements. SMS has the potential to improve the longevity of exercise habits through providing support for longer than the standard eight weeks duration of PR

programmes. A longer duration SMS programme could easily and affordably be set up to send motivating, encouraging SMS to keep exercising and maintain the changes in behaviour.

The key findings of Chapters 5, 6 and 7 showed that the addition of mPR to centre-based services has the potential to increase the reach of PR in NZ, particularly to the groups marginalised in current services. From the preference-based clinical trial (Chapter 6), 36% (38/105) of participants chose mPR rather than centre-based PR, and these were generally younger, employed people who have traditionally been underrepresented in centre-based programmes. This was an important finding as our earlier research showed age was an independent predictor of completion of PR with a greater likelihood of completing PR with each per year increase in age (OR 1.04, (1.03-1.05) p<0.001) (Candy et al., 2020a).

Whilst a key objective of this thesis was to determine if an mHealth delivered PR programme would improve the attendance and completion of PR in NZ, determining a valid and reliable measure of attendance for an unsupervised mHealth PR intervention was inherently challenging. Our proxy measure of attendance in the mPR group, (requiring participants to respond to two key SMS per week regarding their exercise diary and readiness to progress their exercise programme), was designed to be comparable to the centre-based group attendance measure and similar to other unsupervised PR programme that measured adherence through activity diaries and self-reports (Hoaas et al., 2016; Holland et al., 2017) . However, results from the preference based clinical trial (Chapter 6) indicate our measure of attendance had limitations. Participants were less likely to answer the *specific* question regarding 'how many times the patient completed the exercises' than the *general* question regarding progressing their exercise. The *specific* question may have been challenging for participants if they could not recall the exercise completion information, or participants may not have wished to share this information if it was below the recommended frequency. Other web-based applications have collected systems and app usage data to measure adherence (Benzo et al., 2018; Bourne et al., 2017; Chaplin et al., 2017; Hoaas et al., 2016). Such systems measures include the number of times participants log into the app or interact with the app. However, whilst these app usage statistics provide useful information about how often the app is accessed, similar to

the self-reported measure of attendance, they are not able to provide information on if the exercises were completed as prescribed. Whilst the completion rate in the mPR group in our study appeared low (53%) from the self-reported measure of attendance used for this study, integration of findings from the preference-based clinical trial (Chapter 6) and the end-user experience study (Chapter 7), suggested that engagement with mPR was higher than the completion measures suggested. Perhaps a measure of adherence to the programme and fidelity to the intervention should be whether participants achieve clinical benefit. Data from the experiences of end-users in Chapter 7 indicates that most participants engaged meaningfully and reported health benefits from participation in mPR, and this is supported by the clinically significant improvements in HRQoL reported in both the centre-based and mPR groups in Chapter 6. Further work is required to establish an accurate measure of adherence and as technology and technical skills advance it is likely innovative and interactive measures will become more readily available. Ideally participants would enter a BORG score on their device at the end of each exercise, similar to a centre-based PR programme, and this data would be readily available to the PR clinician.

Participants reported feeling supported in managing their health condition and this support from came from the mPR programme, and from family members who became involved in their programme. This echoes findings from other studies (Lahham et al., 2018b) and indicates that people participating in telerehabilitation models can feel similarly supported to those attending centre-based models. Family support has been found to have a statistically significant association with both self-care behaviour and self-efficacy in people living with COPD (Kara Kaşıkçı & Alberto, 2007). The importance of family involvement was identified in our formative study (Chapter 4) with the inclusion of family members being identified as a facilitator to participation in telerehabilitation. This was reinforced in the feasibility study (Chapter 4) by feedback from both participants who had family members involved, and the family members themselves. Providing family members, the option to be involved in the mPR programme was a unique feature of this PR programme that to best of our knowledge has not been offered by other web-based PR programmes, and it was clear that mutual benefits for patients and family members were attained from participation in the mPR programme.

The protocol amendments brought about in response to the COVID-19 pandemic provided interesting data which warrants further consideration. The group that chose centre-based PR but were required to change to telerehabilitation (telephone or video-conferencing models) yet maintained significant engagement with their PR programme despite the change of model, and surprisingly, had a completion rate higher than that previously reported from centre-based PR (Candy et al., 2020a). We believe the forced lockdown is likely to have influenced these results, as patients were at home and available for telephone calls and VC classes and feeling particularly vulnerable during the COVID-19 pandemic because of their CRD diagnosis. This shows patients who had a preference for centre-based PR, were able to consistently engage with an alternative model for delivery of PR. The majority of centre-based participants opted for telephone calls during this time. This is consistent with the findings in our second post COVID-19 survey (Chapter 2) and similar to another study conducted during the COVID-19 pandemic which reported 75% of participants enrolled in PR who were required to transition to telerehabilitation (telephone calls or VC classes), only had access to telephone calls (Grosbois et al., 2021). This further reinforces the findings of our scoping review (Chapter 3), suggesting that having access to the required technical equipment and the skills to operate digital devices remains a significant limitation in the choice of telerehabilitation options.

The provision of technical support for all participants, regardless of digital literacy, is one aspect of our mPR programme that requires further exploration. Providing this support is likely to further enhance engagement with all aspects of the intervention. Furthermore, consideration should be given into exploring the addition of regular, scheduled clinician contact points to the intervention. Studies have shown patient initiated interactions occur less frequently than do clinician-initiated interactions (Bourne et al., 2017; Chaplin et al., 2017; Skibdal et al., 2022) and thus investigating the impact of this on our mPR attendance and completion may be useful. Regular scheduled clinician contact would allow the development of therapeutic relationships allowing for provision of information, motivation, and support which may improve attendance and completion of mPR. For example, it is suggested that BCT, such as goal setting, providing feedback on performance and discussions around how to overcome barriers should be included in the programme. Holland et al. (2017) described

motivational interviewing techniques used during weekly telephone calls to participants enrolled in home-based PR and showed high adherence to the intervention and clinical outcomes equivalent to centre-based PR. Qualitative data from participants enrolled in home based PR receiving telephone calls report the communication has been shown to be effective, increased participation and provide social support (Lahham et al., 2018b). Similarly, adding health coaching to a web-based PR programme via weekly telephone calls has been shown to result in high rates of adherence to the intervention (Benzo et al., 2018).

The key strength of this programme of research is the firm clinical foundations on which this work is based. The candidate has over 20 years clinical experience working with people with chronic respiratory conditions in NZ, and this enabled key clinical perspectives, often specific to NZ, to be considered throughout. The studies in this thesis generally used pragmatic designs that could be adapted to suit the clinical and home settings, and all provided information useful for development and implementation of new knowledge in helping people in NZ to access PR services. For example, NZ has a culturally diverse population and the mPR programme was tailored to culture including greetings and key messages in Māori and Pacific languages, as well as using a range of patients to reflect the culture, age and illness severity of the group the mPR programme was designed for. The process of developing the content of the mPR programme was based on theory and evidence and used a well developed and tested framework to ensure end-users were involved in the design of the mPR programme from the onset. The framework ensured an iterative process whereby the intervention was repeatedly reviewed and refined to be responsive to both patient and clinicians. The design and testing of mPR was completed by a multidisciplinary team of healthcare and mHealth experts.

When testing the mPR programme, a pragmatic approach was taken to evaluate whether mPR would impact upon PR attendance and completion by implementing a preference-based study. Commonly, patients have a preference for how they wish to receive interventions, such as PR, and allowing them a choice of delivery method makes this research valuable. The research design employed in preference-based clinical trials reflects clinical practise and closely mirrors how future interventions could be implemented. Many previous PR studies use patient cohorts that do not

always represent the clinical setting. For example, many studies exclude patients with supplemental oxygen, those that use walking frames and those with co-morbidities. This reduces the external validity of the studies making them less representative of the real-world patient population. The preference study excluded only 19% (24/129) of participants referred to PR and allowed patient-led decision making, thus providing valuable information to PR service providers and funders.

Our necessity to adapt to the COVID-19 pandemic and national restrictions during the period of this programme of study is a major strength of this study. The additional survey (Chapter 2) implemented after COVID-19 restrictions were implemented utilised an opportunity to gather important additional information and showed how programmes adapted at short notice to the cessation of centre-based PR programmes. Likewise, the preference-based clinical trial (Chapter 6) required significant adaption to protocol due to the COVID-19 restrictions but was able to be adjusted and continue, enabling valuable information on how services and patients adapted to the unique circumstances. The study of participant experiences (Chapter 7) highlighted the impact of the pandemic and related restrictions on patients and how this affected them during their engagement with the mPR programme. This study captured data through an uncertain and unique period in history.

8.3 Implications for future research

The preference-based clinical trial has shown that adding telerehabilitation to centre-based PR has the potential to increase the reach of PR in NZ. This study has shown some patients would prefer an mHealth delivered PR programme and these were often those who would not otherwise be able to attend centre-based PR, thus, indicating there is a demand for alternative methods of delivery. Further works should try to elucidate more information regarding the demographic details of those patients who are eligible for and who do or do not currently access PR. Eliciting reasons for non-attendance of eligible participants at all types/modes of PR programmes could assist in developing more participant friendly PR options particularly in those who are currently underserved by our PR services. The surveys reported in Chapter 2 did not capture information on programme capacity or data on attendance and completion; neither did the surveys aim to look at discrepancies regarding availability of PR services across different communities, ethnicities, or socio-economic status. We realise this may influence the uptake and adherence to PR and warrants further

investigation. A national audit programme, such as the series of audits National Asthma and COPD Audit Programme (NACAP) in England and Wales (Steiner et al., 2015b), could provide valuable data on the reach of services across the whole of NZ and identify potential gaps.

Our study investigating the preferences of patients for centre-based PR or mPR (Chapter 6) illustrated that participant who started in centre-based PR and pivoted to telerehabilitation achieved greater than previously reported attendance and completion at traditional centre-based PR. This suggested there may be a role for hybrid models of care, such as a shorter centre-based programme with transitioning to telerehabilitation. This may reduce some of the burden and expense of attending centre-based PR for both participants and health care providers, may increase availability of centre-based PR places and improve completion outcomes. This type of programme structure was used in a six-month intervention in Korea, where participants completed one month of centre-based PR before randomisation to web-based PR or a control group who received one monthly telephone calls (Park et al., 2020b). In this study, adherence to the intervention was high and this was reflected in significant clinical improvements. The evaluation of hybrid models of PR warrants further investigation.

A limitation of our research relates to our lack of measurement of changes in self-efficacy. The mPR intervention had a focus on building self-efficacy through the BCTs incorporated into the intervention but no outcome measure was incorporated for the measurement of changes in self-efficacy. Whilst planning the protocol for the preference-based study (Chapter 5), we opted not to use too many outcome measures due to the increased burden on the participant of completing many questionnaires remotely. Future studies could consider the inclusion of a measure of self-efficacy, such as the PRAISE tool (Liacos et al., 2019; Vincent et al., 2011) to determine the effect of such interventions on self-efficacy.

Importantly, future research should include long term follow up. As defined by ATS/ERS (Martijn A Spruit et al., 2013) an essential component of PR is behaviour change. It could be suggested that unsupervised based PR programmes such as mPR, may have more sustained benefits as they train the participant to become independent in their own exercise programme in their own environment, rather than

reliant on supervision and guidance from a clinician in an 8-week programme. Behaviour change theory was an important foundation in the content development of mPR and many BCT were woven into the mPR intervention. Due to time restrictions associated with study funding longer term follow-up of participants was not possible, but future studies should include longer term follow-up, such as 12 months post intervention, to determine if mPR can achieve sustained clinical improvements.

8.4 Clinical Implications

To address the problem of low reach of PR, we propose that services need to diversify and offer differing options for PR delivery to facilitate better uptake and engagement. We have demonstrated that PR services in NZ, prior to the COVID-19 associated lockdown, had only one delivery model of PR and this limited access for some participants. PR services typically offered one in-person option, and that option was during work hours and often at a busy hospital site. This means that younger, working participants may not be given equitable opportunities to attend current services. This, coupled with earlier onset of CRD in Māori, creates inequitable access to care. The development of new culturally appropriate models to enable all eligible participants to engage with PR should be undertaken and investigated. If such models are mHealth related then consideration must be given to technical training and support, data provision family/peer support and regular scheduled clinician contact points. Our mPR programme is an early prototype that with further refining and developing, such as translating into Māori and Pacific languages along with including diverse patient stories describing the benefits they achieved from PR, may further help to improve the reach of PR.

Developing a therapeutic relationship and having regular communication with a clinician appears to play an important role in participant's adherence and motivation (Lahham et al., 2018b; Skibdal et al., 2022). Lack of clinician contact was reported as a perceived barrier to telerehabilitation and discussed in literature reporting patient experiences with telerehabilitation (Chapter 3). Designing alternative models for delivering PR must consider this as a crucial element. The recent guidelines outlining essential components of new PR programmes (Holland et al., 2021) considers regular clinician contact as a desirable component rather than an essential one. This is due to the lack of available evidence to define this contact further (frequency of contact,

nature of contact, e.g., supervised exercise or individual health coaching). The available evidence does suggest these needs to be clinician-initiated. Future delivery models of PR may consider weekly scheduled clinician contact to overcome challenges to participation and maximise engagement, provide information and build on behaviour change techniques. The frequency of input maybe adapted over time as studies have shown the greatest challenge exists for participants in getting started (Lahham et al., 2018b), suggesting that a fading frequency would work well.

Equally important is the inclusion of family in the intervention. Findings from our formative study (Chapter 4), feasibility study (Chapter 4) and end-user experience study (Chapter 7) all confirm the importance of family support in PR. Future programme developments should ensure there is a strong focus on building capacity and opportunity for family and whānau, to play an important role in the PR programme.

Many users of PR programmes are older adults who have reported feeling intimidated by technology. Providing options with low digital difficulty and adequate technical support will assist outcomes. This, however, is likely to change with time as we move of a technically naive cohort to technology being integrated into everyday lives. The role of SMS as a tool for providing support and delivering behaviour change techniques in PR should be encouraged. The feedback provided in the study exploring the feasibility of our mPR V1 (Chapter 4) along with end-user feedback from participating with mPR (Chapter 7) shows that participants found the SMS useful, and they read all the messages. SMS has been shown to support behaviour change in other groups and may have a valuable role in improving the sustainability of benefits of PR. SMS also reduces known barriers to digital programmes, including access and digital literacy, as it is the most ubiquitous of the technologies. SMS could be implemented in any model of PR, whether centre-based, telephone calls, VC or web-based.

Improving the perception of PR - both centre-based and telerehabilitation- may improve the uptake of PR, by focusing on the benefits that can be achieved from participation and enhancing patient's confidence in their ability to partake and achieve health improvements. The best way to do this is not known, but feedback from end-users in the development of mPR (Chapter 4) reported the value of patient stories,

particularly if the patient was someone they could relate to. Utilising a diverse range of patient's to tell their stories of the benefits they have achieved and their positive experiences participating from in PR may enhance uptake and engagement with PR.

8.5 Conclusion

No one model for PR will fit all potential PR participants. Whilst many prefer centre-based this is not practical, accessible, or preferred by everyone, and telerehabilitation models, such as our mPR programme, may offer an opportunity for some people to attend who would not otherwise be able to participate. There are many known barriers to attending centre-based PR, but equally many barriers exist to participation with telerehabilitation. Important considerations for future PR models include provision of necessary equipment (device, data), assistance with the skills required (technical, language) and personal factors (family inclusion, clinical contact points).

What we have learnt to appreciate most is that there will be no one best model and services need to be adaptable and offer diversity in delivery of rehabilitation to increase the reach of PR. An ideal PR service would allow a flexible menu of delivery options to best suit the needs and preferences of participants.

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Appendices

Appendix A. Ethics Survey 1

3 May 2019

Denise Taylor
Faculty of Health and Environmental Sciences
Dear Denise

Ethics Application: **19/119 Characteristics of pulmonary rehabilitation programmes in New Zealand: A survey of current practice**

Thank you for submitting your application for ethical review. I am pleased to advise that the Auckland University of Technology Ethics Committee (AUTEC) approved your ethics application at their meeting on 29 April 2019, subject to the following conditions:

1. Limit the follow-up reminders about the survey to once only;
2. The data must be stored with the Applicant;
3. In the Introductory email or the Participant Information Sheet please insert the url for the survey to limit the back-and-forth between the researcher and the participants; remove the statement about being sent a link to the survey from the Information Sheet;
4. Amendment of the Information Sheet as follows:
    a. Clarify the criteria for being the 'best person' to respond to the survey on behalf of the programme;
    b. Remove the offer of counselling and the ACC statement;
    c. Disclose the Primary Researcher's professional role;
    d. Ensure complete contact details for both supervisors.

Please provide me with a response to the points raised in these conditions, indicating either how you have satisfied these points or proposing an alternative approach. AUTEC also requires copies of any altered documents, such as Information Sheets, surveys etc. You are not required to resubmit the application form again. Any changes to responses in the form required by the committee in their conditions may be included in a supporting memorandum.

Please note that the Committee is always willing to discuss with applicants the points that have been made. There may be information that has not been made available to the Committee, or aspects of the research may not have been fully understood.

Once your response is received and confirmed as satisfying the Committee's points, you will be notified of the full approval of your ethics application. Full approval is not effective until all the conditions have been met. Data collection may not commence until full approval has been confirmed. If these conditions are not met within six months, your application may be closed and a new application will be required if you wish to continue with this research.

To enable us to provide you with efficient service, we ask that you use the application number and study title in all correspondence with us. If you have any enquiries about this application, or anything else, please do contact us at ethics@aut.ac.nz.

I look forward to hearing from you,

Yours sincerely

Kate O'Connor
Executive Manager
Auckland University of Technology Ethics Committee

Cc: scandy@middlemore.co.nz; Julie Reeve

Appendix B. Ethics Survey 2

21 August 2020

Denise Taylor
Faculty of Health and Environmental Sciences
Dear Denise

Re: Ethics Application: **19/119 Characteristics of pulmonary rehabilitation programmes in New Zealand: A survey of current practice**

Thank you for your responses to the conditions for the amendments to your ethics application.

The amendment for a second survey to be sent to the same participants, with altered questions, related to changes made in their programmes in response to COVID 19 is approved.

I remind you of the **Standard Conditions of Approval**.

1. The research is to be undertaken in accordance with the Auckland University of Technology Code of Conduct for Research and as approved by AUTEC in this application.
2. A progress report is due annually on the anniversary of the approval date, using the EA2 form.
3. A final report is due at the expiration of the approval period, or, upon completion of project, using the EA3 form.
4. Any amendments to the project must be approved by AUTEC prior to being implemented. Amendments can be requested using the EA2 form.
5. Any serious or unexpected adverse events must be reported to AUTEC Secretariat as a matter of priority.
6. Any unforeseen events that might affect continued ethical acceptability of the project should also be reported to the AUTEC Secretariat as a matter of priority.
7. It is your responsibility to ensure that the spelling and grammar of documents being provided to participants or external organisations is of a high standard.

AUTEC grants ethical approval only. You are responsible for obtaining management approval for access for your research from any institution or organisation at which your research is being conducted. When the research is undertaken outside New Zealand, you need to meet all ethical, legal, and locality obligations or requirements for those jurisdictions.

Please quote the application number and title on all future correspondence related to this project.

For any enquiries please contact ethics@aut.ac.nz. The forms mentioned above are available online through http://www.aut.ac.nz/research/researchethics

(This is a computer-generated letter for which no signature is required)

The AUTEC Secretariat
Auckland University of Technology Ethics Committee

Cc: scandy@middlemore.co.nz; Julie Reeve

Appendix C. Advertisement for Participants

Dear CTSIG members

***RE. Characteristics of Pulmonary Rehabilitation Programmes in New Zealand. A survey of current practise**.

I am undertaking a research project in the area of pulmonary rehabilitation. This research is part of my post graduate qualification.

The aim of the survey is to gather a baseline of what current practise of pulmonary rehabilitation looks like, and to see how this has developed over the past decade.

As part of my research I would like to establish where the pulmonary rehabilitation services are located throughout NZ and to make contact with the lead clinician. Ideally, the survey will include all pulmonary rehabilitation services across New Zealand.

If you lead a pulmonary rehabilitation programme, can you please contact me, or alternatively provide my contact details to your lead clinician for pulmonary rehabilitation so they can participate in the survey.

The survey is confidential and no data on individual services will be reported. All data will be collated and reported on as a whole service across NZ. For more information on the research, I would be very happy to discuss or send through further information.

Many thanks for your assistance,

Sarah Candy

Pulmonary Rehabilitation Coordinator

Counties Manukau Health

0274 363116

scandy@middlemore.co.nz

Appendix D. Survey 1 PIS

Participant Information Sheet

Date Information Sheet Produced:

04 May 2019

Project Title

Characteristics of Pulmonary Rehabilitation Programmes in New Zealand. A survey of current practise.

An Invitation

I would like to invite you to participate in an online survey looking at pulmonary rehabilitation services in NZ. This survey will be used to establish a baseline of what current practise looks like in 2019.

The survey is voluntary. Only one response per PR programme is required. The programme coordinator or lead clinician should complete the survey. The survey will be able to provide the most useful information to this field of knowledge if we can include as many of the current services as possible in the survey.

Your responses will be confidential and no personal details will be used. You will not be identified personally.

This survey is part of post graduate study for my post graduate qualification through AUT.

What is the purpose of this research?

This survey is being conducted to establish a baseline of the characteristics of pulmonary rehabilitation programmes in New Zealand. It will aim to identify is service provision is meeting demand. It will also look at how services have evolved in the past decade in terms of; provision, distribution, utilisation, conditions seen and delivery of programmes.

How was I identified and why am I being invited to participate in this research?

All PR services in NZ that meet the definition of a pulmonary rehabilitation programme will be invited to participate in the survey. This inclusion criterion includes;

1. The programme includes a physiotherapist or exercise physiologist
2. Is a minimum of 6 – 8 weeks in duration
3. Includes functional metrics (eg, 6 MWT)
4. Includes a measure of health related quality of life
5. Includes exercise and educations.

The quality of the information will depend on as many services as possible being included.

You have been identified as a pulmonary rehabilitation coordinator or key person for your PR service.

How do I agree to participate in this research?

Your participation in this research is voluntary (it is your choice) and whether or not you choose to participate will neither advantage nor disadvantage you. You are able to withdraw from the study at any time. If you choose to withdraw from the study, then you will be offered the choice between having any data that is identifiable as belonging to you removed or allowing it to continue to be used. However, once the findings have been produced, removal of your data may not be possible.

If you are willingly to be part of the study, please return this email with confirmation you are interested in participating.

What will happen in this research?

The survey can be found on the following link;

Alternatively, you can send an email to me and I will forward the survey link to you.The first section of the survey includes you providing consent to be part of the research. The survey will take approximately 10 minutes to complete. There is no work required prior to completing the survey. Many of the questions will give options for answers and space will be available if you wish to provide more information. If you have any questions, you are welcome to contact me at any time.

Once all data is collated you will be sent a brief research report if requested.

What are the discomforts and risks?

There are no risks with completing this survey.

What are the benefits?

This survey will contribute towards my post graduate qualification.

The benefits to this research are the ability to see what current practise looks like in NZ and how this has changed in the past decade. This will allow areas for potential service development to be identified. For the wider community the benefits of PR are well established, and the research can assist in exploring how we can improve access to this intervention for people living with chronic respiratory conditions.

How will my privacy be protected?

Your personal information will not be recorded or shared at any time.

All information shared will be confidential. The data shared will be combined and no individual service or programme will be reported on.

What are the costs of participating in this research?

The only cost to participation will be the time taken to complete the survey.

What opportunity do I have to consider this invitation?

Two weeks

Will I receive feedback on the results of this research?

A brief research report will be completed and sent to you if requested. This will be prior to publication of results.

What do I do if I have concerns about this research?

Any concerns regarding the nature of this project should be notified in the first instance to the Project Supervisor,

Dr Denise Taylor or Dr Julie Reeve

Concerns regarding the conduct of the research should be notified to the Executive Secretary of AUTEC, Kate O'Connor, *ethics@aut.ac.nz* , 921 9999 ext 6038.

Whom do I contact for further information about this research?

Please keep this Information Sheet and a copy of the Consent Form for your future reference. You are also able to contact the research team as follows:

Researcher Contact Details:

Sarah Candy

Physiotherapist / Pulmonary Rehabilitation Coordinator

Counties Manukau Health

021 414908

Project Supervisor Contact Details:

Dr Julie Reeve

Senior Lecturer

AUT North Campus

09 921 9999 ext 7085

Prof Denise Taylor

Senior Lecturer

AUT North Campus

09 921 9999 ext 9680

Approved by the Auckland University of Technology Ethics Committee on 21 May 2019 AUTEC Reference number 19/119.

Appendix E. Survey 2 PIS

Participant Information Sheet

Date Information Sheet Produced:

20 August 2020

Project Title

Characteristics of Pulmonary Rehabilitation Programmes in New Zealand. A survey of practise in response to COVID 19.

An Invitation

Thank you for completing the survey on the characteristics of your pulmonary rehabilitation service. I would like to invite you to participate in a follow up online survey to identify how services have changed in response to COVID 19.

The survey is voluntary. Only one response per PR programme is required. Ideally, the same person who completed the first survey would complete the follow up survey. If this is not possible, then the lead clinician or pulmonary rehabilitation co-ordinator would complete the follow-up questions. The survey will be able to provide the most useful information to this field of knowledge if we can include as many of the current services as possible in the survey.

Your responses will be confidential and no personal details will be used. You will not be identified personally.

This survey is part of post graduate study for my post graduate qualification through AUT.

What is the purpose of this research?

The purpose of this survey is to identify how PR services have changed in response to COVID 19. This will be compared to the characteristics of PR services identified in the previous survey in 2019.

How was I identified?

You were identified because you completed an earlier survey on the characteristics of PR services in NZ and gave approval for this.

How do I agree to participate in this research?

Your participation in this research is voluntary (it is your choice) and whether or not you choose to participate will neither advantage nor disadvantage you. You are able to withdraw from the study at any time. If you choose to withdraw from the study, then you will be offered the choice between having any data that is identifiable as belonging to you removed or allowing it to continue to be used. However, once the findings have been produced, removal of your data may not be possible.

If you are willingly to be part of the study, please sign the consent form attached and return this to me. You can scan or photograph the consent and return, or you can copy the content of the attached consent form into an email with a sentence indicating your agreement.

The survey link will then be sent to you via email.

What will happen in this research?

If you are happy to be part of the research, you will be sent a link to the survey via email. The first section of the survey includes you providing consent to be part of the research. The survey will take approximately 10 minutes to complete. There is no work required prior to completing the survey. Many of the questions will give options for answers and space will be available if you wish to provide more information. If you have any questions, you are welcome to contact me at any time.

Once all data is collated you will be sent a brief research report if requested.

What are the discomforts and risks?

There are no risks with completing this survey.

What are the benefits?

This survey will contribute towards my post graduate qualification.

The benefits to this research are to see how services adapted and responded to the COVID 19 pandemic and how this has changed the delivery of PR in NZ. The information may also inform the development of telehealth services in NZ in response to the needs of the PR services.

How will my privacy be protected?

Your personal information will not be recorded or shared at any time.

All information shared will be confidential. The data shared will be combined and no individual service or programme will be reported on.

What are the costs of participating in this research?

The only cost to participation will be the time taken to complete the survey.

What opportunity do I have to consider this invitation?

Two weeks

Will I receive feedback on the results of this research?

A brief research report will be completed and sent to you if requested. This will be prior to publication of results.

What do I do if I have concerns about this research?

Any concerns regarding the nature of this project should be notified in the first instance to the Project Supervisor,

Dr Denise Taylor or Dr Julie Reeve ***09 921 9680***

Concerns regarding the conduct of the research should be notified to the Executive Secretary of AUTEC, Dr Carina Meares, *ethics@aut.ac.nz* , 921 9999 ext 6038.

Whom do I contact for further information about this research?

Please keep this Information Sheet and a copy of the Consent Form for your future reference. You are also able to contact the research team as follows:

Researcher Contact Details:

Sarah Candy

scandy@middlemore.co.nz

Physiotherapist / Pulmonary Rehabilitation Coordinator

Counties Manukau Health

021 414908

Project Supervisor Contact Details:

Dr Julie Reeve	***Prof Denise Taylor***
Senior Lecturer	Professor
AUT North Campus	***AUT North Campus***
09 921 9999 ext 7085	***09 921 9680***

Approved by the Auckland University of Technology Ethics Committee on 21 August AUTEC Reference number 19/119.

Appendix F. Survey 1 Questions

Confidential

Pulmonary Rehabilitation New Zealand National Survey

Thank you for taking the time to provide information about your pulmonary rehabilitation programme.

Your responses will help us to develop an accurate baseline of what current practise for pulmonary rehabilitation looks like in New Zealand. The information you provide will contribute to collective data, but no individual programme will be identifiable. The survey is a stocktake of current services and no comparison will be made between services. The responses will be kept confidential.

Please answer all questions to the best of your ability. Questions can be skipped if the details are unknown, but please answer as many questions as possible. The survey can not be saved and needs to be completed in one sitting.

The survey will take approximately 20 minutes to complete.

Consent questions;

I have read and understood the information provided about this research project in the Information Sheet dated March 2019.

I have had an opportunity to ask questions and to have them answered.

I understand the answers I complete in the survey will be stored and collated.

I understand that taking part in this study is voluntary (my choice) and that I may withdraw from the study at any time without being disadvantaged in any way.

I understand that if I withdraw from the study then I will be offered the choice between having any data that is identifiable as belonging to me removed or allowing it to continue to be used. However, once the findings have been produced, removal of my data may not be possible.

I agree to take part in this research.

Thank you!

Consent	
I agree to take part in this research study	◯ Yes ◯ No
Thank you for your time.	_____
Do you currently run an exercise based rehabilitation programme for people with chronic lung conditions?	◯ Yes ◯ No
Thank you for your time	_____

Section One.
This section relates to the set up of your programme.

1.1 Please describe which professional group you belong to?
- ◯ Physiotherapist
- ◯ Exercise Physiologist
- ◯ Nurse
- ◯ Other

1.1b Other (please specify)

_____

1.2 Who funds your pulmonary rehabilitation programme? (tick all that apply)
- ☐ DHB (District Health Board)
- ☐ PHO (Primary Health Organisation)
- ☐ NGO (Non-Government Organisation)
- ☐ Mixed Funding
- ☐ Health Insurance Provider
- ☐ Self Funded
- ☐ Unsure
- ☐ Other

1.2b Other (please describe)

_____

1.3 Please describe who is the provider of the pulmonary rehabilitation programme?
- ☐ DHB (District Health Board)
- ☐ PHO (Primary Health Organisation)
- ☐ NGO (Non- Government Organisation)
- ☐ Partnership
- ☐ Private Clinic
- ☐ Other

1.3b Other (please specify)

_____

1.4 Is your pulmonary rehabilitation programme a group programme?
- ◯ Yes
- ◯ No (individual)
- ◯ Both
- ◯ Other

1.4b Other

_____

1.5 Are all the pulmonary rehabilitation programmes you offer run at the same site or different sites?
- ◯ Same site
- ◯ Different sites

1.6 Where are your programmes held? (Please tick all that apply).
- ☐ Hospital inpatient
- ☐ Hospital outpatient
- ☐ Community site
- ☐ Marae
- ☐ Church
- ☐ Water based
- ☐ Private practise
- ☐ Home based
- ☐ Telerehab
- ☐ Other (please specify)

1.6b Home based	◯ Supervised ◯ Unsupervised
1.6c Telerehabilitation (tick all that apply)	☐ Text Messaging ☐ App Based ☐ Video Conferencing ☐ Exercise Video ☐ Phone calls ☐ Other (please specify)
1.6d Water based	◯ Hospital Pool ◯ Community Pool ◯ Other (please specify)
1.6e Other (please specify)	_____
1.7 What would be the longest travel time for people to attend your pulmonary rehabilitation programme?	◯ < 30 minutes ◯ 30 - 60 minutes ◯ > 60 minutes
1.8 Is your programme a rolling (continuous) or block (set start and finish date) programme	◯ Rolling ◯ Block ◯ Other
1.8b Other (please specify)	_____
1.9 How many times per week do people attend the programme?	◯ Once Weekly ◯ Twice Weekly ◯ Thrice Weekly ◯ Other
1.9b Other (please specify)	_____
1.10 Please state how many weeks the programme runs for?	◯ < 6 weeks ◯ 6 - 8 weeks ◯ 9 - 10 weeks ◯ > 10 weeks ◯ Other (please specify)
1.10b Other (please specify)	_____
1.11 When do you offer your classes? (please tick all that apply).	☐ Normal working hours (0800 - 1700) ☐ Before work (< 8 am) ☐ After work (> 5 pm) ☐ Weekends ☐ Other
1.11b Other (please specify)	_____

1.12 Please describe the content of your programme?

- ◯ Exercise only
- ◯ Education only
- ◯ Exercise and group education
- ◯ Exercise and individual education
- ◯ Other

1.12b Other (please specify)

_____

1.13 Can you please select the respiratory conditions you would enrol in your programme? (tick all that apply)

- ☐ COPD
- ☐ Asthma
- ☐ Bronchiectasis
- ☐ Interstitial Lung Disease (ILD)
- ☐ Obstructive Sleep Apnoea (OSA)
- ☐ Lung Cancer
- ☐ Prehabilitation
- ☐ Post Lung Surgery
- ☐ Other (please specify)

1.13b Other (please specify)

1.14 Is your exercise rehabilitation programme a multi condition rehabilitation programme? (i.e for other conditions not just respiratory)

- ◯ Yes
- ◯ No

1.14b Please describe the conditions seen in your programme

_____

1.15 Does your programme offer any of the following adaptations for people of different cultural backgrounds? (please tick all that apply)

- ☐ Single culture class only
- ☐ Translators / Interpreters available
- ☐ Booklets / handouts in different languages
- ☐ Education sessions in different languages
- ☐ Location of programme adapted to cultural needs (e.g Marae)
- ☐ Programme delivery adapted to different cultures
- ☐ Programme supervisors from own cultural backgrounds
- ☐ Other
- ☐ None

1.15b Which cultures do you provide individual classes for?

_____

1.15c Which languages do you interpreters/translators available for?

_____

1.15d Which languages do you have written resources available in?

_____

1.15e Which languages are your education sessions available in?

_____

1.15f Which locations?

_____

1.15g Please describe

_____

1.15h Which cultures are your staff/supervisors from?

_____

1.15i Please describe

_____

1.16 Who refers to your progamme? (please select all that apply)

- ☐ Self referral
- ☐ GP
- ☐ Respiratory Physician
- ☐ Other Medical Officer
- ☐ Physiotherapist
- ☐ Other Allied Health
- ☐ Nurse
- ☐ Other (please specify)

1.16b Other (please specify)

_____

1.17 Please list the different people who are directly involved in the DELIVERY of your pulmonary rehabilitation in your centre (please tick all that apply)

- ☐ Nurse
- ☐ Exercise physiologist
- ☐ Physiotherapist
- ☐ Doctor
- ☐ Dietician
- ☐ Health psychologist
- ☐ Occupational therapist
- ☐ Health care assistant
- ☐ Fitness instructor
- ☐ Peer support worker
- ☐ Volunteer
- ☐ Other (please specify)

1.17b Other (please specify)

_____

1.18 Does your programme have a minimum staff : patient ratio for exercise training?

- ◯ No
- ◯ 1 : < 4
- ◯ 1 : 4 - 6
- ◯ 1 : 7 - 9
- ◯ 1 : 10 or more
- ◯ Other (please specify)

1.18b Other (please specify)

_____

Section Two

This section relates to the participant assessment.

2.1	Do participants attend an individual assessment prior to starting the programme?	◯ Yes ◯ No
2.2	Do participants complete an assessment at the completion of the rehabilitation programme?	◯ Yes ◯ No
2.2b	Please describe your programmes definition of completion of the programme (e.g, attended > 75% of classes or minimum 12)	_____
2.3	Do participants attend a follow up assessment after the programme is complete?	◯ Yes ◯ No
2.3b	When does the follow up assessment occur?	◯ < one month after completion ◯ 1 - 3 months after completion ◯ 4 - 6 months after completion ◯ > 6 months after completion

2.4 Aerobic Tests

Please select the tests from the list below which you use in an assessment for your exercise program. Please tick if tests are used Pre (before starting PR), Post (after completion) and at follow up if this is applicable. Choose as many as apply.

	Pre rehab	Post rehab	Follow up (> 1 month post programme discharge)
6MWT	☐	☐	☐
ISWT	☐	☐	☐
ESWT	☐	☐	☐
5 rep sit to stand (5RSTS)	☐	☐	☐
One minute sit to stand (1MSTS)	☐	☐	☐
Other	☐	☐	☐

Other pre rehab exercise test (please specify)

_____

Other post rehab exercise test (please specify)

_____

Other follow up exercise test (please specify)

_____

2.5 Other Exercise Tests

Please select the tests from the list below which you use in an assessment for your exercise program. Please tick if tests are used Pre (before starting PR) Post (after completion) and at follow up if this is applicable. Choose as many as apply.

	Pre Rehab	Post Rehab	Follow Up (> 1 month post programme discharge)
Balance Tests	☐	☐	☐
Upper Limb 1RM	☐	☐	☐
Lower Limb 1RM	☐	☐	☐
Upper Limb 10 RM	☐	☐	☐
Lower Limb 10 RM	☐	☐	☐
Other	☐	☐	☐
None	☐	☐	☐

Which balance tests are used?

_____

Other exercise tests pre rehab (please specify)

_____

Other exercise tests post rehab (please specify)

_____

Other exercise tests at follow up (please specify)

_____

2.6 Health Related Quality of Life

Please select the QOL questionnaire which you use in your program. Please select each time the test is repeated if applicable.

	Pre Rehabilitation (tick all boxes which apply)	Post Rehabilitation (tick all boxes which apply)	Follow up (> 1 month post programme discharge)
St George Respiratory Questionnaire (SGRQ)	☐	☐	☐
Chronic Respiratory Disease Questionnaire (CRDQ)	☐	☐	☐
COPD Assessment Tool (CAT)	☐	☐	☐
Short form 36 (SF 36)	☐	☐	☐
EQ5D	☐	☐	☐
Chronic COPD Questionnaire (CCQ)	☐	☐	☐
None	☐	☐	☐
Other	☐	☐	☐

Other quality of life measure pre rehab (please specify) _____

Other quality of life measure post rehab (please specify) _____

Other quality of life measure at follow up (please specify) _____

2.7 Do you use an anxiety and depression measure?
◯ Yes
◯ No

Which measure of anxiety and depression do you use? _____

2.8 Do you use a tool to measure dyspnoea?
◯ Yes
◯ No

Please describe dyspnoea tool used _____

Section Three.

This section relates to the exercise component of your programme.

3.1 Do participants attend supervised exercise sessions?
- ◯ Yes
- ◯ No

3.2 How often do your participants attend supervised exercise sessions?
- ◯ One weekly
- ◯ Twice weekly
- ◯ Thrice weekly
- ◯ Other

Other (please specify)

_____

3.3 What equipment does your programme routinely use for exercise sessions? (tick all that apply)
- ☐ Stationary bicycle
- ☐ Treadmill
- ☐ Weights machine
- ☐ Rowing machine
- ☐ Arm rowers
- ☐ Ground walking
- ☐ Free weights
- ☐ Theraband
- ☐ Stairs
- ☐ Stepping boxes
- ☐ Stepping machine
- ☐ Swiss balls
- ☐ Other (please specify)

Other (please specify)

_____

3.4 Do you have facilities for people to exercise on oxygen?
- ◯ Yes
- ◯ No
- ◯ Other

Other (please describe)

_____

3.5 Do you have the facilities to exercise people with non-invasive ventilation / assisted ventilation?
- ◯ Yes
- ◯ No
- ◯ Other

3.6 Prescribing and supervising exercise

Please select which members of the team from the list below are primarily responsible for prescribing a participants exercise program, and who is involved in supervising participants during exercise.

	Prescribing Exercise (tick all that apply)	Supervising Exercise (tick all that apply)
Physiotherapist	☐	☐
Nurse	☐	☐
Exercise physiologist	☐	☐
Personal trainer	☐	☐
Health care assistant	☐	☐
Peer support worker	☐	☐
Volunteer	☐	☐
Other	☐	☐

Other people prescribing exercise (please specify)

_____

Other people supervising exercise (please specify)

_____

3.7 How is the starting exercise intensity prescribed?

☐ Exercise test (6MWT, ISWT)
☐ Patient symptoms
☐ Set time for class (e,g 5 minute stations)
☐ None
☐ Other (please specify)

Other (please specify)

_____

3.8 What types of exercises are routinely prescribed? (tick all that apply)

☐ Aerobic
☐ UL Resistance
☐ LL Resistance
☐ UL Endurance
☐ LL Endurance
☐ Stretches
☐ Balance exercise
☐ Other (please specify)

Other (please specify)

_____

3.9 What is the duration of each exercise session?

◯ < 20 minutes
◯ 20 - 30 minutes
◯ 35 - 45 minutes
◯ 50 - 60 minutes
◯ > 60 minutes

3.10 Are participants asked to complete a home based programme in addition to the supervised programme?

◯ Yes
◯ No

3.10b	Is the home exercise programme monitored?	◯ Yes ◯ No
3.10c	How is the home exercise programme monitored (e.g activity diary, fitness tracker)?	_____

Section Four.

This section relates to the education component of your programme.

4.1	Does your pulmonary rehabilitation programme include education?	◯ Yes ◯ No
4.2	Is this group based education?	◯ Group ◯ Individual ◯ Both ◯ Other
	Other (please specify)	_____
4.3	How many education sessions per week?	◯ Once ◯ Twice ◯ Thrice ◯ Other (please specify)
	Other (please specify)	_____
4.4	How is the education delivered? e.g, face to face, video, data show etc. (please describe)	_____
4.5	Does your programme include any outcome measures specifically for education?	☐ LINQ (Lung information needs questionnaire) ☐ Bristol ☐ Other (please specify) ☐ None
	Other (please specify)	_____

Section Five.
This section relates to Maintenance and Support Groups.
Maintenance groups provide ongoing exercise.
Support groups are non-exercise groups which meet on a regular basis.

5.1 Are there maintenance programmes in your area that you can refer people to at the end of your pulmonary rehabilitation programme?
- ◯ Yes
- ◯ No
- ◯ Unsure

5.1b Do you feel there is a need to establish a maintenance programme in your area?
- ◯ Yes
- ◯ No

5.1c Please describe maintenance requirements?

_____

5.2 Do you refer participants to a maintenance programme at the end of your programme?
- ◯ Always
- ◯ Sometimes
- ◯ Never

5.2b What are the criteria for referral to maintenance programme?

_____

5.3 Please select the maintenance programme you refer to?
- ☐ Maintenance follows on at same centre
- ☐ Green Prescription
- ☐ Never too old
- ☐ Sing your lungs out
- ☐ Other (please specify)

Other (please specify)

_____

5.4 Do you refer participants to a support group in your area?
- ☐ Yes - all
- ☐ Yes - some
- ☐ No - there is no support group available
- ☐ No - the support group is not suitable
- ☐ No - I do not know of any support group in area

5.5 Do you have a minimum time period before you will accept a referral for a participant who has already completed your programme in the past?
- ◯ No
- ◯ Yes - < 1 year
- ◯ Yes 12 - 18 months
- ◯ Yes 18 - 24 months
- ◯ Never re-enrol
- ◯ Other (please specify)

Other (please specify)

_____

Section Six.
This section relates to your programme demand and capacity.

6.1 Is there a waiting list for people to join your programme?
- ◯ Yes
- ◯ No

6.1b Please estimate your current waiting time

_____

6.2 Do you have a priority system for new referrals?
- ◯ Yes
- ◯ No

6.2b Please describe the priority system (e.g recent hospital admission, based on severity..)

_____

6.3 What is the maximum number of participants you will accept in each class?

_____

6.4 Is your programme currently meeting demand/capacity in your area?
- ◯ Yes
- ◯ No
- ◯ Unsure

6.4b Please comment

_____

6.5 Do you use technology to support your rehabilitation programme delivery?
- ◯ Never
- ◯ Sometimes
- ◯ Always

6.5b Would you like to use technology in your programme? If so, what are the barriers to using technology?

_____

6.5c Please describe the technology used? (select all the answers that apply)
- ☐ Text Messaging
- ☐ Emails
- ☐ Videos
- ☐ Mobile Apps
- ☐ Other

Other (please specify)

_____

6.6 Do you complete an annual service audit of your PR programme?
- ◯ Yes
- ◯ No
- ◯ Other

6.6b Other (please describe)

_____

6.6c Please select the type of data that you audit? (tick all the boxes which apply)

- ☐ Referral rates
- ☐ Attendance rates
- ☐ Completion rates
- ☐ Demographic data (e.g gender, age)
- ☐ Ethnicity data
- ☐ Primary pathology and severity data
- ☐ Hospital readmission data
- ☐ Other

Other (please specify)

_____

6.7 Do you gather any formal participant feedback from your PR classes? (e.g patient satisfaction surveys)

- ◯ Yes
- ◯ No

6.7b Please describe how this feedback is provided?

_____

6.8 Is there anything you would like to do differently in your current programme?

_____

6.9 Do you wish to add any comments about pulmonary rehabilitation that have not been covered here?

_____

Further Information.

If you provide your name and details in the following section, this will not be linked to your survey responses.

Would you be interested in being part of further research in pulmonary rehabilitation?

- ◯ Yes
- ◯ No

Please provide your name and contact details for further research.

_____

If we require further information, would you be happy to be contacted?

- ◯ Yes
- ◯ No

Please provide your name and contact details (email address and phone number) if further information is required.

_____

Would you like a copy of the research report?

- ◯ Yes
- ◯ No

Please provide email address for research report.

_____

Thank you very much for taking the time to complete this survey.

Sarah Candy
Pulmonary Rehabilitation Coordinator, CMDHB
MPhil Student, AUT University
tel. 0274363116

_____

Appendix G. Survey 2 Questions

Confidential

PR survey 2

Participant ID _____

Consent

I agree to take part in this research study
◯ Yes
◯ No

Thank you for your time. _____

Section One.
This section relates to how your services changed during COVID 19 Level 3 & 4 lockdown

Has there been any changes in the funding of your PR service in response to COVID-19? (please describe) _____

Has there been any changes in the staffing of your PR service in response to COVID-19? (eg. staff being deployed to other services) please describe. _____

Please indicate which of the following best describes what your PR programme looked like during level 3/4 lockdown. (you may choose more than one answer)
☐ Home based telephone support
☐ Home based video-conferencing support
☐ No PR
☐ Other (please describe)

Other (please describe) _____

Please describe the content of your programme during Level 3 /4 lockdown?
◯ Exercise only
◯ Education only
◯ Exercise and group education
◯ Exercise and individual education
◯ Other

Other - please describe _____

During COVID-19 restrictions did your PR service continue to prescribe and monitor exercise programmes?
◯ Yes
◯ No

Which modality was used for the assessment?
☐ Telephone
☐ Video conferencing
☐ Face to face (prior to COVID-19 restrictions)
☐ Other

Other (please describe) _____

During COVID-19 restrictions did participants receive an individual assessment prior to starting the programme?
◯ Yes
◯ No

How was exercise capacity assessed? (you may choose more than one option)	☐ Sit to stand test ☐ Walk test ☐ Symptom limitation ☐ Functional capacity ☐ Step count ☐ Other
Please describe walk test used?	_____
Other (please describe)	_____
Did you need to alter your inclusion and exclusion criteria during this time?	◯ Yes ◯ No
Please describe?	_____
What modalities were used for exercise prescription during COVID-19 restrictions?	☐ Telephone consultations ☐ Video-conferencing ☐ Email exercise programmes ☐ Paper material ☐ Other
Other (please describe)	_____
Which modalities were used for monitoring and reviewing of exercise programmes during COVID-19 restrictions?	☐ Telephone consultations ☐ Video-conferencing ☐ Email ☐ Paper information ☐ Step counts ☐ Other
How frequently was the exercise programme monitored or reviewed?	◯ More than once per week ◯ Once per week ◯ Once per fortnight ◯ Once per month ◯ Other
Other (please describe)	_____
Has the delivery of education at your PR programme changed in response to COVID-19?	◯ Yes ◯ No
Please describe how this has changed?	_____

Section Two

This section relates to how your PR services are operating currently.

Will you be re-instating your pre COVID-19 PR programme structure after restrictions have lifted and it is safe to do so?	☐ Yes - will be recommencing with the same structure ☐ Yes will recommence same program structure plus the addition of telehealth options ☐ Unsure at this time ☐ No - different structure (please describe) ☐ Other
No - different structure (please describe)	_____
Other (please describe)	_____
Please describe how you anticipate the content of your programme to look for the remainder of 2020?	◯ Exercise only ◯ Education only ◯ Exercise and group education ◯ Exercise and individual education ◯ Other
Other (please describe)	_____

Section Five.

Has the COVID 19 lockdown had an impact on your wait list? Please describe	_____
Please estimate your current waiting time	_____
Has COVID-19 had a significant impact on your wait list for PR? (please describe)	_____
Is there anything you would like to do differently in your current programme?	_____
Do you wish to add any comments about pulmonary rehabilitation that have not been covered here?	_____

Please tick which region your programme is based	◯ Northland ◯ Auckland ◯ Waikato ◯ Bay of Plenty ◯ Gisborne ◯ Hawkes Bay ◯ Taranaki ◯ Manawatu - Wanganui ◯ Wellington ◯ Tasman ◯ Nelson ◯ Marlborough ◯ West Coast ◯ Canterbury ◯ Otago ◯ Southland ◯ Other
Other - please describe	_____

Further Information.
If you provide your name and details in the following section, this will not be linked to your survey responses.

Would you be interested in being part of further research in pulmonary rehabilitation?	◯ Yes ◯ No
Please provide your name and contact details for further research.	_____
If we require further information, would you be happy to be contacted?	◯ Yes ◯ No
Please provide your name and contact details (email address and phone number) if further information is required.	_____
Would you like a copy of the research report?	◯ Yes ◯ No
Please provide email address for research report.	_____

Thank you very much for taking the time to complete this survey.

Sarah Candy
Pulmonary Rehabilitation Coordinator, CMDHB
PhD Candidate, AUT University
tel. 0274363116

Study Protocol - What are the factors which influence participation in telerehabilitation – A scoping review

Abstract

Objective: The objective of this scoping review is to understand the extent and type of evidence in relation to the factors which impact patient participation in telerehabilitation.

Introduction: Telerehabilitation is an emerging form of delivering PR which has been shown to be safe and likely as effective as centre-based PR (Cox, McDonald, Alison, et al., 2018). Telerehabilitation has the ability to overcome many barriers to centre-based PR. What is not understood are the patient related factors which influence participation in telerehabilitation programmes.

Inclusion criteria: The review will include articles which explore the patient experience r attitude towards participating in telerehabilitation. This includes RCT, non-RCT trials, observation studies, mixed methods research, case studies, opinion pieces. Adult participants living with a chronic respiratory disease who would be eligible for PR. The review will exclude articles not written in English, studies of maintenance programmes / self-management programmes.

Methods: Scopus, MEDLINE, CINAHL and Cochrane Library will be searched. The search will be limited to English language from January 2011 to date. Studies will be included in which participants completed telerehabilitation or were asked their thoughts regarding telerehabilitation. Data will be extracted to a pre-developed template.

Introduction

Pulmonary rehabilitation is a fundamental component in the management of chronic respiratory disease. Despite the overwhelming evidence to support the effectiveness uptake and completion of PR is low worldwide (Levack et al., 2012; McCarthy et al., 2015; Steiner et al., 2015a).

A systematic review by Keating, Lee and Holland (2011) investigated factors limiting attendance and completion of programmes. The percentage of non-completion varied across the studies from 9.7% - 31.8% (Keating et al., 2011). The key themes identified in the studies relating to reduced attendance were illness related to lung disease or comorbid conditions, travel and transport factors, lack of social support and lack of perceived benefit. Current smoking status and depression were the only two baseline demographic factors which clearly increased the likelihood of non-completion.

Much attention has focused on identifying barriers to attending and completing, but to date there is little evidence available on the enablers to completing PR. Ringbaek et al (2016) examined interventions aimed at improving uptake and /or completion of PR and found only one study which could be included in the review (Ringbaek et al., 2016). The study involved providing participants attending PR with a device or tablet, which included videos of the exercises, a training diary and a progress chart (Ringbaek et al., 2016). The improvement in completion rate was small and not found to be statistically significant.

The literature has shown commonality in many of the reasons identified for non-attendance and completion. Several of these factors, such as travel and transport, have the potential to be overcome through delivering PR directly to the participant with the use of tele rehabilitation (telerehabilitation). Telerehabilitation has been proposed as a method to improve access and completion may overcome several of the system related barriers including insufficient number of programmes and convenience of programmes (timing, travel, transport, parking) and also some of the patient identified barriers including access to transport, personal commitments, current smokers, exacerbation of illness or co-morbidity. There are however, a risk that many other patient related barriers previously identified such as lack of social support, lack of perceived benefit, greater levels of dyspnoea and depression, would not be addressed through technology and the gap may widen and these people.

There is a growing body of evidence regarding the use of telerehabilitation with a range of different models being used including telephone, video conferencing and mobile/web-based applications. A recent Cochrane review has shown these interventions are likely to be as safe and effective as traditional centre-based PR,

however, the small number of studies with low sample sizes and methodological heterogeneity makes this conclusion guarded (Cox et al., 2021). What is not well understood is what is the patient preference for intervention delivery and what are some of the barriers and enablers to patients participating in telerehabilitation. This is important information in intervention development to ensure new models of PR are not widening the equity gap but instead making this important intervention available to a larger number of people living with chronic respiratory disease.

The aim of this scoping review is to examine the literature relating to patient's perspective of participating in telerehabilitation in order to identify barriers and enablers to uptake, attendance and completion.

A preliminary search of MEDLINE, the Cochrane Database of Systematic Reviews and *JBI Evidence Synthesis* was conducted and no current or underway systematic reviews or scoping reviews on the topic were identified.

Review question

The following scoping review aims to answer the following questions.

1. What are the factors which influence patient participation in telerehabilitation.
2. Attitudes towards telerehabilitation
3. Willingness to use telerehabilitation
4. Adherence and engagement with telerehabilitation

Keywords

Pulmonary rehabilitation, telerehabilitation, chronic respiratory disease, barriers, uptake

Eligibility criteria

Participants

People living with a chronic respiratory condition who would be eligible for referral to PR. Including COPD, ILD, asthma, bronchiectasis, pre and post lung surgery.

Concept

Pulmonary rehabilitation (PR) delivered as telerehabilitation. Including video conferencing, SMS, web based, APP based, phone-based interventions.

PR must include exercise training (6+ weeks), education and self-management.

Context

What are the factors which impact of telerehabilitation?

Types of Sources

This scoping review will consider both experimental and quasi-experimental study designs including randomized controlled trials, non-randomized controlled trials, before and after studies and interrupted time-series studies. In addition, analytical observational studies including prospective and retrospective cohort studies, case-control studies and analytical cross-sectional studies will be considered for inclusion. This review will also consider descriptive observational study designs including case series, individual case reports and descriptive cross-sectional studies for inclusion.

Qualitative studies will also be considered that focus on qualitative data including, but not limited to, designs such as phenomenology, grounded theory, ethnography, qualitative description, action research and feminist research.

In addition, systematic reviews that meet the inclusion criteria will also be considered, depending on the research question.

Text and opinion papers will also be considered for inclusion in this scoping review.

Methods

The proposed scoping review will be conducted in accordance with the JBI methodology for scoping reviews.

Search strategy

The search strategy will aim to locate both published and unpublished studies. An initial limited search of MEDLINE and Scopus was undertaken to identify articles on the topic. The text words contained in the titles and abstracts of relevant articles, and the index terms used to describe the articles were used to develop a full search strategy for Scopus, MEDLINE and CINHAL. The search strategy, including all identified keywords and index terms, will be adapted for each included database and/or information source. The reference list of all included sources of evidence will be screened for additional studies.

Studies published in English will be included. Studies published since 01/01/2011 will be included.

The databases to be searched include MEDLINE, CINAHL, Scopus and Cochrane. Sources of unpublished studies/ gray literature to be searched include commentaries, conference abstracts, thesis.

Study/Source of Evidence selection

Following the search, all identified citations will be collated and uploaded into EndNote 20.4 and duplicates removed. Following a pilot test, titles and abstracts will then be screened by SC for assessment against the inclusion criteria for the review. Potentially relevant sources will be retrieved in full, and their citation details imported into excel. The full text of selected citations will be assessed in detail against the inclusion criteria by SC. Reasons for exclusion of sources of evidence at full text that do not meet the inclusion criteria will be recorded and reported in the scoping review. The results of the search and the study inclusion process will be reported in full in the final scoping review and presented in a Preferred Reporting Items for Systematic Reviews and Meta-analyses extension for scoping review (PRISMA-ScR) flow diagram (Tricco et al., 2018)

Data Extraction

Data will be extracted from papers included in the scoping review by SC using a data extraction tool developed by SC, JR, DT. The data extracted will include specific details about the participants, concept, context, study methods and key findings relevant to

the review question. The draft extraction form will be piloted by SC and reviewed with JR, DT prior to full data extraction.

A draft extraction form is provided. The draft data extraction tool will be modified and revised as necessary during the process of extracting data from each included evidence source. Modifications will be detailed in the scoping review.

Data Analysis and Presentation

Quantitative and qualitative data synthesis will be performed. The quantitative data includes the counts of studies reporting barriers and enablers along with patient references. Narrative synthesis will be used to report themes reported in qualitative studies.

Preferences and uptake data will be presented graphically. The themes will be presented in diagrammatic form. A narrative summary will accompany figures and tables.

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Conflicts of interest

There is no conflict of interest in this project.

Appendix I. Scoping Review Search Strategy

1	COPD OR asthma OR bronchiectasis OR :"interstitial lung disease" OR "lung fibrosis" OR "chronic respiratory disease" OR "chronic lung disease"
1	Respiratory rehabilitation OR "pulmonary rehabilitation" OR "COPD rehabilitation" OR "lung rehabilitation" OR "respiratory therapy"
2	Telerehabilitation OR tele-rehabilitation OR mHealth OR "web based" OR smartphone OR App OR online OR telehealth OR "video conference" OR mobile OR home-based OR remote OR telephone
3	Barrier* OR enabler* OR challenge* OR uptake OR compliance OR adherence OR obstacle OR completion OR limitation* OR facilitator* OR success OR non-compliance OR attend OR attitude OR participation

Appendix J. Scoping Review Data Extraction Tables

Table 1. Studies reporting patient uptake of telerehabilitation studies

Author (year)	Country	Study Design	Participants (n,age, diagnosis)	PR Concept	Uptake of Telerehabilitation			Comments
					Screened	Not eligible	Declined	
Benzo (2021)	USA	RCT + qual interviews	78 COPD 70 yrs (8)	Web-based with telephone coaching	217		63 Busy (11) Not interested (11) Not tech savvy (5) Lost to followup (30) Time (6)	
Bourne (2017)	UK	RCT	90 COPD (64 online:26 centre-based) (mMRC ≥ 2, > 40 years, access to internet, ability to operate web platform) 70 years (	Web-based c.f. centre-based	163	N = 73 Oxygen levels (n = 36) Exacerbation (n = 13) Comorbidities (n = 8)	Only describes participants who wished to participate. E **significant number excluded who desaturated**	
Cerdan-De-Las-Heras (2022)	Denmark	RCT	54 COPD (27 web:27 centre-based) 67 yrs (10) 47% female	Web-based c.f. centre-based	95	20 (co-morbidities n=4) (unable to do telerehab n=4) (not willing to do protocol n=12)	21	Adherence reported as high 82% but tool for measurement not described. Report matched ex intensity to HR in real time –feedback gave better improvements.

Author (year)	Country	Study Design	Participants (n,age, diagnosis)	PR Concept	Uptake of Telerehabilitation			Comments
					Screened	Not eligible	Declined	
Chaplin (2017)	UK	RCT	103 COPD (51 web:52 centre) Recruited from PR and primary care, MRC 2-5, access to internet >3 mnths, ability to use websites + email. 66 yrs (10)	Web-based c.f. centre-based	641	244	294 + 54 of excluded prefer centre-based	Asked preference before randomisation 38% pref web based. Low completion rate in web-based c.f centre-based. Majority dropped out at beg.
Cox (2021)	Australia	RCT	142 CRD (68 VC:67 centre) 68 yrs (9)	VC c.f. centre-based	651	253	246 (Wanted centre-based n = 95) (no space n = 12)	Large study. 23% recruitment. Adherence high in both groups.
Grosbois (2021)	France	Retrospective audit	105 CRD 63 yrs	Telephone or VC c.f. NO PR (during COVID)	120		15	Phone or VC 75% only had access to telephone calls.
Hansen (2020)	Denmark	RCT,	134 COPD 68 yrs (9) mMRC ≥ 2, recruited from respiratory departments,	VC c.f centre-based	1099		714 (wanted centre-based 251)	More completed PTR than centre based. Slightly higher adherence in PTR. Recruited real world patients. Min exclusion criteria. Changes in CAT + HAD relate to real-time supervision (VC c.f. web-based)

Author (year)	Country	Study Design	Participants (n,age, diagnosis)	PR Concept	Uptake of Telerehabilitation			Comments
					Screened	Not eligible	Declined	
Holland (2017)	Australia		166 COPD (80 home based:88 centre) 69 yrs (13)	Telephone c.f. centre-based	295	58	67 (wanted centre-based n = 54)	Mod to severe CRD Much higher completion rate in telephone c.f centre Broad inclusion criteria Many comorbidit Adherence measured with ex. Diary Those that completed either group had longer to next admission.
Houchen-Wolloff (2021)	UK	Feasibility study. Nonrandomised,	100 AECOPD inpatient Web literate (used device more than once per week) 71 yrs (9)	Web-based c.f. No PR	2080	100	Main exclusion was not web literate or did not have email address	Screened Needed to be web literate and regular email user.
Lahham (2020)	Australia	RCT	58 mild COPD (29 ph: . 68 years	Telephone c.f. centre-based	982 letters sent out			
Lewis (2021)	UK	Service evaluation Mixed methods design.	17 CRD Recruited from PR waitlist 69 yrs (10)	VC + Telephone calls	25		14 (no internet n = 3) (digital confidence n = 3) Personal preference (n = 5) Other n = 4	PR inclusion made possible by digital support provided. Intro session improved engagement.

Author (year)	Country	Study Design	Participants (n,age, diagnosis)	PR Concept	Uptake of Telerehabilitation			Comments
					Screened	Not eligible	Declined	
Marquis (2015)	Canada	Observational study	26 COPD (mod to severe) 65 yrs (7), 58% female Needed internet at home Convenience sample. No control	VC c.f.	77	31	20	High adherence rate. No report of technology competence
Nolan	UK	Nonrandomised	154 COPD 71 yrs (9)	Telephone	1593			154 chose home based
Simony (2019)	Denmark	Non-empirical.	15 COPD Referred to PR 62 yrs	VC	28		12	
Tsai (2017)	Australia	RCT	37 COPD (20 VC : ? Referred to PR 73 years (	VC c.f no PR	128	91 (unable to use computer n = 16) Language (n = (home environment n = 12)		Excluded 39, declined 52. Preferred centre-based (4), excluded if on oxygen or walking frame.

Note. Data presented as n or mean (SD)

Table 2. Studies reporting patient perceptions of participating in telerehabilitation

Author (date)	Country	Study Design	Participant (n,age, diagnosis, recruited from)	PR Concept	Report Intent / willingness	Report barriers	Report enablers	Content Preferences / recommendations	Comments
Almojaibel (2021)	USA	Survey	134 diagnosis not stated 66 yrs (10) Attending PR	Not clearly defined	Yes. 61% positive intent.	Disease duration	Perceived usefulness	Computer literacy culture	Age not a predictor of intent, nor was travel time. Telerehab naiive 20% had never used internet
Alwashmi (2020)	Canada	Mixed methods – survey & interviews	77 COPD 65 yrs Recruited from respiratory clinic.	Web-based PR	No	Technical challenges Financial Privacy/security Lack of interest in telerehab.	Perceived benefits needs to be easy to use need techn. Support.	Training in use of mHealth to build confidence	Mobile phone ownership highest (73%) Low users of social media Likelihood of owning smartph related to education

Author (date)	Country	Study Design	Participant (n,age, diagnosis, recruited from)	PR Concept	Report Intent / willingness	Report barriers	Report enablers	Content Preferences / recommendations	Comments
Bairapareddy (2021)	India	Survey	30 COPD 54 yrs (12) All attended PR Knew about telerehab	Web-based PR	Yes – 70% agree an acceptable option.	Physio may not get good understand of patient condition Ease of use Language Financial cost.	More convenient to contact HCP. Save time. More accessible.	monitoring	High level of interest, but concern about availability and expertise of telerehab.
Dobson (2019)	NZ	Mixed methods - Survey & interview	30 CRD 73% > 65 years Attended AND never attended PR	Web-based PR	No			Yes	Consideration to peer support, digital literacy and confidence. Referral by someone with trusted relationship
Inskip (2018)	Canada	Survey & Focus groups	26 CRD 71 yrs 58% attended PR 42% Did not attend due to travel Most were regular users of computer, ¼ regulr user of smartph	Not defined. Demonstrated portable devices; physical activity, pulse oximeters, pedometers, smartphone apps.	No			Social support Communication with HCP Biosensors for monitoring Evolution of support	Age not a predictor of intent, nor was travel time. Telerehab naiive 20% had never used internet

Author (date)	Country	Study Design	Participant (n,age, diagnosis, recruited from)	PR Concept	Report Intent / willingness	Report barriers	Report enablers	Content Preferences / recommendations	Comments
Polgar (2022)	UK	Survey (x 2)	99 + 101 CRD 74 years (SD…) Referred to PR	Web-based PR	Yes	Yes*			Technical challenges and preference for centre-based.
Seidman (2017)	Australia	Survey	254 CRD 73 yrs (1) Attended/ing PR High users and access to devices	VC	Yes	Yes	Yes		Age not a predictor of intent, nor was travel time. Telerehab naiive 20% had never used internet
Skibdal (2022)	Denmark (2020-2021)	Mixed methods Survey & interviews	84 COPD 70 years (9) All declined centre-based PR	VC, telephone or text messages	Yes			Believing the benefits sig. assoc. with willingness. Daily use of tech assoc with willingness.	28% willing to do telerehab (29% unsure, 43% not keen) Most were daily users of computer. 69% believed they had tech skills for telerehab, but did not prefer this way of comms.

Note. Data presented as n or mean (SD)

Table 3. Studies reporting patient experience of participating in telerehabilitation

Author & Date	Country	Study Design	Population (n,age, diagnosis)	Concept	Outcomes	Results	Comment
Benzo (2021)	USA	RCT + interviews Home based v control. Structured interviews to ransom sample of participants.	78 COPD 69.4 yrs (8)	8-week programme V waitlist control. Video guided exercises to do 6 days/week. Pulse oximetre+ step counter. Health coaching = weekly telephone call – review activity + symptoms + define goals. Goals to visualise progress	Barriers – Enablers – coaching – confidence, support, encouragement, interested in them, aided technology use.	96% would recommend to others. High acceptability + satisfaction. The coach listened and increased their confidence. Liked the technology. Liked to see progress. Coaching- (1) gave encouragement +support,(2)accountability (3) troubleshooting technology allowing them to engage in programme.	Older data 2016-2018. Adherence measured as system use >1 feature Weekly phone calls Effective because breathing improved and that's why they would recommend.
Burkow (2015)	Norway	Mixed methods – Interviews – semi structured with open and closed questions. questionnaires	10 COPD Recruited from PR 61.7 yrs	VC + phone calls Assessed inperson 9-week internet enabled PR. 1 x wk education one hour 2 x online ex sessions 30 mins, warm up/strength+endurance exs, interval training. Online individual consultations weekly 10 – 15mins.	Acceptability – Attendance at sessions Perceptions of delivery mode and components of the programme	High attendance at online sessions – enjoyed the education sessions and learnt from each other. Step counters – motivating for grade 3 and below, mixed results for the grade 4. Valued the individual consultation. No technology concerns	Technical training and tech support given. Small sample All frequent computer user Quite severe COPD (4 LTOT)

Author & Date	Country	Study Design	Population (n,age, diagnosis)	Concept	Outcomes	Results	Comment
Lahham (2018)	Australia	Interviews – individual semi structured interviews with open ended questions.	13 COPD From HomeBase trial 66.4 yrs. 1 completed PR before, 12 naiive to PR	Phone based Initial assessment, 1 home visit with PT, participants exercise 30 minutes most days of week, given exercise diary and pedometer. Seven weekly phone calls from PT	Facilitators and barriers to adherence with HomeBased PR	Improved wellbeing – physical symptoms + mood Flexibility – reduced burden (travel + $), timing – keep own commitments Social support – from Pt but also family and friends Challenges – getting started, unable to complete the exercise or needing variety	Nested in large RCT.
Hoas (2016)	Norway	Survey + focus groups	10 COPD Recruited from inpatient PR programme. 55yrs. 2-year PR programme	VC + webpage Exercise 3 x wk for 30 mins. Individually prescribed, warm up/walking intervals/cool down. Tablet and pulse oximeter for monitoring + daily symptom diary. Weekly VC session with PT who had access to exercise + symptom data.	Adherence – logs on webpage Factors affecting satisfaction + adherence+ potential service improvements	Adherence – no dropouts All had breaks but came back to programme Health benefits Improved self-efficacy Communication with HCP – important for safety and increasing confidence Motivation -	8/10 used internet every day. Physician selected patients from PR and participation was voluntary 3 had LTOT
Houchen Wollooff (2021)	UK	Semi structured interview	14 inpatient COPD 71 yrs (9)	Web SPACE for COPD	Preparing for, engagement with and benefits of porgramme	Technical challenges – even tho they passed screening test.	Needed to be web literate. Did not use VC or email the team.Nested in larger study (n=100).

Author & Date	Country	Study Design	Population (n,age, diagnosis)	Concept	Outcomes	Results	Comment
Simony (2019)	Denmark	Observational study	15 COPD 62 yrs 47% female	Given tablet + SIM card + exercise equipment Supervised group exercise Individual phone call		Highest adherence with group-based exercise c.f individual phone consults. Enabler – reduced travel and time burden Flexibility in comm with HCP allowed managing exac and everyday challenges better. **need shared session with close relatives **	
Tsai (2016)	Australia	Survey + interview.	11 COPD 73 yrs (8)	VC One hour exercise, 30x wk for 8 weeks via VC. Up to four in group. Laptop, 4G cellular data, bicycle, pulse oximetre provided. Physio visited home + set up equipment and provided phone technical support. No formal education provided.	One questionnaire (CSQ-8)and two purpose-built surveys + semi-structured interview which expanded on questionnaires.	Highest rating- timeliness and convenience Lowest use of equipment and interaction with others. Enjoyed having others to exercise with through VC -Equipment easy to sue, except 3 people with internet problems. -convenience for those working and reduced costs -health benefits attributed to supervision of PT	Extensions of TeleR study – random sample from quant study.

Author & Date	Country	Study Design	Population (n,age, diagnosis)	Concept	Outcomes	Results	Comment
Whittaker (2021)	NZ	Feasibility study	26 CRD 70 yrs Recruited from PR programmes 4 family members	Web-based Individual assessment. 9-week PR SMS + app+ sensor Exercise 5 days week, individualised programme. Walking, resistance and balance exercises.	Semi structured interview - satisfaction, usefulness, and usability.	All participants (bar one) reported useful. Facilitator's motivation and empowerment. Felt supported Increased awareness and knowledge Barriers Exercise too hard, need variety, more personalised, more feedback. Technical issues.	

Note. Data presented as n or mean (SD)

Appendix K. Scoping Review PRISMA Checklist

Table 4. Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) Checklist

SECTION	ITEM	PRISMA-ScR CHECKLIST ITEM	REPORTED ON PAGE #
TITLE			
Title	1	Identify the report as a scoping review.	54
ABSTRACT			
Structured summary	2	Provide a structured summary that includes (as applicable): background, objectives, eligibility criteria, sources of evidence, charting methods, results, and conclusions that relate to the review questions and objectives.	54
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of what is already known. Explain why the review questions/objectives lend themselves to a scoping review approach.	55
Objectives	4	Provide an explicit statement of the questions and objectives being addressed with reference to their key elements (e.g., population or participants, concepts, and context) or other relevant key elements used to conceptualize the review questions and/or objectives.	56
METHODS			
Protocol and registration	5	Indicate whether a review protocol exists; state if and where it can be accessed (e.g., a Web address); and if available, provide registration information, including the registration number.	57
Eligibility criteria	6	Specify characteristics of the sources of evidence used as eligibility criteria (e.g., years considered, language, and publication status), and provide a rationale.	56
Information sources*	7	Describe all information sources in the search (e.g., databases with dates of coverage and contact with authors to identify additional sources), as well as the date the most recent search was executed.	57-58
Search	8	Present the full electronic search strategy for at least 1 database, including any limits used, such that it could be repeated.	Click here to enter text.
Selection of sources of evidence†	9	State the process for selecting sources of evidence (i.e., screening and eligibility) included in the scoping review.	57
Data charting process‡	10	Describe the methods of charting data from the included sources of evidence (e.g., calibrated forms or forms that have been tested by the team before their use, and whether data charting was done independently or in duplicate) and any processes for obtaining and confirming data from investigators.	57

SECTION	ITEM	PRISMA-ScR CHECKLIST ITEM	REPORTED ON PAGE #
Data items	11	List and define all variables for which data were sought and any assumptions and simplifications made.	57-58
Critical appraisal of individual sources of evidence§	12	If done, provide a rationale for conducting a critical appraisal of included sources of evidence; describe the methods used and how this information was used in any data synthesis (if appropriate).	n/a
Synthesis of results	13	Describe the methods of handling and summarizing the data that were charted.	58
RESULTS			
Selection of sources of evidence	14	Give numbers of sources of evidence screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally using a flow diagram.	58
Characteristics of sources of evidence	15	For each source of evidence, present characteristics for which data were charted and provide the citations.	appendix
Critical appraisal within sources of evidence	16	If done, present data on critical appraisal of included sources of evidence (see item 12).	n/a
Results of individual sources of evidence	17	For each included source of evidence, present the relevant data that were charted that relate to the review questions and objectives.	61-64
Synthesis of results	18	Summarize and/or present the charting results as they relate to the review questions and objectives.	Click here to enter text.
DISCUSSION			
Summary of evidence	19	Summarize the main results (including an overview of concepts, themes, and types of evidence available), link to the review questions and objectives, and consider the relevance to key groups.	70-71, 76
Limitations	20	Discuss the limitations of the scoping review process.	Click here to enter text.
Conclusions	21	Provide a general interpretation of the results with respect to the review questions and objectives, as well as potential implications and/or next steps.	80
FUNDING			
Funding	22	Describe sources of funding for the included sources of evidence, as well as sources of funding for the scoping review. Describe the role of the funders of the scoping review.	Click here to enter text.

Appendix L. Formative Study

Original Paper

Understanding End User Perspectives of Mobile Pulmonary Rehabilitation: Formative Studies

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Abstract

Background: Pulmonary rehabilitation (PR) is an effective intervention for the management of people with chronic respiratory diseases, but the uptake of and adherence to PR programs is low. There is potential for mobile health (mHealth) to provide an alternative modality for the delivery of PR, overcoming many of the barriers contributing to poor attendance to current services.

Objective: The objective of this study was to understand the needs, preferences, and priorities of end users for the development of an adaptive mobile PR (mPR) support program.

Methods: A mixed methods (qualitative and quantitative) approach was used to assess the needs, preferences, and priorities of the end users (ie, patients with chronic respiratory disorders) and key stakeholders (ie, clinicians working with patients with chronic respiratory disorders and running PR). The formative studies included the following: (1) a survey to understand the preferences and priorities of patients for PR and how mobile technology could be used to provide PR support, (2) ethnographic semistructured interviews with patients with chronic respiratory disorders to gain perspectives on their understanding of their health and potential features that could be included in an mPR program, and (3) key informant interviews with health care providers to understand the needs, preferences, and priorities for the development of an mPR support program.

Results: Across all formative studies (patient survey, n=30; patient interviews, n=8; and key stakeholder interviews, n=8), the participants were positive about the idea of an mPR program but raised concerns related to digital literacy and confidence in using technology, access to technology, and loss of social support currently gained from traditional programs. Key stakeholders highlighted the need for patient safety to be maintained and ensuring appropriate programs for different groups within the population. Finding a balance between ensuring safety and maximizing access was seen to be essential in the success of an mPR program.

Conclusions: These formative studies found high interest in mHealth-based PR intervention and detailed the potential for an mPR program to overcome current barriers to accessing traditional PR programs. Key considerations and features were identified, including the importance of technology access and digital literacy being considered in utilizing technology with this population.

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KEYWORDS

mHealth; rehabilitation; COPD

Introduction

Chronic obstructive pulmonary disorder (COPD), an umbrella term for a range of debilitating respiratory diseases [1], is the fourth leading cause of mortality worldwide [2]. In New Zealand (NZ), COPD affects approximately 14% of adults aged >40 years [3]. M ori, the NZ indigenous population, as well as ethnic minority groups and those from socioeconomically deprived groups are disproportionately affected by COPD with higher prevalence rates and hospitalizations and are more likely to die from the condition [2,3].

One of the most effective interventions for COPD is pulmonary rehabilitation (PR), an evidence-based, interdisciplinary intervention that is a key component in the management of people with respiratory diseases [4]. PR is a formalized structured program comprising, but not limited to, exercise training, education, and behavior change, and it is designed to improve a patient's physical and psychological health and encourage engagement with health-enhancing behaviors [5]. PR is an individually tailored intervention based on thorough patient assessment, which is typically delivered in group programs in hospital or community settings. PR has been clearly demonstrated to improve breathlessness and health-related quality of life and reduce hospital admissions for exacerbations of COPD [4,6]. Clinical guidelines strongly recommend the uptake of PR by all patients with COPD, particularly following hospital admissions [7]. Despite this, and PR programs being available across nearly all regions of NZ, the uptake of, and available across nearly all regions of NZ, the uptake of, and adherence to, PR programs in NZ is poor [8]. It was estimated that in 2012, <1% of all patients with COPD were participating in PR in NZ [8]. Poor attendance and adherence to PR programs is common internationally. Previous literature has suggested that this is because of transportation, lack of perceived benefit, depression, and the interruption to the patient's daily routines [9-11]. In addition, many patients experience significant barriers to accessing PR services, especially those living in rural areas and where transportation to a central service may be unaffordable or unavailable. Home-based PR programs have been shown to overcome some of these access barriers for people with chronic respiratory diseases [12-14].

There is potential for mobile health (mHealth) to provide an alternative modality for the delivery of PR, overcoming many of the barriers contributing to poor attendance to current services. By utilizing mobile technology, PR can be made available to people within their everyday lives at times and places most suitable to the patient, removing the barriers associated with transport, timing, and location. There is a wealth of evidence for the use of mobile technology to deliver health interventions to people with chronic conditions including the delivery of rehabilitation interventions, self-management support programs, behavior change interventions, and supportive care [15-18]. Not only does mHealth allow for individually tailored interventions to be easily delivered in a cost-effective way but also it has potential for interventions to be adapted over time as individual needs and characteristics change [19].

When developing new mHealth tools, engagement with end users in the design is essential. By incorporating the perspectives of end users, it ensures the intervention will meet the population need and enables it to be tailored to specific cultural needs, contexts, and levels of technology access [20]. When end users are not considered in the design, it can contribute to poor uptake and use of tools [21]. Furthermore, it is important that formative research, including adequate description of the population context, is reported in the development of new mHealth interventions [22]. Formative research provides the basis for designing tools to meet user needs within system constraints and the local context.

This study aimed to understand the needs, preferences, and priorities of end users for the development of a mobile PR (mPR) support program. Specifically, it aimed to understand (1) the preferences and priorities of patients for PR and how mobile technology could be used to provide PR support and (2) the needs, preferences, and priorities of health care providers including physiotherapists, respiratory physicians, primary care nurses, and general practitioners (GPs).

Methods

Study Design

This cross-sectional study utilized a mixed method (qualitative and quantitative) approach incorporating surveys and interviews to assess the needs, preferences, and priorities of end users and key stakeholders. The study was split into 3 parts—(1) patient key stakeholders. The study was split into 3 parts—(1) patient survey, (2) patient interviews, and (3) key stakeholder interviews—and was conducted between July and December 2018.

Ethical Approval

Ethics approval was obtained from the NZ Health and Disability Ethics Committee (18/NTA/105). Research approval from each District Health Board (DHB) from which patients were recruited was also obtained. Written informed consent was obtained from survey and interview participants before their participation in the studies.

Part 1: Patient Survey

Inclusion Criteria

Inclusion criteria were adults with chronic respiratory disease who would be eligible for PR, able to read and understand English, and provide informed consent.

Recruitment and Procedures

Potential participants were identified by clinicians at 2 DHBs in the Auckland region, NZ, through respiratory outpatient clinics and inpatient services. Eligible participants were given a letter about the study, the information sheet, and consent form. By selecting patients from this defined subgroup, we were more likely to define patients who had either been invited to attend or had attended a rehabilitation program. Those interested in participating provided informed consent before completing the

survey via 1 of 3 methods: (1) on the web via the study website, (2) over the phone with a member of the research team, or (3) on paper. Surveys completed by phone or on paper were entered into the Web-based version of the survey by the researcher.

Survey Design

The survey comprised 4 parts and contained both closed- and open-ended questions to allow participants to elaborate on their answers: (1) your health including diagnosis, attendance at PR, and barriers to attendance and completion of PR; (2) technology access, including current use and access to technology and devices; (3) technology and pulmonary support, including perceptions of mPR, preferences for technology-based support, and perceived barriers and benefits to technology-based pulmonary support; and (4) demographics, specifically age group, gender, and ethnicity.

The survey was designed in paper format and then uploaded into REDCap software (v8.5.0). It was pretested by the research team and a selection of patients before finalization.

Part 2: Patient Interviews

Inclusion Criteria

Survey participants who had consented to be contacted for future research following completion of the survey were eligible for inclusion in an interview.

Procedures

Patients who completed part 1 of this study and identified that they were happy to be contacted about further research were contacted to invite them to take part in an interview. Participants provided informed consent to participate as well as consent to access medical records related to their eligibility for PR. Interviews were conducted in person, or over the phone, by a trained interviewer (PH) at a time and location convenient to the participant. If needed, interviews were split over multiple sessions to reduce burden for participants. Notes were taken by the researcher during the interviews, and the interviews were recorded to supplement the notes. At the end of the interview process, the participants were offered a NZ $20.00 (approximately US $13.00 or €11.50) voucher for their time.

Interview Design

Ethnographic, semistructured interviews were undertaken. The interviews were designed to explore in-depth beliefs and perceptions of chronic respiratory disorders and their treatments, perspectives on potential features of an mPR intervention, and patient understanding of their health.

Part 3: Key Stakeholder Interviews

Inclusion Criteria

Inclusion criteria were clinicians managing patients with COPD and other chronic pulmonary disorders (eg, bronchiectasis and interstitial lung disorders), able to read and understand English, and able to provide informed consent.

Procedures

Potential participants were identified through respiratory and PR services by coinvestigators RW, PH, SC, and JR and invited to take part via email. Interviews were conducted in person or via phone at the participant's preference by a trained interviewer (RD) and were between 30 min and 1 hour in duration. Notes were taken by the interviewer, and the interviews were recorded to supplement the notes.

Interview Design

Interviews were semistructured and designed to cover the current use of technology in care of people with chronic respiratory conditions, experiences with PR, and perceptions of mPR including enablers and barriers.

Statistical Analysis

Quantitative data from the survey were analyzed and summarized using descriptive quantitative analyses including means, standard deviations, and proportions. Qualitative comments were analyzed using a simple, general inductive thematic approach to identify common themes and meanings from the data. Only completed surveys were included in the analysis. Prioritized ethnicity was used as recommended by the NZ Ministry of Health for the reporting of ethnicity data; only 1 of the ethnic categories nominated by the participant was used according to a predetermined hierarchy (M ori, Pacific Islander, Asian, European, and other ethnic groups, in order of prioritization).

Results

Part 1: Patient Survey

There were 34 entries to the survey site from which 30 people consented to take part and completed the survey. Slightly more than half of the sample were male (17/30, 57%), and the majority were aged >65 years (22/30, 73%; Table 1). Over one-third of the participants identified as M ori or Pacific Islander (11/30, 37%). Approximately half the sample reported that they had been diagnosed with COPD (16/30, 53%). A total of 7 (7/30, 23%) participants reported that they were unsure, or did not know, their diagnosis.

Table 1. Demographic and clinical characteristics (N=30).

Characteristics	Participants, n (%)
Gender	
Male	17 (57)
Female	12 (40)
Did not answer	1 (3)
Ethnicity	
New Zealand European	17 (57)
M ori	7 (23)
Pacific	4 (13)
Asian	0 (0)
Other	1 (3)
Did not answer	1 (3)
Age (years)	
<45	0 (0)
45-54	3 (10)
55-64	4 (13)
65-74	10 (33)
75-84	12 (40)
>85	0 (0)
Did not answer	1 (3)
Patient-reported diagnosis	
Chronic obstructive pulmonary disorder	16 (53)
Emphysema	3 (10)
Bronchitis	1 (3)
Pulmonary fibrosis	1 (3)
Bronchiectasis	1 (3)
Asbestosis	1 (3)
Do not know or unsure	7 (23)

Pulmonary Rehabilitation

Participants were asked if they had attended a PR program. Almost half (14/30, 47%) reported that they had completed PR or were intending to complete it in the future. Nearly a quarter of participants (7/30, 23%) had started a PR program but had not completed it. The reasons for not completing the program included issues related to location and transport (n=2), timing of the sessions (n=2), being hospitalized (n=2), and other commitments (n=1). A total of 3 participants (3/30, 10%) were offered PR but did not attend because of transport (n=2) or other commitments (eg, having to care for grandchildren; n=1). The remaining 6 (6/30, 20%) participants reported that they had not been offered PR or did not remember being offered PR.

Access to Technology

Participants were asked about their access to digital devices (eg, mobile phones, tablets, computers, and sensors) for personal use, with all but 4 (4/30, 13%) participants reporting having access to a mobile phone. Of those who had a mobile phone, the majority had a smartphone (20/26, 77%) and the remainder (6/26, 23%) a mobile phone without internet capability. Of those that had a smartphone, only 60% (12/20) reported having access to the internet on the smartphone all the time. A total of 5 (5/20, 25%) had access to the internet on the phone sometimes, 2 (2/20, 10%) not at all, and 1 (1/20, 5%) did not answer.

One-third of the sample (10/30, 33%) reported having access to a tablet for personal use, 14 (14/30, 47%) a computer (ie, laptop or desktop), 2 (2/30, 7%) a Fitbit or other fitness tracking device, and only 1 participant reported access to no devices for personal use. A total of 23 (23/30, 77%) participants reported access to internet at home, and an additional 3 (3/30, 10%) reported they sometimes had access to internet at home. There were 4 (4/30, 13%) that had no access to the internet at home.

In relation to the use of technology-based devices and tools to manage health, there was only 1 participant (1/30, 3%) that reported using an app, 1 (1/30, 3%) who reported using a smart watch, 3 (3/30, 10%) used a fitness tracking device, and 4 (4/30,

13%) a peak flow meter. A total of 20 (20/30, 67%) participants reported no use of these tools to manage their health.

Technology and Respiratory Health Support

Participants were asked about their perceptions of a technology/mobile phone program that would allow people to receive PR support at home. The majority (23/30, 77%) reported that they liked this idea, and 7 (7/30, 23%) did not like the idea. The proportion of those that liked the idea was highest in M ori participants (6/7, 86%) compared with NZ European (13/17, 77%) or Pacific (2/4, 50%). Those that liked the idea (n=23) were asked what they liked about the idea. The most common theme was around the access at home meaning no need to travel (n=10), and others reported the cost reduction related to parking and travel (n=3), being able to access the program wherever and whenever (n=1), less embarrassment within the home (n=1), and that family would be able to help and be involved (n=1):

> *Privacy—don't have to be embarrassed.* [45-54-year-old male, ID number 27]
>
> *Would make it easier as would not have to travel in bad weather.* [75-84-year-old male, ID number 8]
>
> *The convenience. At the moment, travel outside the home is quite onerous for me.* [65-74-year-old male, ID number 9]
>
> *Family would be able to help Dad to do this at home.* [75-84-year-old male, ID number 25]
>
> *Would have saved me some trips... Transport is hard for people, don't have a car.* [45-54-year-old male, ID number 27]

There were 5 participants whose responses were moderately supportive of it being a good idea and 3 who did not answer the question. In addition, 3 participants identified concerns around the proposed idea potentially resulting in less social contact and less access to health care professionals:

> *Sounds good although I do like meeting other people.* [65-74-year-old female, ID number 33]
>
> *But it is good to meet other people and learn from others.* [65-74-year-old female, ID number 22]

Those that did not like the idea (n=7) were asked the reason, with the most common theme being that they found technology too difficult/hard (n=3). Other themes included not having internet (n=1), wanting the company/social aspect of an in-person group program (n=1), or preferring to go to the hospital (n= 1). A participant did not provide a reason:

> *Too hard to use computer.* [75-84-year-old male, ID number 18]
>
> *No internet at home.* [55-64-year-old male, ID number 19]
>
> *I would feel isolated, when you are older you need company.* [75-84-year-old female, ID number 21]

Participants were asked about the features they thought would be helpful to include in the proposed program. Of those that liked the proposed idea and who responded to the question (n=22), 19 (19/22, 86%) selected tips and suggestions for managing their breathing, 17 (17/22, 77%) information and education about their condition, 12 (12/22, 54%) access to their health information, 11 (11/22, 50%) tracking of their health data, and 9 (9/22, 41%) motivational and support messages. A total of 23 (23/30, 77%) reported that they would consider wearing a sensor (eg, a Fitbit or activity tracker) as part of an mPR program, and 22 (22/30, 73%) reported that they would want the program to be linked into their existing health record and information so that the program could be tailored to their individual health condition and treatment.

Participants were asked to identify the barriers to using the proposed mPR program (Table 2). The most common barrier was concern about not being comfortable or confident using technology.

Table 2. Barriers to using a mobile pulmonary rehabilitation program (N=30).

Barriers	Participants, n (%)
No barriers	6 (20)
No access to technology	5 (17)
Do not feel comfortable using technology	11 (37)
Security concerns regarding my health information	3 (10)
Not interested in this type of support	3 (10)
Could increase worry and anxiety	1 (3)
Would not be useful if not translated	1 (3)

When asked about the perceived benefits of using technology to support people with health conditions in the community, the majority (25/29, 86%) identified the convenience of having access at any time or anywhere as a benefit. There were 15 (15/29, 52%) participants who identified the benefit of being able to involve/include family/whanau, and 4 (4/29, 14%) identified feeling more comfortable not being in the group or clinical environment.

Part 2: Patient Interviews

A total of 8 patient interviews were conducted. Participants included 2 women (2/8, 25%) and 6 men (6/8, 75%), with 2 of the 8 (2/8, 25%) individuals identifying as M ori and the remaining (6/8, 75%) as NZ European. The majority were aged 75 to 84 years (4/8, 50%), 2 (2/8, 25%) aged 65 to 74 years, and the remaining (2/8, 25%) aged 45 to 54 years. Participants were registered across 2 DHBs and interviewed at home (2/8,

25%), in the hospital (5/8, 63%), or via phone (1/8, 13%). Analysis of the interview data is summarized in 4 major themes.

Condition and Health

Participants identified themselves as having COPD, emphysema, and asbestosis, but only 6 participants were able to clearly describe their diagnosis and treatment. Diagnosis was reported as being a shock to receive; however, this shock did not necessarily change behavior:

> *Well I didn't know much about it, so it didn't make much of a difference to me. I continued smoking, didn't I?* [75-84-year-old male, ID number 4]
>
> *I knew from the day he said that, that things were not so good for me.* [75-84-year-old male, ID number 6]

Participants described COPD affecting all facets of their lives negatively. Despite this, all expressed some form of resilience and stoicism during the interviews:

> *It affects everything: social, mental, physical.* [75-84-year-old female, ID number 5]
>
> *It can't be cured you just have to live with it and get on with life and do what you've got to do.* [75-84-year-old male, ID number 2]
>
> *I'm pretty humble with it. I've lived a pretty good life.* [45-54-year-old male, ID number 3]

Only 2 participants showed some degree of understanding of their test results, and the remaining participants did not understand the results of their tests; they knew what their diagnosis was but found the presentation of the test results difficult to comprehend. All participants struggled to remember which tests had been conducted and at which point in their illness trajectory:

> *Honestly, I just go when I am told to go and have it done, and that's it.* [75-84-year-old female, ID number 5]

Of the 8 participants, 7 were ex-smokers and acknowledged this as a contributing factor to their current respiratory condition; however, 5 offered additional environmental factors as contributors including asbestos and work environments.

Pulmonary Rehabilitation

All patients interviewed had some experience of hospital-based PR programs. A total of 2 had completed programs within the past 3 years, 2 had started but stopped indefinitely because of hospitalization, 3 were in the process of completing an 8-week program, and 1 had tried a program over a decade previously. All but 1 reported enjoying the programs:

> *I wish I had done it earlier.* [75-84-year-old male, ID number 2]
>
> *I love it. I wish they had it 12 months of the year.* [65-74-year-old female, ID number 7]
>
> *Yeah, I enjoy the exercise. It's just a matter of getting your mind in the right place. I get up and I do it and I feel a lot better afterwards.* [65-74-year-old male, ID number 1]

Reasons for this included socializing during the training, being able to compare progress and daily lived experiences with others with a similar condition, compassionate and dedicated staff who were known to the participants, and both a measurable and perceived improvement in physical ability. However, a participant reported anxiety and an increased sense of vulnerability after he was transferred to community support, following completion of the hospital-based PR program, arising from inconsistency in times and scheduling, different staff members at each visit, and a decreased sense of support.

Technology-Based Pulmonary Rehabilitation

All but 1 of the participants (7/8, 88%) described that they preferred to be offered a PR program in person at the moment of diagnosis by a medical professional they trusted and had an existing relationship with, rather than when in hospital with an exacerbation:

> *When you're really sick and they come at you, like the physio comes, and this one comes, and that one comes, and you just feel like being left alone, I felt, just leave me alone sort of thing... maybe after being first diagnosed.* [75-84-year-old female, ID number 5]

The main barrier to mPR was a perceived incompetence with technology and a fear that this would be difficult to work with; however, 6 participants appeared to be confident of texting during interviews, and 4 talked about using Facebook to communicate with family. A participant enjoyed using health apps to measure the aspects of his health.

Feature suggestions for mPR included knowing which part of the body exercises were targeting, with the most ambitious proposals suggesting:

> *I think you should give them every feature that you can and maybe give them the option to choose... incorporating videos of people doing it and how they started and then how they finished... a motivational start, and then a talk and showing "look at me, now I can run two kilometers.* [45-54-year-old male, ID number 3]

Imaging

During the interview, participants were shown a model of the lung [23,24] and an interactive website [25]. The subsequent discussion revealed the underlying power of visual imagery to reveal the *truth* of diagnosis, with patients reporting that they struggled to accept their diagnosis until they saw an image and that seemed more *real* than paper, which they saw as a tool for the medical professional:

> *I didn't get how bad my lungs were until I saw it.* [45-54-year-old male, ID number 3]
>
> *She said "have you ever seen your lung?" and showed me this x-ray and I thought, "whoa."* [75-84-year-old male, ID number 2]

A participant said she had never been shown an x-ray or image of her lungs and insisted that this would have caused her to stop smoking earlier.

Part 3: Key Stakeholder Interviews

A total of 8 key stakeholder interviews were completed. Key stakeholders included 2 doctors (ie, GP and respiratory specialist), 2 nurses, 3 physiotherapists, and 1 health psychologist. Participants worked across either predominantly urban (5/8, 63%) or predominantly rural (3/8, 37%) populations. A total of 5 (5/8, 63%) participants were directly involved in the delivery of PR, whereas the remaining 3 (3/8, 37%) were involved in referring patients to PR services.

When asked about their perceptions of patients' understanding of COPD, all acknowledged that it was generally poor. A total of 3 participants acknowledged that understanding varied, and those that had attended PR or sought health information through the internet had a better understanding. Common tools for explaining COPD to patients included handouts and pamphlets (n=3), Web resources (ie, websites and YouTube videos; n=2), drawings and models (n=2), and patient scans (n=1).

Mobile Pulmonary Rehabilitation

All participants thought that a technology- or mobile-based PR program was a good idea, particularly for overcoming the barriers their patients currently experienced to attending PR. However, the majority of the participants also raised concerns that an mPR program would lack the social element and not be suitable for some groups such as older patients or those with limited confidence and access to technology.

Participants were asked how they felt an mPR program would fit into current models of care. Responses could be grouped into 3 main categories: (1) an alternative service to increase the access to PR for those that were not able to attend current services, (2) a maintenance program following traditional in-person PR programs, and (3) a combination/mixed model of care where patients used an mPR program to complement the in-person program. All participants reported that an mPR program should include the following components: (1) education, (2) exercise information, (3) motivation and support, (4) the ability to view personal health information/data, and (4) monitoring of health behaviors.

Other components identified by the participants for inclusion in an mPR program included health psychology content, medication reminders, personalized action plans, step-by-step videos, social features, sharing of information between patient and health care professional, and general self-care information. Participants also identified that it would be essential for a program to be both individually and culturally tailored.

When asked about the different technologies the potential program should utilize, many different technologies were identified including sensors, smart inhalers, apps, and text messages. But consistent across all participants was that the technologies used needed to consider differing access to technology, devices, and data, as well as confidence with using technology:

> *Important to use mobile phone as a lot of people won't have anything else.* [ID number 1]
>
> *An app would be a good way of doing it... Sensors are useful for helping patients to see progress to goals.* [ID number 2]
>
> *Text messages are easy for patients to get, older patients to get, minority populations do not tend to have a lot of money on their phones.* [ID number 3]
>
> *A lot of people don't have internet at all. We text or phone them, they aren't able to text, call as they have no money on their phones. Some people don't even have mobile coverage...* [ID number 6]
>
> *We already use SMS, people are used to getting text messages.* [ID number 7]

There were conflicting views from participants around how an mPR program should be accessed. A participant felt that referrals should be through the same avenues as current services to ensure safety was prioritized, and only people who were appropriate were accessing the program. Others felt that in addition to clinician referrals, patients should be able to access it directly to reduce barriers to access. There was only 1 participant who felt that clinicians should not be involved in referring to the program at all because of concerns that the clinician would need to then provide technical support:

> *Referred [by a clinician] is best rather than self-referral, ensures that the info will be right for that patient. Same criteria as current groups.* [ID number 1]
>
> *Shouldn't put up a barrier of the clinician referring them. Especially if they can't afford to see their GP.* [ID number 2]
>
> *Anyone should be able to have access to it but there needs to be some sort of way of knowing people are safe with it, that they are safe to exercise.* [ID number 4]
>
> *Patients should be able to access it themselves. Health care professionals could promote it but don't want to become IT support.* [ID number 5]

Finally, participants were asked about the potential barriers/downsides to an mPR program. All but 1 participant (7/8, 88%) reported concerns relating to the digital divide, including access to technology and the confidence to use it. A full list of barriers identified can be seen in Table 3.

Table 3. Barriers to using a mobile pulmonary rehabilitation program (N=8).

Barriers	Participants, n (%)
Digital divide	7 (88)
The lack of the social/group environment	6 (75)
Lack of relationship between clinician and patient	4 (50)
Safety for patients not being supervised	2 (25)
Patient compliance to the program	2 (25)
Health care professional digital literacy	1 (13)
Successful marketing and promotion of the program	1 (13)
Patient access to exercise equipment	1 (13)

Discussion

This study aimed to identify the needs, preferences, and priorities of end users in the development of an adaptive mPR support program. A survey of patients, together with interviews of patients and key stakeholders, found a common interest in an mPR program. The potential for mPR overcoming barriers to accessing traditional PR programs was highlighted. These findings are consistent with previous research reporting high acceptability of digital health tools in patients with chronic respiratory conditions [26-28].

This formative study has identified important aspects of our target audience and their diversity of needs. Some have low access to digital technology as well as low digital literacy and confidence, although most would like the option of a technology-delivered program. Needs include support during PR programs (between group sessions), support after a PR program to maintain behavior change, and a complete program for those unable to attend a traditional inpatient PR program. The study also identified a difference in clinicians' perceptions of patients' understanding of their condition (poor) versus patients' actual comprehension and management of their condition.

From these findings, our key considerations in designing a user-centered mPR support program will be in replicating the benefits of social support provided by the in-person group sessions, ensuring options are available for differing levels of digital literacy and confidence with technology while not providing a *second class* program for those with lower technology access is essential. Providing a program that not only considers individual technology access and literacy but also considers personal preferences and characteristics is also needed to ensure that it will be positively received by users. As indigenous populations, ethnic minority groups, and those from socioeconomically deprived groups suffer worse outcomes from COPD, ensuring an mPR program that strives for equity is essential. A strength of the survey sample was that it comprised over one-third M ori and Pacific participants. Key stakeholders highlighted the importance of considering culture and of culturally tailoring the mHealth tool.

Key considerations in terms of satisfying referring clinicians are ensuring safety can be maintained and providing appropriate programs for different groups within the population. Finding a balance between ensuring safety and maximizing access is vital to ensure that an mPR program overcomes the barriers and increases access to PR support. Although the majority of the participants in the survey and interviews had attended PR or intended to, this study has identified a range of barriers to traditional in-person PR services that align with the previous studies [9-11]. These barriers related to transport and timing can be overcome with an mHealth alternative.

It is important that these findings are interpreted in light of the study's limitations, including the small number of participants surveyed and interviewed, the potential sampling bias in those who agreed to participate, and the patients who participated having a higher proportion accessing PR services than the general population categories. It is likely that those patients who did participate had more interest in mHealth; therefore, engagement with this type of tool may be lower in the wider population. Pretesting of an mPR program with a wider patient sample will be essential to understand the acceptability of this type of intervention.

Although there is a proliferation of technology in health care and increasingly innovative technologies being embraced for patient self-management, our study, consistent with previous studies, has shown that a digital divide exists, contributed to by differing access to data and tools as well as confidence and digital literacy to effectively use them [29-31]. Although our study demonstrated interest in using technology for PR support, the current use of many tools such as sensors and apps was low among the participants. If an mPR program is to utilize more than basic modalities, such as text messaging, then there is likely a need for these tools to be provided to patients with training and ongoing support when issues arise. This equates to additional resources and associated costs that must be considered not only in setting up an mPR program but in sustaining it.

Conclusions

We have developed a prototype mHealth-based PR program based on the results of this mixed methods research. This includes different components suggested in the paper that will be pretested with people with chronic respiratory disorders. Feedback will be provided, and funding will be sought for the development of a full mPR program. The findings support the need for involving patients in the initial design and development of an mHealth intervention and in a feasibility pilot study, once the intervention is developed, to try and better understand the

degree of support required by health professionals and the degree of technical support required.

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Authors' Contributions

TB, SC, RD, JG, GH, PH, JR, MT, DT, JW, and RW contributed to the study design and procedures. Data collection was performed by SC, RD, and PH. RD and PH analyzed and interpreted the data. RD and RW prepared the draft for the paper. TB, SC, JG, PH, and DT provided critical feedback on the paper.

Conflicts of Interest

None declared.

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Abbreviations

COPD: chronic obstructive pulmonary disease
DHB: District Health Board
GP: general practitioner
mHealth: mobile health

mPR: mobile pulmonary rehabilitation
NZ: New Zealand
PR: pulmonary rehabilitation

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Appendix M. Feasibility Study

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ORIGINAL RESEARCH
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Mobile Pulmonary Rehabilitation: Feasibility of Delivery by a Mobile Phone-Based Program

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Background: Pulmonary rehabilitation (PR) has been proven effective but is not well accessed due to transport, time, cost, and physical limitations of patients. We have developed a mobile phone-based PR program (mPR) that could be offered as an alternative for those unable to attend in-person. This was developed following formative research with patients, their families and clinicians. mPR has a core text message program plus an app that includes an action plan, exercise videos, lung visualization, symptom score questionnaire and 1-min sit-to-stand test.

Aims: To determine the feasibility of delivering pulmonary rehabilitation by mobile phone.

Methods: A 9-week non-randomized (1-arm) pilot study was conducted. Participants were 26 adults with chronic obstructive pulmonary disease plus four family members, who were offered participation at first assessment or during group PR sessions. Outcomes included satisfaction, engagement with the program, and perceived impacts.

Results: Eight people (31%) opted for text messages only, and 18 (69%) chose text messages plus the app. Three people stopped the program early, 20 said they would recommend it to others, 19 said it helped them to feel more supported, 17 said it helped them to change their behavior.

Conclusion: It is feasible to deliver PR support *via* mobile phone, including exercise prescription and support. Our mPR program was appreciated by a small number of people with chronic respiratory disorders and family members. Suggestions for improvements are being used to inform the further development of the program, which will then be tested for effectiveness. Registered with the Australia New Zealand Clinical Trials Registry ACTRN12619000884101 (www.anzctr.org.au).

Keywords: mHealth, pulmonary rehabilitation (PR), COPD, COPD—chronic obstructive pulmonary disease, digital health (eHealth), mobile phone

INTRODUCTION

Pulmonary rehabilitation (PR) has been shown to be effective in improving symptoms and quality of life in people with chronic respiratory disorders (McCarthy et al., 2015). PR is a structured program involving exercise training, education and behavior change, which is designed to improve a patient's physical and psychological health (Spruit et al., 2013). However only a very small proportion of those eligible access PR for reasons including transport, time off work, difficulty attending due to symptoms of their illness, lack of perceived benefit, and depression (Hayton et al., 2013; Guo and Bruce, 2014; Harrison et al., 2015). In recent times, those with long term respiratory disorders may be even more reluctant to attend group sessions, particularly those based in hospitals, due to the risk of COVID-19 infection. To increase the accessibility of PR (and consequently reduce the risk to this vulnerable population) we wanted to determine whether many of the aspects of PR could be delivered using mobile phones, in the same way other long-term condition self-management support programs have successfully been delivered (Chow et al., 2015; Dobson et al., 2018; Dobson et al., 2019b).

This project aims to develop a mobile phone-based PR support program using the steps outlined in the mHealth Development and Evaluation Framework (Whittaker et al., 2012). Formative work undertaken for this project found high interest in mPR from both patients and healthcare professionals (Dobson et al., 2019a). Both patients and healthcare professionals identified potential for an mPR program to overcome current barriers to traditional PR programs but had concerns regarding technology and the lack of a group environment within a digital program. Differing technology access, digital literacy and patient characteristics highlighted the need for a range of solutions to meet individual needs. There were differing views on how a potential mPR program should be accessed or how the program should sit in relation to current PR models of care. The findings from the formative work has led to the development of an mPR prototype intervention including a personally tailored text message program (mPR-SMS) and a personally tailored smartphone app (mPR-app).

The mPR prototype is an individually tailored and theoretically based PR intervention designed to support people with chronic respiratory conditions to: 1) Increase exercise capacity; 2) Increase health related quality of life; and 3) Decrease hospitalisations for acute exacerbations. The program is designed to support people (and their families) before, during, or after PR, or as an alternative for those not able to access traditional PR services. mPR consists of a core text message program with an optional mPR-app. In line with the findings from the formative work, a core text message program ensures that the intervention is accessible to everyone regardless of level of digital access and digital literacy.

The aim of this study was to pilot the prototype to assess the feasibility, acceptability and usability of a prototype mPR intervention, in order to inform the potential further development of a comprehensive integrated and adaptive mPR intervention.

METHODS

A nine-week, non-randomized one-arm pilot intervention study was conducted between July and November 2019. All study documents and procedures were approved by the Health and Disability Ethics Committee (19/NTA/74). It was registered with the Australia New Zealand Clinical Trials Registry (ACTRN12619000884101).

Intervention

The content for the mPR program was developed by a multidisciplinary team including physiotherapists, a respiratory physician, a health psychologist, a public health physician, mHealth behavior change experts, computer scientists, patients and engineers. The development of this program followed the mHealth Development and Evaluation framework (Whittaker et al., 2012), which provides a process to guide the development and testing of mHealth interventions with a focus on implementation, behavioral change theory, and involvement of the target population. The development of the content was informed by a review of current PR program content, literature, existing mHealth interventions, patient resources, and our formative research with the target audience (Dobson et al., 2019a). The program was informed by behavior change theories and incorporates behavior change techniques (BCTs) (Michie et al., 2013) including information about health consequences, social support, (practical) instructions on how to perform the behavior, and graded tasks.

Participants could stop the intervention and any of its components at any time by free texting back "STOP" and uninstalling the app.

mPR Text Messages

mPR consisted of a personally tailored package of text messages over a 9-week period. Different modules allowed content to be tailored to individual clinical characteristics, preferences and demographics. All participants received one mPR information/support message per day. In addition, smokers received a smoking module (encouraging consideration of quitting smoking) and an airway clearance module was available for participants who experienced increased respiratory secretions. All participants were also allocated an exercise prescription module based on their baseline exercise capacity and dyspnoea score as defined by the PR physiotherapist. Current smokers could opt to add a proven smoking cessation program (Bramley et al., 2005; Rodgers et al., 2005). **Table 1** provides more specific detail of the content of the modules. Family members who signed up for the program received core messages and could also receive the smoking module if a smoker. Messages across all modules were tailored and personalized by culture, the person's name, their motivations and the names of their support people.

Message delivery was managed by a specifically developed content management system, with messages sent and received through a gateway company to allow for participants to be registered with any New Zealand mobile network. The system maintained logs of all outgoing and incoming messages.

TABLE 1 | Description of the text message mPR modules.

Module name	Description	Who can receive this module
Core	One message per day includes motivation, support and information messages designed to encourage correct engagement with the program, healthy behaviors, and the healthcare system. Messages covered; general wellbeing, motivational messages, links to support services, general PR information/education, physical activity, breathing and healthy eating	All
Exercise prescription	Weekly exercise prescription based on exercise capacity including aerobic, resistance and balance exercises. There are 3 levels of exercise prescription	Patients only
Smoking	For those identified as smokers at baseline, one message every 2 weeks encouraging quitting smoking and offering a smoking cessation program	Current smokers
Smoking cessation	Those receiving the smoking module who reply text "quit" if they want support to quit to be enrolled in a smoking cessation program consisting of - Countdown to quit day (2 messages per day for a week), - Quit day (3 messages/day), - Main program (2 per day for 4 weeks) and - Relapse prevention (3 per week for the reminder of the time they receive mPR)	Current smokers who identify as wanting to quit
Airway clearance	One message per week including education and reminder messages regarding techniques for airway clearance	Patients who were productive of airway secretions only

TABLE 2 | Description of the mPR app components.

Component	Description
Tailored exercise prescription videos	Tailored exercise videos of people completing the prescribed exercises for people to follow Tailored to 3 levels based on baseline exercise capacity level
1-min sit-to-stand test	Instructions, timer, and ability to input number of repetitions completed. Reminder to complete this every 2 weeks
CAT[a] questionnaire	Questionnaire that could be completed in the app. Reminder to complete this every 2 weeks
Action plan	The standard action plan for respiratory disease exacerbations that could be completed in the app by the participant
Lung model visualization video	An educational tool to demonstrate to participants how their lungs work and changes that may have occurred related to their disease. This video was created using anatomically-realistic computational models, demonstrating the lungs and the airway structure, to provide visually appealing and accurate representations of the lungs [(Burrowes et al., 2008). In addition, the users were referred to a web-based lung model app (https://sites.bioeng.auckland.ac.nz/medtech/lungs/) to provide further exploration of these models
Relaxation audio files	Freely available audio for participants to listen to and help them relax
Information for family	Brief information on how to support your loved one with their chronic respiratory disease

[a]*CAT, COPD (Chronic Obstructive Pulmonary Disease) Assessment Test.*

mPR app

The mPR app was designed to complement the text message program and was developed by students and staff under the supervision of the study team (see **Table 2** for components and **Figure 1** for screenshots). It was loaded onto the Apple and Play app stores for download and was accessed using a study specific code. Each individual's profile was set up according to their baseline exercise prescription level.

Although no specific instructions were given to those choosing the app, participants may have been expected to use it approximately three times per week in order to view the exercise videos three times weekly and relaxation audio as needed. Other aspects of the app would expect to be used less frequently (for example, 1-min sit-to-stand test and CAT questionnaire every two weeks; lung model visualization and information for family only as desired).

Exercise Prescription

A key component of the mPR program is the exercise prescription. To ensure appropriateness, this was tailored to baseline exercise capacity. Participants were stratified to one of three exercise levels (1, 2, or 3). The exercise level was determined from their initial assessment findings, including; balance, dyspnoea score [MMRC Dyspnoea Scale Score (Bestall et al., 1999)] and functional exercise capacity [6-min walk test, 6 MWT (Holland et al., 2014)]. The exercise program included a generic warm up, walking program, and resistance training for upper and lower limbs using hand held weights. The level one program also included balance exercises. Participants were advised to exercise on five days of the week. The program was incremental - each week either the walking time, or the number of repetitions of strengthening exercises, increased. The progressed exercise prescription was sent to participants *via* SMS and updated on the mPR app. Participants were given instructions to use a scale of breathlessness (modified BORG scale) to guide the intensity of exercise. Participants were provided with instructions on how to complete each of the exercises as well as advice on when to stop exercise should they have pain or feel unwell.

The program was also adaptive to the patient's current health state utilizing assessment *via* free reply message. From week 2, each week the participant received a message asking for their current rating of their health on a Visual Analogue Scale (VAS)

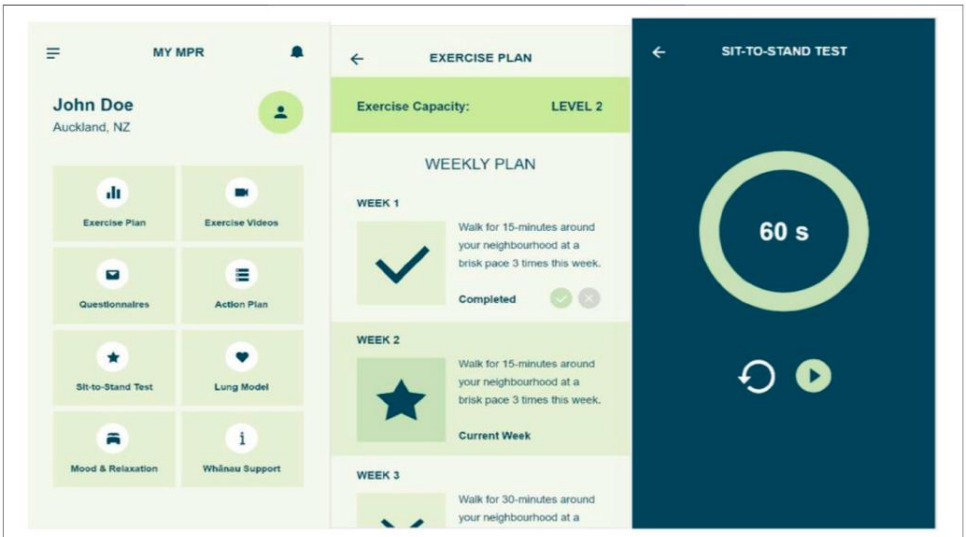

FIGURE 1 | mPR app screenshots.

from 1 to 10. If their health was rated three or above, they received a reply message with the exercise prescription recommendation for the week corresponding to the level associated with their baseline exercise capacity (level 1, 2, or 3). If their current health was rated less than three then no exercise prescription was sent, and a general self-care message sent instead. If people did not respond or reported ratings of less than three for three weeks in a row, a tailored message was sent to encourage them to engage with their clinical team.

The program was also designed to monitor compliance with exercise prescription by 2-way messaging. At the end of each week a message was sent asking how many times they completed the exercise prescription for that week. An automated response was sent based on the number of times they had completed the prescription designed to congratulate them and encourage continued engagement with the program.

Participants and Recruitment

Eligibility criteria included adults aged 16 years and over with a chronic respiratory disease e.g., chronic obstructive pulmonary disease (COPD), being eligible for PR, having completed a PR initial assessment by a PR clinician, being able to read and understand English, being able to provide informed consent, and owning or with regular access to a mobile phone. The only reason for exclusion aside from the above criteria was not being available for the duration of the study. Recruitment was carried out in two secondary care hospitals in Auckland, New Zealand. Clinicians at each site identified potential participants and gave them information about the study. Informed consent was obtained before the participant was registered for the study and baseline assessment completed. The clinician then explained the exercise prescription, including providing demonstrations of each exercise and written instructions on how to perform them correctly.

Participants were asked about their intervention preferences (whether they wanted the mPR app alongside the core text message program) and intervention tailoring factors including cultural version, preferred message delivery time, names of support people and motivations. Participants were asked if a family member would be interested in also receiving the program, and if so, they were contacted separately to inform them about the study and complete informed consent.

The program was completely free to receive (no costs for text messaging or apps). Participants were given a voucher at the conclusion of the study to reimburse them for their time.

Safety

Participants were advised to contact the study physiotherapist (SC) if there were any issues arising from participation in the program. Multiple contact methods were provided.

Measures

Baseline measures were those routinely collected at assessment including demographics, exercise capacity and clinical measures [MMRC Dyspnea Scale Score (Bestall et al., 1999), 6-min walk test (6 MWT) (Holland et al., 2014), 1 min sit-to-stand test

TABLE 3 | Patient participant characteristics (n = 26).

	N	%
Gender: Male	13	50
Ethnicity		
Māori (indigenous NZ population)	4	15
NZ european	17	65
Other	5	19
Mean age	70 years	(Range 57–84)
Diagnosis		
COPD	20	77
Asthma	1	4
Bronchiectasis	1	4
Interstitial lung disease (ILD)	3	12
Other	1	4
Attendance at pulmonary rehabilitation (PR)		
PR attender (attended previously or currently attending)	20	77
PR non-attender	6	23
1 min sit-to-stand (mean)	16.65	(Range 0–31)
6 min walk test (6MWT) (mean)	374.58 m	(Range 98–570)
FEV1%		
GOLD 1-mild: FEV1≥ 80% predicted	1	4
GOLD 2-moderate: 50% ≤ FEV1 <80% predicted	14	54
GOLD 3-severe: 30% ≤ FEV1 <50% predicted	8	31
GOLD 4-very severe: FEV1 <30% predicted	2	8
Lowest SpO_2 (mean)	92%	(Range 73–100)
Secretion load: Does the patient have difficulty clearing phlegm? Yes	11	42
Smoking status: Non-smoker	26	100
COPD assessment test (CAT) score (mean)	17.08	SD = 7.05

(Vaidya et al., 2016)], plus symptom and quality of life measures [COPD Assessment Test, CAT (Jones et al., 2009)].

At the end of the nine-week program all participants (including those that stopped the intervention) were invited to complete questions about their satisfaction with the program, its usefulness and usability, and perceived impacts *via* a semi-structured telephone interview conducted by a research assistant. Engagement with the intervention was assessed using self-reports and system-recorded measures including text message responses and app data. In addition, participants were invited to repeat the exercise capacity and quality of life measures from baseline in person with the referring clinician for the purpose of assessing the feasibility of using these measures in the mPR context.

Statistical Analysis

Descriptive statistics were generated for baseline demographic and clinical characteristics, and measures of engagement with the system. Qualitative comments were analyzed using a simple, content analysis approach to identify common themes and meanings from the data.

RESULTS

A total of 30 people registered for the mPR pre-testing study with 26 patients recruited and four of their whānau (family members) invited and consenting to participate. **Table 3** presents characteristics of the patient participants only.

TABLE 4 | Mean ratings of usefulness from 1 (not at all useful) to 5 (extremely useful).

	N	Mean rating
Overall	20	4.00 (SD = 0.73; range 3–5)
Intervention type		
SMS only	11	4.09 (SD = 0.70; range 3–5)
SMS + app	9	3.89 (SD = 1.43; range 3–5)
PR attendance		
PR attender (past or current)	16	4.06 (SD = 0.68; range 3–5)
PR non-attender	4	3.75 (SD = 0.96; range 3–5)

Three of the 26 (10%) participants requested to stop the program early, one during the second week of messages due to the program being too simple for what he wanted, and two in the eighth week of messages, one of which went overseas and one whose health deteriorated significantly.

Of the 26 patient participants enrolled, six (23%) were lost to follow-up: one was too unwell, one had a family bereavement, one was overseas during the follow up period, two were unable to be contacted and one declined due to commitments. The 20 who provided follow-up interviews were representative of the full group (that is, there were no major differences in demographics or condition).

Seventeen (85%) of the 26 participants completed the 1-min sit-to-stand at follow-up, 19 (95%) completed the 6-min walk test and 16 (80%) the CAT questionnaire, indicating that it was feasible for these outcome measures to be used as part of the mPR program. Due to this being a small pilot study, not powered

for testing significance in these outcomes, change in the outcomes was not assessed.

All participants (n = 20) reported that they would recommend the program to other people with chronic respiratory conditions. A total of 17 participants (85%) reported that the program had helped them to learn about their condition. Almost all reported the program made them feel more supported with their condition (19; 95%). All bar the participant who withdrew early due to the program being too simplistic, reported the program to be useful (19/20; 95%). Mean ratings of usefulness are shown in **Table 4**.

Participants were asked what they liked most about the program. The most common themes included that it was motivational and empowering (n = 8) and provided reminders and prompts (n = 8). Other themes included: that it was supportive (n = 3); it increased awareness and knowledge (n = 4); it increased confidence (n = 1); the exercise component and becoming more active (n = 2); and that you could do the program at your own pace (n = 1).

> "Liked it because it motivated me, mostly when I got the texts every day, it was like they were there with me, I found it really good" (Female, 65–74 years, ID#20)
>
> "Keeps it [exercising] in the front of your mind and you can't ignore" (Female, 65–74 years, ID#3)
>
> "Someone checking in on you." (Female, 65–74 years, ID#12)

When asked what they liked least about the program, themes included: nothing (n = 5); the exercises were too hard, progressing too quickly or exercise frequency unrealistic (n = 5); that the messages were not personalized enough (e.g., not specific to condition, irrelevant/inappropriate messages, n = 4); lack of feedback during the program (n = 1).

> "None. Should be compulsory with attending PR" (Male, 65–74 years, ID#10)

Exercise Prescription

There were three participants (12%) allocated to the level 1 exercise prescription, 20 (77%) level 2, and three (12%) level 3. Of the 26 patients receiving the program, there were four (15%) who did not respond to any of the question messages rating their health and therefore received no exercise prescriptions during the program, and eight (31%) who responded to all eight health ratings. There were two participants who rated their health at a level below the cut-off to get an exercise prescription for the week. On average participants received five exercise prescriptions (range 0–8).

At the end of each week that participants received an exercise prescription, they were asked to provide the number of times (0–5) they completed the prescription *via* reply message. Seven out of the 22 participants (32%) responded to all these questions, with participants responding on average to 64% of these question messages.

Participants stated that they liked the exercise program (n = 18, 2 did not answer this question) although 16 (80%) reported that there had been reasons that impacted their ability to perform the exercises. **Table 5** presents the frequencies of reported impacts.

TABLE 5 | Reasons impacting participants ability to do the exercises (n = 16).

Impact	Frequency
Health	13 (81%)
Personal circumstances	3 (19%)
Weather	3 (19%)
Motivation	2 (13%)
Exercise difficulty	2 (13%)
Time	1 (6%)
Energy level	1 (6%)

Engagement

At registration eight people (31%) opted for text messages only, and 18 (69%) chose to also download the mPR app. Participants reported that they read "all or nearly all of the messages" (19; 95%) or "most, more than half" of the messages (1; 5%). There were 12 (60%) participants who reported that they shared the messages with others. When asked about the dosage of messages, 12 (60%) felt that they received the right number of messages whereas seven (35%) reported that there were too many (one did not answer this question).

Of the 16 participants who selected to receive the app at registration, only 11 accessed the app (that is, completed app registration and logged in) according to system captured data. The mean number of days between users first logging into the app and their final visit was 39.2 (range 0–71). There was one user who only accessed the app on the day they first logged in. The mean number of unique days that a user accessed the app during this period was 13.3 (range 1–27).

The most viewed page in the app (excluding administration pages) was the Action Plan but only eight (73%) filled in their action plan. The individual exercise video pages were viewed a total of 88 times (11 people accessing these three times each week would mean an expected 297 times). All 11 participants who accessed the app completed the symptom score (CAT) questionnaire at least once with the average number of times completed per person being 3.1 (range 1–11; expected number of times would be at least 4). Four participants (36%) completed the 1-min sit-to-stand test through the app with the mean number of completions per participant for those that did complete it being 4.3 (range 2–6; expected number of times would be at least 4). Nearly all the participants (10, 91%) viewed the lung model visualization video page with a total of 25 views. Although nearly all of the participants viewed the mood and relaxation page (8; 82%) only three listened to one of the relaxation audio files.

In the follow up interview, participants who had not used the app stated their reasons, these included: forgetting (n = 2); difficulties downloading it or finding it on the app store (n = 3); that they did not feel it added anything above the messages so logged out (n = 1); and difficulties logging in (n = 1). Four participants felt that they needed more information on how to use

the app. When asked for suggestions for how the app could be improved the following were suggested: warm up videos added; reminders to complete tasks; more consistency of information between app and text; adjustable plans and ability to go back into plans and edit; clearer instructions at the beginning; and more results reported back regularly to keep engaged.

Reported Impact

Seventeen (85%) participants reported that the program had impacted on how they managed their condition or helped them to change their behaviors.

> "how to live with it generally. I had a negative attitude before it, but after it (I now know) you can pretty much still do everything as long as you pace yourself and breath carefully, it helped me a lot" (Female, 65–74 years, ID#20)

Self-reported positive impacts included: improved breathing, increased physical activity or exercise, and reduced inhaler use. They also reported changes in sedentary behavior and physical activity with 11 (58%) reporting spending less time sitting down since taking part in the program, 16 (84%) reporting more time being up and about, 16 (84%) doing more walking and 17 (89%) exercising more.

Family members' feedback

All four patients who had family receiving the program reported that they found this beneficial and all reported that they felt it was beneficial to the family member.

> "Made him (husband) more aware of what I go through." (Female, 65–74 years, ID#9)

When interviewed, all four family members reported positive experiences with the program and that they appreciated being included. All said that it was useful to take part and would recommend it to other families.

> "(it taught me) how to encourage her and support her willpower... to support her to move . . . I've noticed a change in her exercise since and her mentally coping." (ID#23)

Safety

No adverse events were reported. Although alternatives were provided for anyone unable to comfortably complete the prescribed exercises, one participant did contact researchers about knee pain and was advised to stop lower limb exercises until the pain settled.

Suggestions for Improvement

Participants were asked to identify areas where mPR could be improved. Suggestions included: more condition specific information including more tailoring of the messages to conditions; and more details about the program and what it entails needs to be provided at registration including more information about what is included in the app and its functionality. It was suggested that the exercise component could be improved with more variability in exercises and more exercise options.

DISCUSSION

This study found that it is feasible to deliver a pulmonary rehabilitation program solely by smart phone. There are currently no existing mPR programs being delivered in this way in New Zealand. There has been considerable scepticism from clinicians that a program developed for in-person group sessions could be adapted to be delivered over mobile phones. However, the lessons learned from the global COVID-19 pandemic have included the importance of remote delivery of support and services for vulnerable populations who do not want to or are not able to attend in person (Houchen-Wolloff and Steiner, 2020). This work will help to inform all future remote patient support programs.

Issues with digital literacy and confidence in using digital tools appear to remain with some in this patient cohort. Offering a text message only program, as well as a more integrated smartphone-based program, is therefore still worthwhile. Some people may require more instructions on using an app, regardless of its simplicity. Offering a version to patients' family appears to be appreciated by both patients and their family members.

The exercise program was liked by participants, and they did report improvements in behaviors, however it seems that this may need further development. Future iterations of the mPR program will look to develop and strengthen the exercise component. This may include; increased feedback to the participant, resistance exercise prescription based on time rather than repetition, step counters and feedback loops, alternative exercises, and the possibility of a circuit option. We also intend to make the program more responsive and more tailored to the individual. More time is required to orientate participants to the program, especially the app, if they have low digital confidence.

Feedback from our participants aligns with our previous research in mHealth healthy behavior change (Bramley et al., 2005; Rodgers et al., 2005; Free et al., 2011), self-management support (Maddison et al., 2015; Dobson et al., 2018; Dobson et al., 2019b) and cardiac rehabilitation programs (Chow et al., 2015; Pfaeffli Dale et al., 2015). That is, that mHealth programs can be effective at improving health outcomes and that many people appreciate the motivation and support such programs are able to provide. Messages can provide timely reminders of desired behaviors and can align with existing in-person programs or act as an alternative where existing services are not accessible. To date, there has been less support for the effectiveness of smartphone apps than for mobile phone messaging in these areas (Whittaker et al., 2019). However, several current studies are investigating integrating the two forms of mHealth technology (Graham et al., 2016; Chen et al., 2020).

There is little other published research on mHealth pulmonary rehabilitation programs internationally. Bourne et al. (2017)

completed a randomized control trial comparing the effectiveness of an online pulmonary rehabilitation program with a center-based program for people living with COPD. The exercise prescription included in the online program was a generic program and not individually prescribed or monitored. The authors found comparable improvements in exercise capacity and quality of life measures achieved from both programs, although it had a small sample size and recruitment was limited to participants who had internet access in their own home.

Chaplin et al. (2017) examined whether an interactive online web-based PR program was a feasible alternative to center-based PR in a randomized controlled feasibility study. Their program was individually tailored and intensely monitored. The study found comparable results for both groups. The authors noted the challenges associated with recruitment to the web-based program and the declining adherence to both programs. Parks et al. (Park et al., 2020) compared a smart phone app-based self management program with a control group for people living with COPD. Both groups started with a four week center based group exercise and education program. The app-based group had significant improvements in physical activity time compared to the control. The duration of program was six months, much longer than the previous trials, and the study showed adherence remained consistent throughout the six-month trial (Park et al., 2020).

The visualization included in the mPR app is novel and requires further investigation. One example from a clinically focused study identified that using visual images of the effect of skipping doses of anti-retroviral medication for the management of HIV, improved adherence (Jones et al., 2018). Another similar example has demonstrated the impact of model-based animation to improve recovery from acute coronary syndrome (Jones et al., 2016). Active visualization includes the application of live demonstrations or animations to communicate information about the effects of medication or other aspects of how the body works in a more impactful way (Perera et al., 2014). When information that is intangible, such as how our lungs work and what can go wrong in this complicated system, is presented visually with the assistance of computational modeling and/or animation, it may be easier for many people to process than factual material provided in text format.

CONCLUSIONS

A prototype mPR program was appreciated by a small number of patients and family members. More work is required to develop the next version of the mPR program based on the feedback from participants. We intend to develop a more integrated program, with the text messaging and app working together. It will also be a more adaptive and responsive program, tailored to the individual, their disease and their current condition. This will undergo more rigorous testing of effectiveness.

DATA AVAILABILITY STATEMENT

The raw data supporting the conclusions of this article will be made available by the authors, without undue reservation.

ETHICS STATEMENT

The studies involving human participants were reviewed and approved by the Health and Disability Ethics Committee (19/NTA/74), New Zealand. The patients/participants provided their written informed consent to participate in this study.

AUTHOR CONTRIBUTIONS

The intervention was designed by RW, RD, SC, JW, KB, TT, JR, DT, GH, JG, MT, SK, and FH. The study was designed and conducted by TT, SC, RD, and RW. Data collection by TT, RD, SC, and TW. Data analysis and interpretation by RW, RD, SC, JR, and GH. Manuscript prepared by RW, RD, SC and reviewed and edited by all.

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Conflict of Interest: The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

ARTICLE

Patient characteristics and predictors of completion of a pulmonary rehabilitation programme in Auckland, New Zealand

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ABSTRACT

AIM: Chronic respiratory diseases, such as chronic obstructive pulmonary disease, are a worldwide public health problem. Pulmonary rehabilitation is a gold-standard intervention for these diseases, yet attendance and completion rates are poor. Counties Manukau Health, in Auckland, New Zealand, has a high prevalence of chronic respiratory disease and a culturally diverse population, comprising large numbers of Māori and Pacific Island people, who are known to be disproportionately affected by chronic respiratory disease. The aim of this study was to investigate patient characteristics affecting engagement with the Counties Manukau Health pulmonary rehabilitation programme and identify factors predicting completion of the programme.

METHODS: Investigators performed a retrospective analysis using routinely collected data of 2,756 patients invited to attend the pulmonary rehabilitation programme at Counties Manukau Health. Data were analysed to compare demographic and clinical outcomes of patients who completed, did not complete or did not attend the programme, and identified factors predicting completion.

RESULTS: Significant differences were found between groups in demographic and clinical characteristics. Increasing age, higher six-minute walk test distance at programme commencement and European ethnicity were significant predictors of completion of the PR programme.

CONCLUSIONS: Compared to European people, Māori were 52% less likely and Pacific Island people were 40% less likely to complete the programme. These findings are significant for the Counties Manukau Health population. Further work needs to focus on determining how to make programmes more engaging to different cultures and how we can aim to reduce health inequities in these populations.

Chronic obstructive pulmonary disease (COPD) was the third leading cause of death in 2016 [1] and resulted in more than three million deaths worldwide in 2015.[2] In New Zealand, the population prevalence of COPD is estimated to be 14.2%.[3] The disease is associated with a significant burden on the healthcare system.[4] Internationally, COPD disproportionately affects people living in developing countries[2] and indigenous people in developed countries.[5] In New Zealand, COPD is more prevalent among Māori, Pacific Island people and those living in more deprived areas.[3]

Pulmonary rehabilitation (PR) is an evidence-based, multi-disciplinary programme, comprising exercise and education for people with chronic respiratory disease.[6] It is an essential component of therapy for COPD.[7] Pulmonary rehabilitation has been shown to improve exercise capacity, dyspnoea and health-related quality of life,[6] reduce hospital readmissions and mortality.[8] Despite this, rates of attendance at, and completion of PR programmes are poor; internationally, up to 50% of people referred to PR programmes fail to attend and rates of non-completion have

been reported between 9.7% and 31.8%.[9] One New Zealand-wide study estimated that only 0.9% of people over 40 with COPD were offered PR per year, and of those, only 56% completed the programme.[10] Another PR programme in New Zealand found their programme enrolled less than 2% of the region's population with COPD.[11]

Counties Manukau Health (CMH), in the Auckland region, is one of 20 district health boards in New Zealand. Better Breathing is a PR programme, which runs at four different sites in CMH—one acute care facility and three community-based sites. Patients attend a one-off initial assessment, then attend the exercise and education-based PR programme twice-weekly for eight weeks. The population at CMH is culturally diverse, with 16% Māori, 21% Pacific Island, 24% Asian and 38% New Zealand European/other.[12] The population has a distinct socioeconomic makeup, with over 36% of people living in the most deprived deciles, based on the New Zealand Deprivation Index [NZDep2013].[13] Within CMH, the prevalence of chronic respiratory disease is high[14] especially among Māori, Pacific Island people and those living in deprived areas.[3] With guidelines widely recommending PR as a gold-standard intervention,[7,15,16] it is important to consider factors impacting upon engagement with PR in the context of contemporary practice in culturally and socioeconomically diverse populations, such as CMH.

The primary aim of this study was to identify and compare the key factors in predicting patients who complete and those who did not complete the PR programme. The secondary aim was to compare the characteristics of those who attended and those who never attended the PR programme.

Methods

Investigators performed a retrospective analysis of routinely collected health information data of 2,756 patients invited to attend the Better Breathing PR Programme, run across the four sites at CMH. We evaluated data from all patients who were invited to attend between 1 January 2010 and 31 December 2015. Patients were divided into four groups:

1. 'Never-attenders'—who did not attend either the initial assessment or programme;
2. 'Initial assessment-only attenders'—who attended an initial assessment but did not commence the programme;
3. 'Non-completers'—who completed less than 75% of the programme;
4. 'Completers'—who completed at least 75% of the programme.

Data for extraction and analysis were determined prior to commencement of the study and were extracted from routinely collected data from the CMH electronic patient information system by a Senior Analyst at Health Intelligence and Informatics at CMH and two researchers (NJ and SC). Following data extraction, retrieval of missing data was undertaken by two members of the research team (NJ and SC), who used the hospital's patient information systems to extract any available missing data. Data collected included demographic characteristics (age, gender, self-reported ethnicity, marital status, smoking status, occupation, spoken language, level of deprivation) and clinical characteristics (referral source, percent predicted forced expiratory volume in one second (FEV1%), Hospital Anxiety and Depression Scale (HADS) score, Medical Research Council Dyspnoea Score (MRC), Body Mass Index (BMI) and six-minute walk test (6MWT) distance). The clinical data were taken at the initial assessment and therefore only available for those who attended at least an initial assessment.

Data were analysed in four ways:

1. To compare the characteristics of those who did not attend the programme (never-attenders and initial assessment-only attenders) to those who did attend the programme (completers and non-completers);
2. To compare the characteristics of never-attenders to initial assessment-only attenders;
3. To compare the characteristics of completers to non-completers;
4. To identify factors predicting completion of the programme.

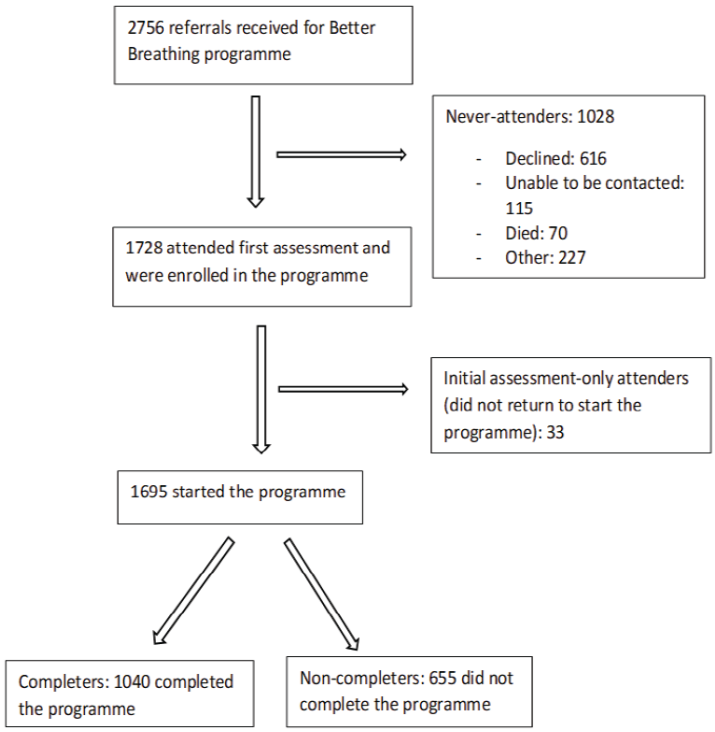
Chi-square, two-sample t-tests and Kruskal-Wallis tests were undertaken to assess associations between demographic and clinical characteristics between the groups. Univariate and multiple logistic regression were carried out to test for significant factors that were associated with completion of the programme. To identify significant predictors in the model after accounting for the demographics variables, three model selection techniques were used, such as forward, backward and stepwise procedures, in SAS version 9.4. For those variables with more than 20% of missing data, the variables were not included for model selection. The model with the smallest Akaike Information Criterion was selected and variables that were deemed significant were kept in the model. A p-value <0.05 was considered statistically significant. Sensitivity analysis was also carried out by using a single imputation method and compared to the complete cases using likewise deletion. This involved replacing the missing values for the continuous variables by the median.

The New Zealand Health and Disability Ethics Committee stated ethical review was not required. Approval for the study was granted by CMH Research Committee on 21 April 2016 (Research Application Numbers 5 and 6).

Results

Of the 2,756 patients that were referred to the Better Breathing programme, 1,028 (37%) never attended and 33 (1%) attended the initial assessment only. The remaining 1,695 (62%) patients commenced the programme; 1,040 (61%) of those were completers and 655 (39%) were non-completers (see Figure 1). This shows that, of all referrals to the Better Breathing programme, 1,716 (62%) never attended or did not complete the programme.

Figure 1: Flow chart showing the numbers of referrals to, attendance at and completion of the Better Breathing Pulmonary Rehabilitation programme between 2010 and 2015.



Characteristics of those who attended the programme (completers and non-completers combined) and those who did not attend the programme (never-attenders and initial assessment-only attenders combined) are summarised in Table 1. There were significant differences between these groups in marital status (p=0.001), deprivation index (p=0.021), smoker (p=<0.001), distance from home to PR site (p=<0.001) and site location

Table 1: Demographic characteristics by group—attenders (completers and non-completers combined) and non-attenders (never attenders and initial assessment-only attenders combined).

		Attenders n=1,695	Non-attenders n=1,061	P value	Missing proportion
		n (%)	n (%)		
Gender	Female	898 (62.1)	549 (37.9)	0.53	0%
	Male	797 (60.9)	512 (39.1)		
Ethnicity	Asian	102 (68.5)	47 (31.5)	0.44*	1.1%
	European	824 (61.0)	526 (39.0)		
	Māori	395 (60.1)	262 (39.9)		
	Pacific Island	334 (62.0)	205 (38.0)		
	Other	18 (60.0)	12 (40.0)		
Marital status	Married/partnered	956 (64.2)	533 (35.8)	0.001*	4.6%
	Separated/divorced	161 (61.5)	101 (38.6)		
	Single	221 (59.2)	152 (40.8)		
	Widowed	275 (54.4)	231 (45.7)		
Smoker	Ex-smoker	968 (62.4)	584 (37.6)	<0.001	5.0%
	Smoker	247 (52.6)	223 (47.5)		
	Non-smoker	394 (66.2)	201 (33.8)		
Language spoken	English	1,465 (61.8)	906 (38.2)	0.75*	5.7%
	Other	144 (62.9)	85 (37.1)		
Site location	Acute Care Facility	962 (64.1)	540 (36.0)	<0.001*	0%
	Community	733 (58.4)	521 (41.6)		
Employment status	Not working	427 (61.8)	264 (38.2)	0.96*	6.2%
	Retired	733 (61.3)	463 (38.7)		
	Working	431 (61.8)	266 (38.2)		
Age	Mean (SD)	66.8 (11.0)	67.0 (12.1)	0.64*	0%
	Age range	19–92	21–93		
Distance from home – PR site (kms)	Median (IQR)	4.0 (1.9–7.1)	4.9 (2.4–9.9)	<0.001‡	0%
Deprivation index	Median (IQR)	9 (6–10)	9 (7–10)	0.021	0%

*The parametric p-value is calculated by two sample t-test for numerical covariates and chi-square test for categorical covariates.
‡The non-parametric p-value is calculated by the Kruskal-Wallis test and Mann-Whitney-U test for numerical covariates and Fisher's exact test for categorical covariates.
KEY: kms, kilometres; IQR, inter quartile range; n, number; PR, pulmonary rehabilitation; SD, standard deviation.

(p=<0.001). There were no statistically significant differences between attenders and non-attenders in age (p=0.64), gender (p=0.53), ethnicity (p=0.44), language spoken (p=0.75) or occupation (p=0.96).

Comparison between demographic characteristics of those who never attended (n=1,028) and initial assessment-only attenders (n=33) showed a statistically significant difference in ethnicity (p=0.001), with never-attenders having a larger proportion of European and Māori patients. The initial assessment-only group also had a significantly higher proportion of patients who did not speak English as a first language (22% vs 8%, p=0.02) and a larger proportion of married/partnered patients (80% vs 52%, p=0.03) compared to the never-attenders. The small sample size in the initial assessment-only group limits the significance of these findings.

When comparing demographic and clinical characteristics between the completer and non-completer groups, there were statistically significant differences between the two groups in all characteristics except for gender, distance from home to PR site and site location (Table 2). Furthermore, for each year increase in age, patients were 4% more likely to complete the programme (OR 1.04 95%CI 1.02–1.05, p=<0.001). For every 10m extra that a patient walked in their 6MWT at programme commencement, they were 3% more likely to complete the programme (OR 1.03, 95%CI 1.02–1.04, p=<0.001). Compared with Europeans, Māori were 53% (OR 0.47, 95% CI 0.35–0.65, p=<0.001) and Pacific Island people were 46% (OR 0.64, 95% CI 0.44–0.92, p=<0.001) less likely to complete the programme. Results of the univariate and logistic regression model predicting completion of the better breathing programme are displayed in Table 3. Results of multivariate logistic regression models for both complete and imputed cases can be seen in Table 4.

Discussion

Data were collected on 2,756 patients referred to the Better Breathing programme in the period under investigation; this data set is larger than those previously described in other New Zealand studies.[10,11] Our study has shown that 62% of all patients referred to the Better Breathing programme either do not take part in the programme at all, or do not complete the programme. An older study exploring attendance at a PR programme in an Auckland clinic reported that 41% of patients either did not attend, or failed to complete the programme.[17] A more recent study in a different New Zealand region showed that 46% of those referred to PR completed the programme.[11] Our results compare poorly with this, whereby only 38% of all patients referred completed the Better Breathing programme. In a review of 11 international studies, non-completion rates were reported to be up to 32%,[9] so it is of concern that our non-completion rates in those who commenced the Better Breathing programme (39%) appear to be higher than those reported elsewhere.[9]

When comparing the characteristics of those who attended with those who did not attend, significant factors included distance travelled, site location, deprivation index and marital status. Other studies investigating reasons for non-completion of PR have cited transport and the distance from home to PR site as problematic.[18,19] While we found that the distance from home to PR and the location of PR was significantly different between attenders and non-attenders, once patients commenced the programme, distance and location were no longer a significant factor influencing attendance. This suggests that factors relating to the running of the PR programme itself may be more important than geographical location when considering completion rates.

Some studies have demonstrated that people with lower socioeconomic status may find it harder to access transport and parking costs associated with attending primary healthcare services[20,21] and these factors have also been linked to poor attendance at PR programmes.[21] A widely used measure of social deprivation in New Zealand[13] was used to investigate whether social deprivation affected completion rates at the Better Breathing programme. Even though there was an indication of deprivation index being a significant risk factor (Table 3), after accounting for other characteristics, the deprivation index was not strongly correlated. However, it should be noted that the univariate results indicate that for every one unit increase in deprivation index, the likelihood of completing the programme reduces by 8%.

Table 2: Demographic and clinical characteristics by group–completers vs non-completers.

		Completers n=1,040	Non-completers n=655	P value	Missing proportion
		n (%)	n (%)		
Gender	Female	536 (59.7)	362 (40.3)	0.13*	0%
	Male	504 (63.2)	293 (36.8)		
Ethnicity	Asian	61 (59.8)	41 (40.2)	<.001*	1.3%
	European	595 (72.2)	229 (27.8)		
	Māori	184 (46.6)	211 (53.4)		
	Pacific Island	173 (51.8)	161 (48.2)		
	Other	14 (77.8)	4 (22.2)		
Marital status	Married/partnered	593 (62.0)	363 (38.0)	0.002*	4.8%
	Separated/divorced	84 (52.2)	77 (47.8)		
	Single	116 (52.5)	105 (47.5)		
	Widowed	181 (65.8)	94 (34.2)		
Smoker	Ex-smoker	605 (62.5)	363 (37.5)	0.018	5.1%
	Smoker	130 (52.6)	117 (47.4)		
	Non-smoker	240 (60.9)	154 (39.1)		
Language	English	908 (62.0)	557 (38.0)	<.001*	5.1%
	Other	69 (47.9)	75 (52.1)		
Site location	Acute Care Facility	449 (61.3)	284 (38.7)	0.94	0%
	Community site	591 (61.4)	371 (38.6)		
Distance from home to PR site (kms)	Median (IQR)	3.8 (1.9–7.2)	4.1 (1.5–7.0)	0.28‡	0%
Employment status	Not working	227 (53.2)	200 (46.8)	<.001*	3.4%
	Retired	480 (65.5)	253 (34.5)		
	Working	251 (58.2)	180 (41.8)		
Age	Mean (SD)	68.3 (10.1)	64.3 (12.0)	<.001*	0%
Deprivation index	Median (IQR)	9 (6–10)	9 (7–10)	<.001‡	0%
BMI	Median (IQR)	28 (24–34)	31 (25–39)	<.001‡	3.4%
MRC	Mean (SD)	3 (1.2)	3.3 (1.2)	<.001‡	6.0%
Anxiety	N	878	421	<.001‡	23.4%
	Median (IQR)	6 (3–9)	7 (4–10)		
Depression	N	876	420	0.005‡	23.5%
	Median (IQR)	5 (3–7)	5 (3–8)		
FEV1%	N	994	553	<.001*	8.7%
	Mean (SD)	51.5 (18.9)	47.8 (17.7)		
6 MWT (m)	N	1,030	563	<.001*	6.00%
	Mean (SD)	336.5 (107.2)	304.8 (116.6)		

*The parametric p-value is calculated by two sample t-test for numerical covariates and chi-square test for categorical covariates.
‡The non-parametric p-value is calculated by the Kruskal-Wallis test and Mann-Whitney-U test for numerical covariates and Fisher's exact test for categorical covariates.
KEY: BMI, body mass index; FEV1, forced expiratory volume in one second; IQR, inter quartile range; kms, kilometres; MRC, Medical Research Council Dyspnoea Scale; n, number of patients; PR, pulmonary rehabilitation; SD, standard deviation, 6MWT, 6 minute walk test distance.

Table 3: Results of univariate logistic regression model showing variables predicting completion at the Better Breathing Pulmonary Rehabilitation Programme.

Variable	Levels	Odds ratio (95% CI)	P value
Gender	Female	0.84 (0.67–1.06)	0.15
	Male	Reference	
Ethnicity	Asian	0.60 (0.36–0.99)	<0.001
	Māori	0.34 (0.26–0.46)	
	Other	1.29 (0.27–6.14)	
	Pacific Island	0.44 (0.33–0.60)	
	European	Reference	
Marital status	Married/partnered	1.50 (1.06–2.11)	<0.001
	Separated/divorced	0.90 (0.56–1.43)	
	Widowed	1.95 (1.27–2.98)	
	Single	Reference	
Smoking	Ex-smoker	0.94 (0.71–1.24)	0.218
	Smoker	0.73 (0.50–1.06)	
	Non-smoker	Reference	
Language	English	1.50 (1.01–2.25)	0.046
	Other	Reference	
Site location	Community	1.02 (0.81–1.29)	0.872
	Acute care facility	Reference	
Employment status	Retired	1.56 (1.18–2.06)	0.002
	Working	1.06 (0.78–1.45)	
	Not working	Reference	
Age	Per year increase	1.04 (1.03–1.05)	<.001
Distance from home to PR site	Per km increase	0.99 (0.97–1.01)	0.414
Deprivation	Per unit increase	0.92 (0.88–0.96)	<.001
BMI	Per unit increase	0.97 (0.96–0.99)	<.001
MRC	Per unit increase	0.86 (0.78–0.95)	0.002
FEV1 (%pred)	Per 1% increase	1.01 (1.01–1.02)	<.001
6 MWT	Per 10m increase	1.03 (1.01–1.04)	<.001

Table 4: Results of multivariate logistic regression model showing variables predicting completion of the Better Breathing Pulmonary Rehabilitation Programme for the complete and imputed cases.

		Complete cases (n=1,296)		Single imputed cases (n=1,508)	
Variable		**Odds ratio (95% CI)**	**P value**	**Odds ratio (95% CI)**	**P value**
Gender	Female	0.97 (0.75, 1.26)	0.83	0.99 (0.78, 1.26)	0.93
	Male	Reference		Reference	
Ethnicity	Asian	0.84 (0.46, 1.51)	<0.001	0.76 (0.45, 1.28)	<0.001
	Māori	0.47 (0.35, 0.65)		0.44 (0.33, 0.59)	
	Other	1.23 (0.25, 6.16)		1.30 (0.33, 5.08)	
	Pacific Island	0.64 (0.44, 0.92)		0.60 (0.43, 0.84)	
	European	Reference		Reference	
Marital status	Married/partnered	1.09 (0.75, 1.59)	0.22	1.11 (0.79, 1.56)	0.29
	Separated/divorced	0.74 (0.45, 1.21)		0.79 (0.5, 1.24)	
	Widowed	1.21 (0.75, 1.97)		1.16 (0.76, 1.79)	
	Single	Reference		Reference	
Smoking	Ex-smoker	0.99 (0.72, 1.35)	0.87	1.12 (0.85, 1.48)	0.29
	Smoker	0.91 (0.6, 1.37)		0.88 (0.61, 1.28)	
	Non-smoker	Reference		Reference	
Language	English	1.52 (0.93, 2.49)	0.09	1.78 (1.15, 2.75)	0.009
	Other	Reference		Reference	
Site location	Community	0.95 (0.74, 1.22)	0.71	0.96 (0.77, 1.2)	0.72
	Acute care facility	Reference		Reference	
Employment status	Retired	1.03 (0.75, 1.42)	0.76	1.13 (0.85, 1.51)	0.33
	Working	1.13 (0.81, 1.59)		1.26 (0.93, 1.71)	
	Not working	Reference		Reference	
Age	Per year increase	1.04 (1.02, 1.05)	<.001	1.03(1.01, 1.04)	0.0001
6 MWT	Per 10m increase	1.03 (1.02–1.04)	<.001	1.03 (1.02–1.04)	<.001

KEY: m, metre; 6MWT, 6-minute walk test distance.

In comparing participants who completed with those who did not complete the PR programme, many factors were significantly different between the groups. However, when all variables were included in a fully adjusted model, only three factors were identified as independent predictors of completion of PR: age, distance walked on 6MWT and ethnicity. Consistent with other literature,[23-26] the results of our study found that patients had a greater likelihood of completing the programme as age increased. It is possible that this is related to work schedules. The Better Breathing programme, which runs during normal working hours, may be less accessible to the working population. Māori and Pacific Island people tend to develop COPD at an earlier age (the average age of onset of COPD in New Zealand is 70.3 years, but for Māori and Pacific Island people it is 62.6 and 62.5 years respectively),[3] so these populations may be more severely impacted by timing of PR programmes. An increase in flexibility of services including; offering classes outside of working hours, a home-based service and/or a telehealth based programme may allow younger participants, who may be working or looking after dependents, the opportunity to complete PR.

Patients who walked further in their 6MWT at commencement of our programme were also more likely to complete the programme; this is consistent with other literature.[26-28] 6MWT distance correlates with MRC dyspnoea score and pulmonary function testing,[29,30] and our study found that non-completers had significantly greater dyspnoea and disease severity. These factors may make exercise more challenging, potentially increasing the likelihood of non-completion. Potential strategies to overcome this challenge for participants may involve; increased time spent on orientation to PR including strategies to manage breathlessness, starting exercise at lower intensities and ensuring increased levels of supervision and/or support for people with lower exercise capacity. The location of PR, including access to the building and close parking facilities may also facilitate completion for this group.

An important finding of this study is that Māori and Pacific Island patients are significantly less likely to complete the programme compared with European patients, supporting the findings of others in New Zealand.[11] Ethnicity was not significantly different when comparing attenders to non-attenders (p=0.44), but became significant when comparing completers to non-completers (p=0.001). When all variables were accounted for, ethnicity was found to be an independent predictor of completion of PR. This finding is important because the CMH population comprises large numbers of Māori and Pacific Island people in the community, who are disproportionately affected by chronic respiratory diseases in New Zealand.[3] The results of this study, therefore, show that the people who may potentially benefit from PR the most are those who are least likely to complete the programme. Differences in attendance between people of various ethnicities may be related to differences in the culture of attendees or of the programme itself. Cultural factors appear to play an influential role in how well PR programmes are able to engage with Māori and Pacific Island people. Levack et al[31] found that when the cultural needs of Māori attending PR were not addressed adequately, patients were less willing to attend those PR programmes.[31] To our knowledge, two New Zealand-based studies[11,31] are the only other studies to have specifically explored the influence of ethnic diversity on participants' engagement with PR. We encourage others undertaking PR programmes with ethnically diverse populations to further explore issues with engagement and completion of PR programmes and identify factors that may improve these. Levack et al[31] have suggested that indigenous-led PR programmes may overcome barriers for indigenous and minority participants and the feasibility of this requires further investigation. Other factors such as the venue in which PR programmes are held—such as a Marae—could be important for many Māori participants. Future research should ensure collaboration with cultural experts, and participants who have attended PR, to work towards co-design of culturally responsive PR programmes.

In our cohort, there was a significant difference in completion rates between English and non-English speaking participants. Indeed, in comparing the characteristics of never-attenders with initial assessment-only attenders, a large proportion of participants who reported English as a second language attended only the initial assessment and did not go to further attend or complete the programme. Additionally, while in our multivariate regression modelling, language was not found to be significant in predicting completion, following data imputation speaking English as a first language became statistically significant, suggesting this may be a relevant factor in completion of PR. Attention should be given to whether the delivery of programmes in different languages might improve completion rates in non-English speakers, and this together with how language aligns with delivering culturally relevant programmes should be considered.

Limitations

It should be noted that during the period of the study, we implemented several changes arising from quality improvement initiatives to the PR programme that may have influenced interpretation. During this period, the service expanded and the hospital outpatient programme moved from the hospital site to four community venues, which we considered may better fulfil the needs of our population. It is feasible that

these changes may have impacted on the results of this study, particularly regarding distance from home to PR. However, because distance from home to PR was calculated using each individual's home address and their closest PR site, we believe that this measure will account for these location changes.

The nature of the data collection and retrieval meant that not all data was available for all groups. For example, data from those who attended the PR programme was more extensive than those who did not attend, due to extensive assessment and monitoring undertaken during the PR programme. Even following completion of the programme, some data was missing on retrieval, eg, HADS. Reasons for some of this missing data could be spoken language/literacy issues, assessment burden or clinician or administration error. Where data were known to be missing, imputation of the continuous variables into the statistical modelling for analysis was carried out and compared with complete cases. Furthermore, we acknowledge a prospective matched cohort study could have improved the ability to account for the effect of confounding variables in our analyses, increasing the confidence regarding the impact of each of the different variables individually.

Conclusion

Of everyone referred to CMH Better Breathing PR programme during the period of our study, only 38% completed the programme. Considering that less than 2% of people with COPD in New Zealand are referred to a PR programme,[10] it is problematic that so few patients are completing this gold-standard intervention. Age, 6MWT distance at commencement of PR and ethnicity were important predictors of completion of PR in this population. Strategies to make PR more engaging must be considered for varying age groups, those with poorer exercise tolerance, and, importantly, in different ethnic groups.

Competing interests:
Nil.

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Appendix O. Summary of feedback from end-user pretesting

Section	Feedback	Suggestions	Implemented
Written exercise instructions	Wording not clear/ambiguous	Avoid "shoulder width apart"	✔
	Font too small	Increase font size	✔
	Not familiar with term 'reps'	Use 10 times each arm	✔
	Use of colours – red unclear	Utilise green colour	✔
Entering exercise repetitions	Clear, straight forward, no concerns		
	Entered the number, did not use arrow keys		
	Did not enter confirm and lost information		
	Needed prompting to enter confirm		
	One participant did not understand the arrows and was unsure what to do next	Suggested maybe 'next' and 'back' written under the arrows	✔
Exercise video	Liked the speed (not too fast) clear and easy to follow		
	Needed prompting to know it was there … was not sure what that was for		
	Great to have		
Alternative exercise	Font / title too small		✔
	Did not see this without prompting (x3)		
	Did not understand picture		
	Thought it was a good idea to have but was not clear		
Tips and Tools	Liked pictures	Would like to see patient stories	To include in future prototype
	Titles were engaging – wanted to find out more		
	Topics appropriate		
My Progress page	Liked the concept – felt feedback was important	Would like to do sit to stand test weekly to monitor progress	Not implemented as concerned this may be too much for some participants
	Interested in step count and believe this data would be motivational		

Section	Feedback	Suggestions	Implemented
I feel unwell	Content was not what they expected	Prefer information on what to do when unwell	Consideration to including participant action plan
Menu	Widget was overlooked by all participants When prompted found the content useful	Incorporate into training for participants	✔
Other	Timer	Would have liked a timer that counted down and doing the exercises with the timer, particularly when walking.	Further consideration

Health and Disability Ethics Committees

Health and Disability Ethics Committees
Ministry of Health
133 Molesworth Street
PO Box 5013
Wellington
6011

0800 4 ETHICS
hdecs@health.govt.nz

23 March 2021

Mrs Sarah Candy
Pulmonary rehabilitation
Colving Complex
Middlemore Hospital
Otahuhu 1640

Dear Mrs Candy

Re:	**Ethics ref:**	**21/NTB/54**
	Study title:	Pulmonary rehabilitation: A preference clinical trial of centre based and mHealth delivered rehabilitation in chronic respiratory disease.

I am pleased to advise that this application has been *approved* by the Northern B Health and Disability Ethics Committee. This decision was made through the HDEC-Expedited Review pathway.

Conditions of HDEC approval

HDEC approval for this study is subject to the following conditions being met prior to the commencement of the study in New Zealand. It is your responsibility, and that of the study's sponsor, to ensure that these conditions are met. No further review by the Northern B Health and Disability Ethics Committee is required.

Standard conditions:

1. Before the study commences at *any* locality in New Zealand, all relevant regulatory approvals must be obtained.

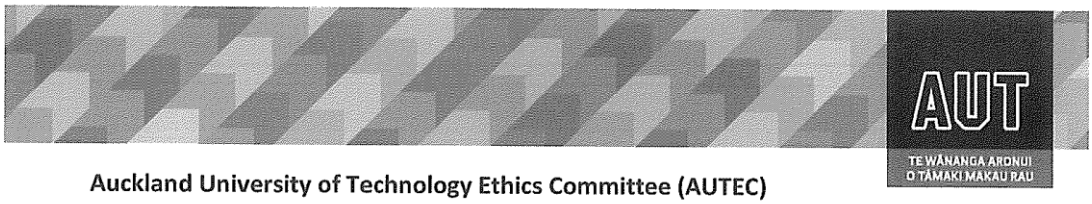
2. Before the study commences at *any* locality in New Zealand, it must be registered in a clinical trials registry. This should be a WHO-approved registry (such as the Australia New Zealand Clinical Trials Registry, www.anzctr.org.au) or https://clinicaltrials.gov/.

3. Before the study commences at *each given* locality in New Zealand, it must be authorised by that locality in Online Forms. Locality authorisation confirms that the locality is suitable for the safe and effective conduct of the study, and that local research governance issues have been addressed.

After HDEC review

Please refer to the *Standard Operating Procedures for Health and Disability Ethics Committees* (available on www.ethics.health.govt.nz) for HDEC requirements relating to amendments and other post-approval processes.

Appendix Q. Ethics Approval - AUTEC



Auckland University of Technology Ethics Committee (AUTEC)

Auckland University of Technology
D-88, Private Bag 92006, Auckland 1142, NZ
T: +64 9 921 9999 ext. 8316
E: ethics@aut.ac.nz
www.aut.ac.nz/researchethics

11 May 2021

Denise Taylor
Faculty of Health and Environmental Sciences

Dear Denise

Re Ethics Application: **21/113 Pulmonary rehabilitation – a preference clinical trial of centre based and mHealth delivered rehabilitation.**

Thank you for providing evidence as requested, which satisfies the points raised by the Auckland University of Technology Ethics Committee (AUTEC).

Your ethics application has been approved for three years until 11 May 2024.

Non-Standard Conditions of Approval

- Include advice about the future use of data in the 'what will happen to my information' section of the Information sheet and inclusion in the Consent Form of a bullet point about this with a yes/no tick box that allows participants to consent to this.

Non-standard conditions must be completed before commencing your study. Non-standard conditions do not need to be reviewed by AUTEC before commencing your study but please send through update documents for file.

Standard Conditions of Approval

1. The research is to be undertaken in accordance with the Auckland University of Technology Code of Conduct for Research and as approved by AUTEC in this application.
2. A progress report is due annually on the anniversary of the approval date, using the EA2 form.
3. A final report is due at the expiration of the approval period, or, upon completion of project, using the EA3 form.
4. Any amendments to the project must be approved by AUTEC prior to being implemented. Amendments can be requested using the EA2 form.
5. Any serious or unexpected adverse events must be reported to AUTEC Secretariat as a matter of priority.
6. Any unforeseen events that might affect continued ethical acceptability of the project should also be reported to the AUTEC Secretariat as a matter of priority.
7. It is your responsibility to ensure that the spelling and grammar of documents being provided to participants or external organisations is of a high standard and that all the dates on the documents are updated.

AUTEC grants ethical approval only. You are responsible for obtaining management approval for access for your research from any institution or organisation at which your research is being conducted and you need to meet all ethical, legal, public health, and locality obligations or requirements for the jurisdictions in which the research is being undertaken.

Please quote the application number and title on all future correspondence related to this project.

For any enquiries please contact ethics@aut.ac.nz. The forms mentioned above are available online through http://www.aut.ac.nz/research/researchethics

(This is a computer-generated letter for which no signature is required)

The AUTEC Secretariat
Auckland University of Technology Ethics Committee

Cc: scandy@middlemore.co.nz; Julie Reeve

Health and Disability Ethics Committees
Ministry of Health
133 Molesworth Street
PO Box 5013
Wellington
6011
hdecs@health.govt.nz

Ethics reference: 2021 AM 10295

10 November 2021

Tēnā koe

APPROVAL OF AMENDMENT

Study title: Pulmonary rehabilitation: A preference clinical trial of centre based and mHealth delivered rehabilitation in chronic respiratory disease.

I am pleased to advise that this amendment was **approved** by the Northern B Health and Disability Ethics Committee (the Committee). This decision was made through the post-approval pathway.

Further information and assistance

Please contact the HDECs Secretariat at hdecs@health.govt.nz or visit our website at www.ethics.health.govt.nz for more information.

Nāku noa, nā

Ms Kate O'Connor

Chair

Northern B Health and Disability Ethics Committee

Encl: Appendix A: documents submitted

Participant Information Sheet

mPR

Pulmonary Rehabilitation

Lead Researcher: Sarah Candy

Study Site: Auckland University of Technology

Contact phone number: 021 414908

Ethics committee ref.: 21/NTB/54

We would like to invite you to take part in a study investigating different forms of delivering pulmonary rehabilitation. In the study you will have the choice of centre-based PR (standard care) or mhealth delivered PR (mPR). The mPR programme includes a personally tailored text message programme (SMS), a web-based app (mPR-app) which can be accessed from smart phone, tablet or computer, and a wearable sensor. Whether or not you take part is your choice. If you do not want to take part, you do not have to give a reason, and it will not affect the care you receive. If you do want to take part now, but change your mind later, you can pull out of the study at any time.

This Participant Information Sheet will help you decide if you would like to take part. It sets out why we are doing the study, what your participation would involve, what the benefits and risks to you might be, and what would happen after the study ends. We will go through this information with you and answer any questions you may have. You do not have to decide today whether you will participate in this study. Before you decide, you may want to talk about the study with other people, such as family, whānau, or friends. Feel free to do this.

If you agree to take part in this study, you will be asked to sign the Consent Form on the last page of this document. You will be given a copy of both the Participant Information Sheet and the Consent Form to keep.

This document is eight pages long, including the Consent Form. Please make sure you have read and understood all the pages.

Voluntary participation and withdrawal from this study

Your participation in this study is entirely voluntary (your choice). You do not have to take part. If you choose not to take part in this study your treatment will not be affected in any way. You may withdraw from the study at any time, without having to give a reason. Your withdrawal from the study will not affect your relationship with the pulmonary rehabilitation team or Auckland University of Technology. You are encouraged to ask questions at any time.

If you wish to withdraw from the mPR group, you are still welcome to attend the centre-based programme.

What is the purpose of this study?

The purpose of this study is to determine if delivering a PR programme through mHealth (mPR) can be as engaging and effective as a centre-based programme. The study will look to see if participants in both groups find the programme engaging and gain similar health outcomes.

How is the study designed?

We are looking for 100 participants for the study. When someone is referred to PR and attends an assessment they will be invited to participate and offered the choice of which group they would like to be in.

Both groups will undergo the same assessment at the start of the programme and be asked to complete a follow up assessment at the end of the eight-week programme. The initial assessment takes approximately 90 minutes and the follow up assessment 60 minutes.

Who can be in the study?

To take part in the study you must:

- Be eligible to attend pulmonary rehabilitation
- Be able to read English
- Be able to provide informed consent
- Be referred onto the study by a pulmonary rehabilitation clinician
- Have access to a mobile phone if you choose the mPR group

What will my participation in the study involve?

If after reading this information sheet, you decide that you would like to take part in the study, one of the PR clinicians will enrol you in the research project. During sign up, you will be asked some questions about your health. You will be offered the opportunity to undertake PR in one of two groups (group A or B). Both programmes are eight weeks long. The same assessment occurs at the beginning and the end of the programme for both groups.

Group A: Centre based pulmonary rehabilitation

If you choose this group, you will attend your local pulmonary rehabilitation programme twice per week for eight weeks. Each class is 90 minutes in duration. This includes one hour of exercise and 30 minutes of group education. You will also be given a home exercise programme to complete on three days of the week. This will follow the standard care of this pulmonary rehabilitation service.

Group B: mobile phone based pulmonary rehabilitation

If you choose mPR, you will be asked to try one of the below three options for the mPR programme. We will ask you to try the option selected for a period of up to 8 weeks. This will involve between 30 and 60 minutes on five days of the week.

Option 1: SMS mPR programme: If you choose this option, you will receive support-based text messages on your mobile phone. These text messages contain information on self-care, respiratory health and a personalised exercise plan that has been developed by your clinical respiratory team. Occasionally, you will be asked to answer questions about your health and wellbeing via free reply text. You are also given the choice to sign up to three friends, family (whānau), or support people to also receive some support messages over the 8-week period.

Option 2: SMS mPR Programme + App: If you choose this option, you will receive Option 1. In addition to this, you will be asked to download a unique mPR mobile application (app) on your device. The mPR mobile app will provide you with useful information about self-care, a personalised exercise plan and contains videos and resources about your health. The mPR app will provide you with some feedback on your progress. You will also be asked to complete a one-minute sit-to-stand exercise test via the mobile app halfway through the programme.

Option 3: SMS mPR Programme + App + Wearable Sensor: If you choose this option you receive both Options 1 and 2. In addition to this, you will be asked to wear a smart watch over the 8-week period. The watch will measure your step count and heart rate. There are a limited number of watches available and so this option may not be available to everyone.

At the end of the eight weeks, you may be asked to complete a follow up interview. This will be a one-on-one interview to find out more about your experiences and opinions of the mPR programme. The interview will be conducted by a member of the research team and at a time convenient to you. This can be completed at the PR site or remotely via telephone or videoconference facilities. This will follow a semi structured format and the interview will be audio recorded and later transcribed. You will have the option at the bottom of this form to choose if you would be happy to be part of this. If you choose to be part of the interviews, you will have the opportunity to review the transcript. All identifiable information will be removed from the transcript. Quotes from the transcript maybe used in future publications and these will not include any information which may identify you.

At the end of the study, you will receive a $20 voucher as reimbursement for your time taking part in the study.

What are the possible risks of this study?

As the programme involves unsupervised exercise training there is risk of injury to the participant while carrying out the exercises. To manage this risk, the exercises are designed and prescribed by qualified PR clinicians and each prescription is tailored to baseline exercise capacity. Exercises are demonstrated and technique checked at registration. Exercise safety information is provided verbally, in paper and the mPR-app.

What are the possible benefits of this study?

Pulmonary rehabilitation has been shown to improve health outcomes for people with a long-term respiratory condition. Participating in PR can reduce shortness of breath, improve exercise tolerance and improve your health-related quality of life.

Your participation in the study will help us to improve the mPR programme which could benefit people with chronic respiratory conditions in the future.

Will any costs be reimbursed?

The cost of parking at the hospital for baseline and follow up assessments will be provided.

What if something goes wrong?

If you were injured in this study, you would be eligible to apply for compensation from ACC just as you would be if you were injured in an accident at work or at home. This does not mean that your claim will automatically be accepted. You will have to lodge a claim with ACC, which may take some time to assess. If your claim is accepted, you will receive funding to assist in your recovery. If you have private health or life insurance, you may wish to check with your insurer that taking part in this study won't affect your cover.

What will happen to my information?

The study files and all information that you provide will remain strictly confidential. No material that could personally identify you will be used in any reports on this study. Identifiable information is any data that could identify you (e.g. your name, or address). Only the study researchers will have access to the identifiable information you provide. To make sure your personal information is kept confidential, information that identifies you will not be included in any report generated by the researchers and any study information sent to the sponsor. Instead, you will be identified by a code.

The results of the study may be published or presented, but not in a form that would reasonably be expected to identify you. Quotes from the interviews maybe published but would not include any personal information that may identify you.

All future use of the information collected will be strictly controlled in accordance with the Privacy Act, 2020. The research team will consider reasonable requests for sharing of de-identified patient level data with other researchers for research purposes only. Access would be subject to approval by principle investigator and completion of a data access agreement. Any data shared would be aggregated de-identified data.

Your identifiable information is securely held at Middlemore Hospital during the study. After the study is completed all data is transferred to a secure archiving site and stored for at least 10 years, then destroyed. All storage will comply with local and/or international data security guidelines.

Although efforts will be made to protect your privacy, absolute confidentiality of your information cannot be guaranteed. Even with coded and anonymised information, there is no guarantee that you cannot be identified. The risk of people accessing and misusing your information (e.g. making it harder for you to get or keep a job or health insurance) is currently very small, but may increase in the future as people find new ways of tracing information.

You have the right to request access to your information held by the research team. You also have the right to request that any information you disagree with is corrected. If you have any questions about the collection and use of information about you, you should ask the lead researcher (Sarah Candy).

Rights to withdraw your information.

You may withdraw your consent for the collection and use of your information at any time, by informing the interviewer of lead researcher. If you withdraw your consent during the study, your study participation will end.

If you agree, information collected up until your withdrawal from the study will continue to be used and included in the study. You may ask for it to be deleted when you withdraw, unless you withdraw after the study analyses have been undertaken at which point it may be impossible to withdraw data provided.

What happens after the study or if I change my mind?

If you change your mind during the study you should contact the lead researcher. You may ask for any information collected about you to be deleted when you withdraw, unless you withdraw after the study analyses have been undertaken.

Can I find out the results of the study?

You will be provided with a summary of study results, if requested, within 3 months of the end of the study.

Who is funding this study?

This study has been funded by a research grant from the MedTech CORE.

Who has approved this study?

This study has been approved by an independent group of people called a Health and Disability Ethics Committee (HDEC), who check that studies meet established ethical standards. The Northern A Health and Disability Ethics Committee has approved this study.

Who do I contact for more information or if I have concerns?

If you have any questions, concerns or complaints about the study at any stage, you can contact:

Name: Sarah Candy

Phone: 021 414908

Email: scandy@middlemore.co.nz

If you want to talk to someone who is not involved with the study, you can contact an independent health and disability advocate on:

Phone: 0800 555 050

Fax: 0800 2 SUPPORT (0800 2787 7678)

Email: advocacy@advocacy.org.nz

Website: https://www.advocacy.org.nz/

For Maori health support please contact:

Name:	Dr Helen Wihongi – Māori Health Research
Phone:	+64 9 486 8920 ext. 43204
Email:	helen.wihongi@waitematadhb.govt.nz

You can also contact the health and disability ethics committee (HDEC) that approved this study on:

Phone:	0800 4 ETHIC
Email:	hdecs@health.govt.nz

Thank you for taking time to read about this study.

Please keep this sheet for your information.

CONSENT FORM
mPR

Pulmonary Rehabilitation

Please tick to indicate you consent to the following:

- I have read, or have had read to me in my first language, and I understand the Participant Information Sheet.	☐
- I have been given sufficient time to consider whether to participate in this study.	☐
- I have had the opportunity to use a legal representative, whanau/ family support or a friend to help me ask questions and understand the study.	☐
- I am satisfied with the answers I have been given regarding the study and I have a copy of this consent form and information sheet.	☐
- I understand that taking part in this study is voluntary (my choice) and that I may withdraw from the study at any time without this affecting my medical care.	☐
- I agree to an approved auditor appointed by the New Zealand Health and Disability Ethics Committees, or any relevant regulatory authority or their approved representative reviewing my relevant medical records for the sole purpose of checking the accuracy of the information recorded for the study.	☐
- I understand that my participation in this study is confidential and that no material, which could identify me personally, will be used in any reports on this study.	☐
- I understand the compensation provisions in case of injury during the study.	☐
- I know who to contact if I have any questions about the study in general.	☐
- I understand my responsibilities as a study participant.	☐

- If I decide to withdraw from the study, I agree that the information collected about me up to the point when I withdraw may continue to be processed.	Yes ☐	No ☐
- I would be happy to undertake a follow up interview on completion of the study	Yes ☐	No ☐
- I would be happy to be contacted about extending this research in the future	Yes ☐	No ☐
- I would be happy for my health practitioner to be informed of my participation in the study	Yes ☐	No ☐
- I am happy for de-identified aggregate data to be shared with other researchers	Yes ☐	No ☐
- I wish to receive a summary of the results from the study.	Yes ☐	No ☐

Declaration by participant:

I hereby consent to take part in this study.

Participant's name:

Signature: Date:

Declaration by member of research team:

I have given a verbal explanation of the research project to the participant and have answered the participant's questions about it. I believe that the participant understands the study and has given informed consent to participate.

Researcher's name: Researcher's contact number:

Signature: Date:

Appendix S. Schedule of Data Collection – Preference Study

Description	Baseline	During study period	8 weeks
Eligibility criteria	X		
Consent	X		
Demographic and clinical information			
Name	X		
Date of birth	X		
Ethnicity	X		
Gender	X		
DHB region	X		
Diagnosis	X		
Contact number	X		
PR Attendance (> 1 yr previous) yes or no	X		
6MWT	X		X
1 minute sit to stand test	X	X	X
MMRC	X		X
FEV1%	X		
BMI	X		X
Smoking status	X		X
Social situation (living alone)	X		
Intervention preference	X		
Quality of life measures			
EQ-5D	X		X
CAT	X		X
Intervention tailoring questions	X		
Attendance (in centre or digital attendance)		X	
Adherence with exercise prescription		X	X
Participant satisfaction			X

Confidential

Form S: Screening

Baseline Data

Data collected at initial assessment. Data should be collected within 6 weeks of starting the intervention.

Record ID	_____
Screening Date	_____

Inclusion Criteria

1.01 Age	○ over 18 years ○ under 18 years
1.02 Confirmed chronic respiratory condition	○ Yes ○ No
1.03 Eligible for PR	○ Yes ○ No
No, please describe why person is not eligible (eg, mobility concerns, cardiac concerns, cognitive)	_____
1.04 Read and Understand English	○ Yes ○ No
1.05 Able to provide informed consent	○ Yes ○ No
1.06 Access to mobile phone	○ Yes ○ No

Exclusion Criteria

1.07 Available for duration of study	○ Yes ○ No
1.08 Completed PR within last one year	○ Yes ○ No

This participant is not eligible to participate in this trial at this time.
Please do not proceed with any other forms.

Form D: Demographics

Baseline Data

Data collected at initial assessment. Data should be collected within 6 weeks of starting the intervention.

Record ID	_____
Unique Identifier Phone number Please use the format +6427#######	_____

Section One - Demographic information

1.01 What is your gender	○ Male ○ Female ○ Another Gender
1.02 When were you born? (day/month/year)	_____
1.03 Postcode	_____
1.04 Living situation	○ Alone ○ Married/Partner ○ Family/Whanua ○ Other
1.04b Other (please describe)	_____
1.05 Which ethnic group do you belong to? (tick as many as approporiate)	☐ NZ European ☐ Maori ☐ Samoan ☐ Chinese ☐ Cook Island Maori ☐ Tongan ☐ Niuean ☐ Indian ☐ Other
105b Other ethnicity (please describe)	_____
105c Are you descended from a Māori (that is, did you have a Māori birth parent, grandparent or great-grandparent, etc)?	○ Yes ○ Do not know ○ No
105d Do you know the name(s) of your iwi (tribe or tribes)?	○ Yes ○ No

Form C: Clinical Information

Baseline Data

Data collected at initial assessment. Data should be collected within 6 weeks of starting the intervention.

Record ID	_____
1.01 Primary respiratory diagnosis	☐ COPD ☐ Asthma ☐ Bronchiectasis ☐ ILD ☐ OSA ☐ Post thoracic surgery ☐ Other
1.01b Other (please specify)	_____
1.01c COPD severity	○ Mild (FEV1% > 80) ○ Moderate (FEV1% 50 - 80) ○ Severe (FEV1% 30 - 50) ○ Very severe (FEV1% < 30)
1.02 Other respiratory conditions	☐ COPD ☐ Asthma ☐ Bronchiectasis ☐ ILD ☐ OSA ☐ Post thoracic surgery ☐ Other
1.02b Other (please specify)	_____
1.03 Co morbidities (please tick all that apply)	☐ IHD ☐ CHF ☐ Diabetes ☐ Arthritis ☐ Cancer ☐ Depression ☐ Other
1.03b Cancer (please specify)	_____
1.03c Other (please specify)	_____

Form B: Baseline

Baseline Data
Data collected at initial assessment. Data should be collected within 6 weeks of starting the intervention.

Record ID

Assessment Date

1. Blood pressure
Two manual BP measurements should be taken for each participant. If the second measure if not within 5 mmHh for systolic and diastolic BP, or is >160 systolic, and/or >100 diastolic, take a third measure.

Blood pressure reading - measurement 1

1.01 Systolic Blood pressure

1.02 Diastolic Blood pressure

Blood pressure - Measurement 2

1.03 Systolic Blood pressure

(If this measure is >5mmHg different, or >160, then take a third measure)

1.04 Diastolic blood pressure

(Of this measure is >55mH different, or >100, take a third measure)

Blood pressure - measurement 3 (if required)

1.05 Systolic blood pressure

1.06 Diastolic blood pressure

Form F: Follow up

Record ID

Re-Assessment Date

Assessment Outcome

- ○ Information Available
- ○ Lost to Follow Up
- ○ Formally Withdrew
- ○ Other

If Other, please specify

1. Blood pressure

Two manual BP measurements should be taken for each participant. If the second measure if not within 5 mmHh for systolic and diastolic BP, or is >160 systolic, and/or >100 diastolic, take a third measure.

Blood pressure reading - measurement 1

1.01 Systolic Blood pressure

1.02 Diastolic Blood pressure

Blood pressure - Measurement 2

1.03 Systolic Blood pressure

(If this measure is >5mmHg different, or >160, then take a third measure)

1.04 Diastolic blood pressure

(Of this measure is >55mH different, or >100, take a third measure)

Blood pressure - measurement 3 (if required)

1.05 Systolic blood pressure

1.06 Diastolic blood pressure

Appendix U. Data Management Plan – Preference Study

Introduction

This Data Management Guide outlines how data will be handled during the study (mPR) and after its completion.

Study Structure

This project has been designed by independent investigator(s) at the Auckland University of Technology (AUT), and the National Institute for Health Innovation (NIHI), School of Population Health, Faculty of Medicine and Health Sciences, University of Auckland, Auckland. The overall design and conduct of this project is the responsibility of the co-ordinating investigator and members of the Steering Committee and Project Management Committee. Publication of data from this project will be the responsibility of members of the Steering Committee. The project will be co-ordinated from NIHI (or AUT).

TABLE 1. STUDY STRUCTURE

Sponsor	MedTech Core
Contract Research Organisation	National Institute for Health Innovation r.whittaker@auckland.ac.nz
Lead Site (New Zealand)	Auckland University of Technology North Campus, Akoranga
Co-ordinating Investigator	Sarah Candy Sarah.Candy@middlemore.co.nz

Organisational Data Governance Oversight

The following institutional data policies apply for the Study:

- University of Auckland Data Governance Policy
- Privacy Act 2020

Consent for Data Collection and Use

Consenting: All participants will be informed of, and provide consent for, the collection and use of their data for the purposes of this study, and for any mandatory secondary uses.

Additional written consent will be sought for optional secondary uses of data.

Data Collection
Data will be collected from the following sources:

- Direct communication with the participant
- Study assessments, including laboratory test results, imaging, biomedical monitoring, questionnaires, interviews, and data downloaded from apps
- REDCap Databank / Registry

- Participant medical records (if indicated)
- Communications with participant's clinical care team (if indicated).

Data will be collected primarily by the Investigator or designated study staff. All study personnel involved in data collection will be trained in GCP, study protocol, and collection requirements.

Collection of data will be limited to that necessary for the specified purposes of the study, or for additional purposes that the participant has explicitly consented to.

Privacy and confidentiality
Participants' privacy and confidentiality will be respected through the protection of their data as outlined in this plan. The Investigator will comply with legal and regulatory requirements regarding the privacy and confidentiality of participants' data.

Participants have the right to access and correct personal data held by the site.

Breach of Privacy / Confidentiality
A breach of privacy means unauthorised or accidental access to, or disclosure, alteration, loss, or destruction of a participant's information.

In the event participant privacy and confidentiality is breached during the study, the following steps will be taken:

- Action will be taken to reduce the risk of harm following the breach. Where possible, the recipient will be contacted and asked to destroy or return any electronic the disclosed material.

- The participant will be informed of the breach as soon as practicable (unless the participant is under the age of 16 and notification would be contrary to his/her interests; or notification would be likely to prejudice the health of the participant (after consultation with the participant's health practitioner, where practicable), and provided with support as required.
- The approving HDEC will be informed.
- For notifiable privacy breaches of privacy under the Privacy Act 2020, the New Zealand Privacy Commissioner will be notified in accordance with that Act.

Forms of Data

Identifiable Data

Some Study data will be collected in identifiable form.

Source documents refer to identifiable data collected for the purposes of this study. For the purposes of this data management plan, identifiable data includes the participant's existing medical / clinical records.

Source documents will be held at the site in identifiable form.

De-identified Data

De-identified data in this study includes but is not limited to:

- Case Report Forms.
- Safety and screening results entered into the analysis data set.

De-identified data will carry the participant's unique study code. The Investigator will retain a log linking participant code with identifiers. This log will not be made available to the Sponsor.

All data sent to the Sponsor will be de-identified. All data generated by these parties will be in de-identified form. No attempt will be made to re-identify participants.

Anonymous / Anonymised Data

Data will be collected anonymously, i.e., it will not contain any identifiers. The signed consent form and contact information (if provided) will not be linked in any way to data collected for study purposes.

Access to and Use of Data

Collected data will be used to answer the research questions and fulfil the study requirements described in the study protocol.

Identifiable Data

Identifiable data may be accessed by the following groups:

- The Investigator and designated study staff, to fulfil protocol requirements.
- Study monitor(s), for eligibility confirmation and source data verification purposes.
- The Health and Disability Ethics Committee, for legal and regulatory purposes.
- Health, regulatory, or government agencies, for legal and regulatory purposes.
- The participant's GP or appropriate specialist, to inform them of study participation, and in the event of an incidental finding of potential clinical significance.

Rarely, it may be necessary for the Investigator to share identifiable data with people or groups not listed above – for example, in the event of a serious threat to public health or safety, or to the life or health of the participant or another person; or if the data is required for certain legal situations.

De-identified Data

De-identified data may be accessed and used by the following groups:

- The Investigator and suitably trained and experienced study staff, to conduct the study.
- Sponsor for source data verification purposes.
- The Sponsor, for study conduct, data analysis and product registration and marketing, or as otherwise permitted by applicable local and international laws and regulations.
- The Health and Disability Ethics Committee, to comply with legal and regulatory duties.
- Health, regulatory, or government authorities, to comply with legal and regulatory duties.

De-identified data may be included in published study results including, but not limited to, peer-reviewed publications, clinical trial registry websites, scientific meetings, and regulatory / marketing submissions.

[Anonymous/Anonymised] Data

Anonymous/Anonymised data may be accessed and used by the groups described in Section

Sending of Data Overseas

Not Applicable

Future Use of Data

De-identified data will be used by the Sponsor for future medical or scientific research as specified below:

- unspecified purposes which are directly related to the study question(s)
- unspecified purposes which are related to the item and/or condition under study
- unspecified medical or scientific purposes which are not related to the study questions
- other unspecified research

If participants provide optional additional consent De-identified [and/or anonymised] data will be made available to other researchers on request for future research as specified above and / or will be added to data from other sources to form larger datasets.

In all cases, the Sponsor must be satisfied that appropriate Data Management Plans are in place and that ethical approval for use has been obtained in accordance with local laws and regulations.

Commercial Use of Data

Study data analysis may lead to discoveries and inventions or development of a commercial product or producers. The rights to these will belong to NIHI. Participants will not receive any financial benefits or compensation from, nor have any rights to, any developments, inventions, or other discoveries arising from this analysis.

Data Linking

The study will link data obtained from wearable sensors (Fitbit, Withings smart watch) to the mPR app. Participants are asked via pop up to give permission for the mPR app to access their wearable device data.

Participants must choose to be in the SMS + mPR-app + sensor group for this pop up function to be enabled. The purpose is for the participant to track their fitness data within the app.

All linked data will be stored locally on the participant's devices and will maybe accessed by the investigators for use in the data analysis.

Databank / Registry

Not applicable.

storage and Destruction of Data

Identifiable Data and Source Documents
During the study, study-specific source documents will be maintained on a password protected data stick within a locked cabinet, located in a locked office at Counties Manukau Health.

Post-study, study-specific source documents will be archived electronically on a password protetcted memory stick stored in a locked filing cabinet within a locked office.

Source documents will be retained for at least 10 years then destroyed by deletion of all electronic files.

The following forms of data will be retained by the participants GP and will form part of the participant's clinical record. These documents will not be archived or destroyed as described above:

- *Clinic assessment letter*

De-identified Data
Identifiable data will be converted to a de-identified form at the study site, at which point it is entered into electronic case report forms using the secure data platform, REDCap. The data platform complies with international and national regulatory requirements for electronic data capture systems in the countries where it is used. Data entry will be limited to designated study staff trained and experienced in transcribing data for this purpose.

De-identified data will carry unique participant identifiers. The Investigator will retain a log linking participant code with identifiers. This log will not be made available to the Sponsor.

The de-identified database will remain on NIHI secure servers for up to approximately ten years.

Consultation

Consultation regarding data management will be undertaken with the lead data manager at the NIHI.

Māori Data Sovereignty

During the study, data may be collected from participants identifying as Maori.

Personal and health information is a tāonga (treasure) and will be treated accordingly.

Formal Māori consultation for this study will be completed as part of the Locality Approval Process for New Zealand study site(s). Any recommendations for additional measures to improve Māori rights and interests in relation to data will be acted upon.

Return of Results

Screening and safety results will be provided to participants on request.

Participants have the right to request a lay summary of study results.

Incidental Findings

In the event that a study assessment returns a result of potential clinical significance, the participant will be informed. The participant's usual doctor and / or an appropriate specialist will be notified, and follow-up will be arranged.

Results Arising from Future Research

Data

No future unspecified research is planned for data collected in this study.

Databank / Registry

Not applicable

Withdrawal of Data

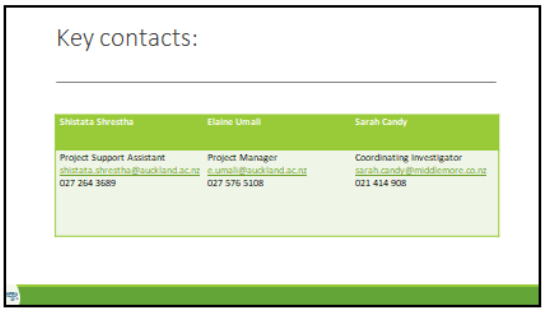
Participants may withdraw consent for the collection of data at any time, without providing a reason.

Should a participant withdraw consent, no further data will be collected by study staff.

Data collected prior to the participant's withdrawal will continue to be used and analysed.

Appendix V. Copy of Training for Research Team

1



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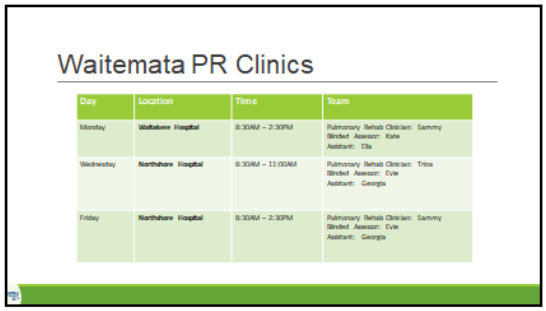

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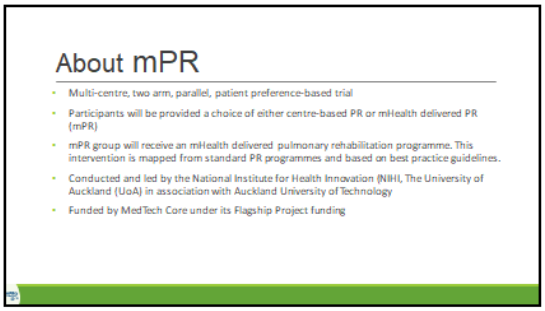

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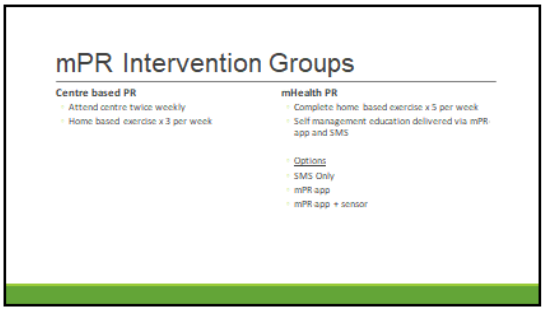

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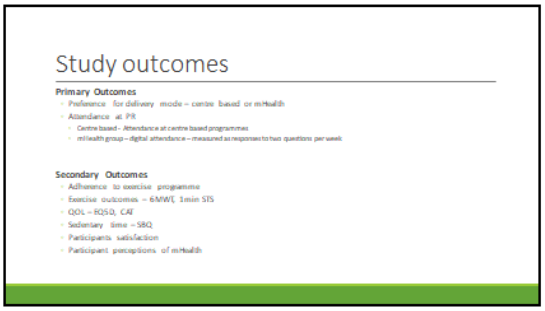

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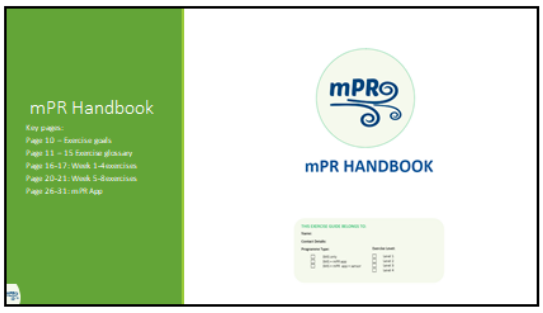
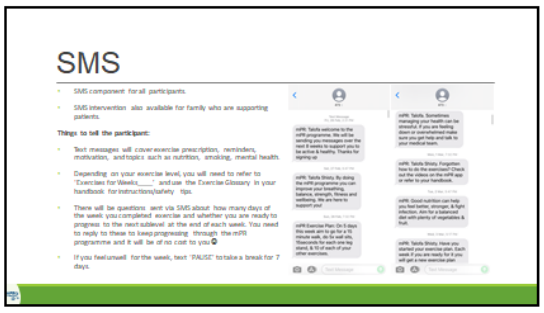
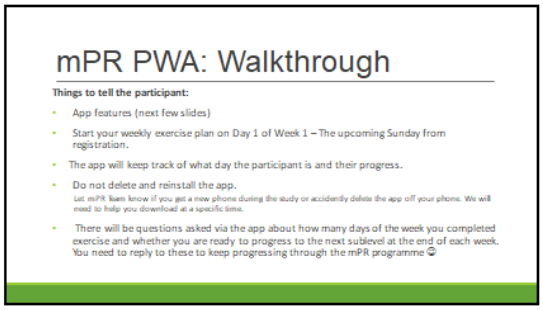

mPR Handbook
Key pages:
Page 10 – Exercise goals
Page 11 – 15 Exercise glossary
Page 16-17: Week 1-4 exercises
Page 20-21: Week 5-8 exercises
Page 26-31: mPR App
mPR HANDBOOK

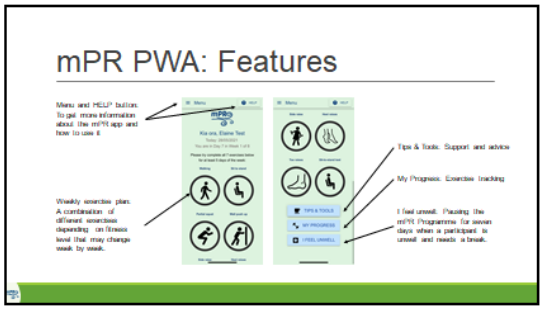
7


SMS
SMS component for all participants.
SMS intervention also available for family who are supporting patients.
Things to tell the participant:
Text messages will cover exercise prescription, reminders, motivation, and topics such as nutrition, smoking, mental health.
Depending on your exercise level, you will need to refer to "Exercises for Weeks ____" and use the Exercise Glossary in your handbook for instructions/safety tips.
There will be questions sent via SMS about how many days of the week you completed exercise and whether you are ready to progress to the next sublevel at the end of each week. You need to reply to these to keep progressing through the mPR programme and it will be of no cost to you
If you feel unwell for the week, text "PAUSE" to take a break for 7 days.

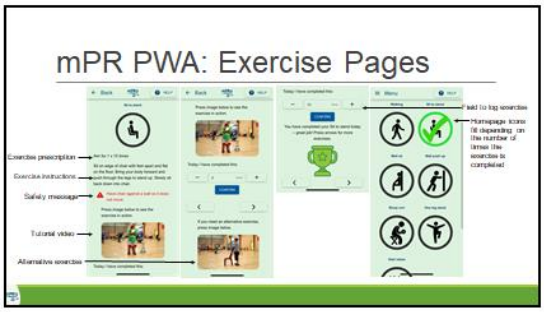
8


mPR PWA: Walkthrough
Things to tell the participant:
App features (next few slides)
Start your weekly exercise plan on Day 1 of Week 1 – The upcoming Sunday from registration.
The app will keep track of what day the participant is and their progress.
Do not delete and reinstall the app.
Let mPR Team know if you get a new phone during the study or accidently delete the app off your phone. We will need to help you download at a specific time.
There will be questions asked via the app about how many days of the week you completed exercise and whether you are ready to progress to the next sublevel at the end of each week. You need to reply to these to keep progressing through the mPR programme

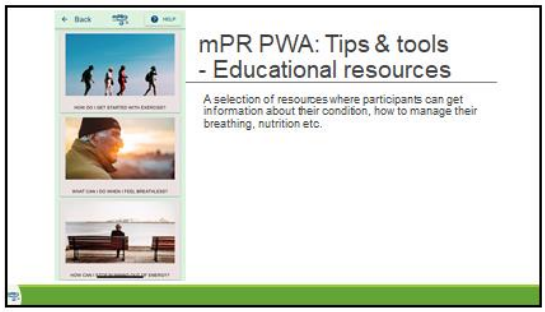
9


mPR PWA: Features
Menu and HELP button. To get more information about the mPR app and how to use it
Weekly exercise plan. A combination of different exercises depending on fitness level that may change week by week.
Tips & Tools. Support and advice
My Progress. Exercise tracking
I feel unwell. Pausing the mPR Programme for seven days when a participant is unwell and needs a break.

10

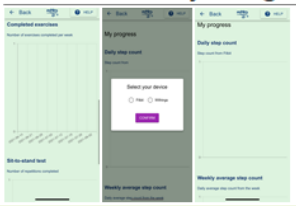

mPR PWA: Exercise Pages
Exercise prescription
Exercise instructions
Safety message
Tutorial video
Alternative exercise
Add to log exercise
Homepage icons fill depending on the number of times the exercise is completed

11


mPR PWA: Tips & tools - Educational resources
A selection of resources where participants can get information about their condition, how to manage their breathing, nutrition etc.

12

mPR PWA: My Progress



This section graphs the number of exercises per week a participant completes, enabling them to monitor their progress.

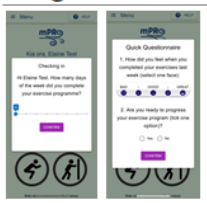
If the participant is part of the SMS + App + Sensor intervention, they can connect a Fitbit or Withings sensor to track their daily step count.

13

Pausing programme and getting help

14

Programme Questions



At the end of each week, participants are asked:

- to record the number of days they completed their exercise programme

  'Answers are graphed in the My Progress page

- to record how they felt during exercise
- whether they are ready to progress to the next exercise plan

If participants reply 'no', they will receive the same exercise as the week before.

15

Recruitment Process

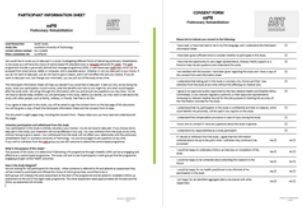
1. Participants are recruited from PR clinics.
2. PRC screens notes prior to clinic to check for eligibility
3. At baseline assessment:

16

Overview of different roles

PRC	RA	RA
Responsible for patient care	Completes Pre exercise screening	Completes consent process
Complete screening form	2 x 6MWT	Completes registration on AWS
Complete normal PR assessment	1 min STS	Completes form D
Complete registration form – includes tailoring	CAT SBQ EQSD MRC	Enters Forms S, B and C into REDcap
Complete clinical info form	Completes Form B	Sets up mPR-app +/- sensor
Patient Documentation		Walks participant through the mPR-app, how to use it
Provides instruction and demonstration of how to complete exercises – mPR app Home exercise programme – centre based		Provides information on the questions to be completed
Clinic summary		

17



PIS & Consent Form

GET PARTICIPANT TO SIGN, THEN SCAN AND SEND TO MPR.PROJECT@AUCKLAND.AC.NZ

18

The PRC roles

1. Completes pre-screening checks
2. Welcomes the patient, provides information on PR and introduced the study
3. Outlines the process of the assessment to participant
4. Completes PR assessment as per normal protocol
5. Completes the following forms
   - Form S – screening
   - Form Z – registration (mPR ONDY)
   - Form C – Clinical information
6. Documentation

19

Form S - Screening form

20

Form C – Clinical information

Add as much information regarding co-morbidities as available

21

Registration Form – intervention tailoring

Module selection				
Core	Maori	Pacific	Non-Maori/Pacific	
Exercise level	One	Two	Three	Four
Smoking cessation	Yes	No		
Secretion Clearance	Yes	No		
Nutrition	Low BMI	Other		
Tailoring selections				
Preferred name				
Preferred delivery time	Morning	Afternoon	Evening	No preference
Motivations				
Key support people				

22

Tailored Modules

Smoking cessation

For those identified as smokers at baseline, one message every 2 weeks encouraging patients/family to consider quitting smoking and offering a smoking cessation programme. There are 2 versions of this module:

- Smoking
- Smoking_family

Secretion Clearance

Nutrition

Low BMI or other

23

Exercise Levels

The exercise programmes have been stratified into four levels. The following is a guide. The level chosen should be based on clinical judgement.

Level	6MWT	ABBRC	Balance
1	<200m	4	History of falls / reduced mobility
2	200 – 350m	3	Walking aide /
3	350 – 500	2	
4	>500m	1	

24

Demographic Data Collection

FORM D: DEMOGRAPHICS ON REDCAP

25

Monitoring attendance

1. Class attendance

Each time the participant attends class – this is recorded.

If the participant is unable to attend and they advise the team – coded as UTA (paused)

If the participant does not attend (DNA) and there is two consecutive DNAs – the PRC is to call and/or text the participant.

If they do not attend a further two appointments they will be called again.

If they still do not turn up – considered lost to follow up. They are still invited to attend follow up assessment

Participant have 12 weeks to complete the intervention. At 12 weeks a follow up assessment is undertaken.

26

Monitoring adherence

Participants are provided with a home exercise record card.

They are asked to write an 'E' on the days they have completed their home exercise programme.

The minimum number of exercises to have achieved 'completion' if 4 exercise (out of 7).

Participants are asked to tear off the top sheet and bring this to first class of week. Please record the number of times exercise is completed.

If participant forgets to bring sheet – record the number of times they state.

27

Monitoring adherence

Home exercise monitoring

Participants are asked to complete home exercise programme three times per week.

Provided with HEP which corresponds to the same levels as mPR-app.

Level	6MWT	mWC	Balance
1	<200m	0	History of falls
2	200 – 450m	1	Walking aids / unsteady gait
3	450 – 600	2	
4	>600m	3	

28

Progression of HEP

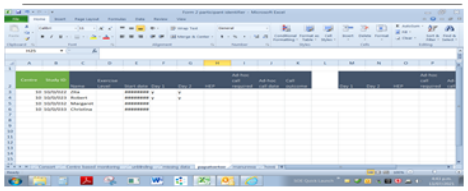
At the beginning of week five the HEP is progressed.

For the centre based group – you can change the level as required.

Please make a note of which level has been prescribed.

29

For discussion …



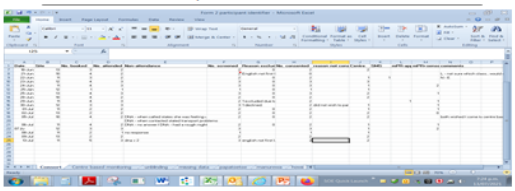
30

Documentation

1. Patient notes
   - Follow normal site process.
   - Addition of patient involvement in study
   - *XXX has given consent to be part of a preference trial comparing centre based and mHealth delivered pulmonary rehabilitation. She has opted for the mHealth group. This involves eight weeks of tailored exercise prescription and self management education. We will complete a follow up assessment in eight weeks.*
2. Monitoring forms
3. Clinic summary form
4. Reporting of unblinding
4. Reporting of adverse events

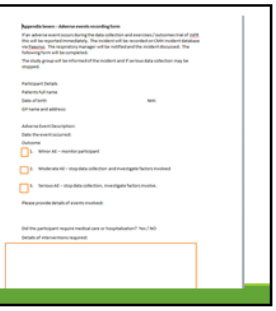
31

Clinic summary



32

Adverse Events



33

The Blinded Assessor roles

Pre exercise screen

Complete all outcome measures

Complete paper copy Form B – baseline

Report any instances of unblinding

Report any adverse events

34

Pre exercise screen

Number	Question	Yes/No
1.	Are you feeling well today?	
2.	Have you taken all your usual medications this morning?	
3.	Have you eaten breakfast this morning?	
4.	Have you had any changes in your health or normal symptoms today?	
5.	Have you experienced any chest pain today?	

35

Outcome measures

Every effort will be made to complete the outcome measures without knowledge of the intervention group.

The following measures will be undertaken;

1. Practise 6MWT
2. Second 6MWT
3. 1 min STS
4. Questionnaires – MRC, CAT, EQ.5D, SBQ
5. Height / weight

All data recorded on paper copy of Form B and given to RA for data entry to REDcap.

Please check all data is complete prior to handing over the form.

36

Form B – baseline form

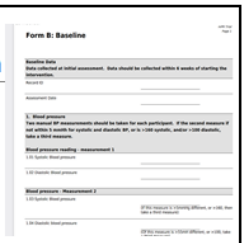
To be completed on paper form

To be entered into REDcap by RA at clinic

All forms are scanned to;

mPR.project@auckland.ac.nz

All data verified by SC


Form B: Baseline

Baseline Data
Data collected at initial assessment. Data should be collected within 6 weeks of starting the intervention.

Record ID

Assessment Date

1. Blood pressure
Two manual BP measurements should be taken for each participant. If the second measure if not within 5 mmHg for systolic and diastolic BP, or is >160 systolic, and/or >100 diastolic, take a third measure.

Blood pressure reading - measurement 1

1.01 Systolic blood pressure

1.02 Diastolic blood pressure

Blood pressure - Measurement 2

1.03 Systolic blood pressure

If the measure is >5mmHg different, or >160, then take a third measure

1.04 Diastolic blood pressure

If the measure is >5mmHg different, or >100, take

37

Baseline readings

Blood pressure

Blood pressure will be taken with a OMRON electronic sphygmomanometer. Participants will be seated with back supported. The left arm should be supported on a table at the forearm. The arm should be level with their heart.

The correct size cuff should be used to ensure accuracy.

The cuff should be wrapped around the arm at 1 – 2 cm above the elbow joint.

The blood pressure readings will be taken twice. If the second reading is not within 5 mmHg of the first reading a third recording is required.

Heart rate

Oxygen saturations

38

6MWT

Follow the standardised instructions provided on the laminated card.

If a participant is on LTOT – test is to be completed with supplemental oxygen.

Do not walk alongside the participant. If you wish/need to walk with them – remain just behind the participant.

Use the prompts on the standardised instruction sheet.

The walking track length should be checked at the beginning of the clinic

Measure the distance at which the test finished – please measure to nearest cm (eg. 335.5m)

39

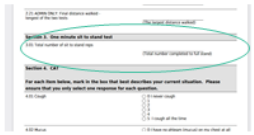
1 min STS

Use chair against a wall and 43 cm in height

Please demonstrate the correct technique with the participant prior to the test.

Read the standardised instructions on the sheet.

Record the number of repetitions on Form B


2.21 ADMIN ONLY: Total distance walked
(the longest distance walked)

Section 3. One minute sit to stand test

3.01 Total number of sit to stand reps

(Total number completed to full Stand)

Section 4. CAT

For each item below, mark in the box that best describes your current situation. Please ensure that you only select one response for each question.

4.01 Cough

0 I never cough
1
2
3
4 I cough all the time

4.02 Mucus

0 I have no phlegm (mucus) on my chest at all

40

EQ-5D

Please provide the participant with a laminated print out of the questions and will read out loud each questions to the participant. Participants are provided with a choice of three answers. The participant is to provide the answer which best describes their health state on that day.

Participants are given a marker to mark the answer which best describes them.

Please mark the corresponding answer on Form B.

41

Responding to mental health concerns

The mPR registration form contains the EQ-5D, which is a tool commonly used to assess overall Quality of Life. The measure does include a question related to mental health (see below), where participants may indicate that they are experiencing mental health issues (as indicated by selecting "moderately" or "extremely" options below. PRC's should exercise their clinical judgment in determining if participants should be referred to mental health support services. PRC's should act in accordance with any relevant DHB policies.

EQ-5D Question on Anxiety/Depression in Registratin Form

Anxiety/Depression	
I am not anxious or depressed	
I am moderately anxious or depressed	
I am extremely anxious or depressed	

42

CAT

Participants are asked to complete the CAT. Participants will be provided with a laminated printed version of the questions. They are asked to mark the box that best describes their current situation. Only one response can be provided for each question. The BA marks the responses on Form B.

43

SBQ

The BA provides the participant with a laminated card with the SBQ written on both sides. The BA reads the question out loud to the participant and asks them to report on a typical weekday how much time would you spend doing the following (between when you wake up and when you go to bed)?

The BA marks the response on Form B.

The same process is completed for a typical weekend day.

44

mMRC

Use laminated card to determine level of breathlessness.

1959 MRC Breathlessness Scale

Grade 1: Are you ever troubled by breathlessness except on strenuous exertion?

Grade 2: (If yes) Are you short of breath when hurrying on the level or walking up a slight hill?

Grade 3: (If yes) Do you have to walk slower than most people on the level? Do you have to stop after a mile or so (or after ¼ hour) on the level at your own pace?

Grade 4: (If yes to either) Do you have to stop for breath after walking about 100 yds. (or after a few minutes) on the level?

Grade 5: (If yes) Are you too breathless to leave the house, or breathless after undressing?

45

Un-blinding

date	study id	name	group	Comments		
		Sue				
30/06/2021	12	Gillian	centre	BP readings too high for walk test - sent to GP and test completed at first class		
06/07/2021		Eric	centre	Told the BA which group he was in before second walk test.		

46

Questions

47

Appendix W. Consort Checklist for Pragmatic Trial

Table 5. Consort checklist for reporting pragmatic trials

Section	Item	Standard CONSORT description	Extension for pragmatic trials	
Title and abstract	1	How participants were allocated to interventions (eg, “random allocation,” “randomised,” or “randomly assigned”)		**Providing choice in pulmonary rehabilitation: Results from a preference clinical trial of centre based and mHealth delivered rehabilitation**
Introduction				
Background	2	Scientific background and explanation of rationale	Describe the health or health service problem that the intervention is intended to address and other interventions that may commonly be aimed at this problem	Pg 3. PR improve outcomes for CRD, but too few people attend or complete. Utilising technology may provide a solution however is this preferred by people living a CRD.
Methods				
Participants	3	Eligibility criteria for participants; settings and locations where the data were collected	Eligibility criteria should be explicitly framed to show the degree to which they include typical participants and/or, where applicable, typical providers (eg, nurses), institutions (eg, hospitals), communities (or localities eg, towns) and settings of care (eg, different healthcare financing systems)	Pg 5 describes participant recruitment and further information provided in supplemental information.
Interventions	4	Precise details of the interventions intended for each group and how and when they were administered	Describe extra resources added to (or resources removed from) usual settings in order to implement intervention. Indicate if efforts were made to standardise the intervention or if the intervention and its delivery were allowed to vary between participants, practitioners, or study sites	Three study sites centre-based programme was standard but location varied – see supplemental. The programmes followed best practise guidelines (Alison et al., 2017). See pg 5 and supplement 1.
			Describe the comparator in similar detail to the intervention	See pg 4 and supplement 1.
Objectives	5	Specific objectives and hypotheses		Pg 8

Section	Item	Standard CONSORT description	Extension for pragmatic trials	
Outcomes	6	Clearly defined primary and secondary outcome measures and, when applicable, any methods used to enhance the quality of measurements (eg, multiple observations, training of assessors)	Explain why the chosen outcomes and, when relevant, the length of follow-up are considered important to those who will use the results of the trial	Pg 6 Time of follow based on end intervention Outcome measure chosen reflect measures used in clinical practise
Sample size	7	How sample size was determined; explanation of any interim analyses and stopping rules when applicable	If calculated using the smallest difference considered important by the target decision maker audience (the minimally important difference) then report where this difference was obtained	Page 6
Randomisation—sequence generation	8	Method used to generate the random allocation sequence, including details of any restriction (eg, blocking, stratification)		n/a
Randomisation—allocation concealment	9	Method used to implement the random allocation sequence (eg, numbered containers or central telephone), clarifying whether the sequence was concealed until interventions were assigned		n/a
Randomisation—implementation	10	Who generated the allocation sequence, who enrolled participants, and who assigned participants to their groups		n/a
Blinding (masking)	11	Whether participants, those administering the interventions, and those assessing the outcomes were blinded to group assignment	If blinding was not done, or was not possible, explain why	Pg 5 Assessments completed by blinded assessor. Not possible to blind participants. Not possible to blind follow-up assessor as telephone based.

Section	Item	Standard CONSORT description	Extension for pragmatic trials	
Statistical methods	12	Statistical methods used to compare groups for primary outcomes; methods for additional analyses, such as subgroup analyses and adjusted analyses		Pg 6-7
Results				
Participant flow	13	Flow of participants through each stage (a diagram is strongly recommended)—specifically, for each group, report the numbers of participants randomly assigned, receiving intended treatment, completing the study protocol, and analysed for the primary outcome; describe deviations from planned study protocol, together with reasons	The number of participants or units approached to take part in the trial, the number which were eligible, and reasons for non-participation should be reported	See Figure 1 at end of manuscript.
Recruitment	14	Dates defining the periods of recruitment and follow-up		Pg 4
Baseline data	15	Baseline demographic and clinical characteristics of each group		Table 1
Numbers analysed	16	Number of participants (denominator) in each group included in each analysis and whether analysis was by "intention-to-treat"; state the results in absolute numbers when feasible (eg, 10/20, not 50%)		Pg 8 and Figure 1
Outcomes and estimation	17	For each primary and secondary outcome, a summary of results for each group and the estimated effect size and its precision (eg, 95% CI)		Pg 8 for primary outcome Table 3 for secondary outcome

Section	Item	Standard CONSORT description	Extension for pragmatic trials	
Ancillary analyses	18	Address multiplicity by reporting any other analyses performed, including subgroup analyses and adjusted analyses, indicating which are prespecified and which are exploratory		There were no subgroup analyses
Adverse events	19	All important adverse events or side effects in each intervention group		Pg 11
Discussion				
Interpretation	20	Interpretation of the results, taking into account study hypotheses, sources of potential bias or imprecision, and the dangers associated with multiplicity of analyses and outcomes		Pg 11 - 12
Generalisability	21	Generalisability (external validity) of the trial findings	Describe key aspects of the setting which determined the trial results. Discuss possible differences in other settings where clinical traditions, health service organisation, staffing, or resources may vary from those of the trial	Pg 11 - 14
Overall evidence	22	General interpretation of the results in the context of current evidence		Pg 11-13

Appendix X. Conserve Checklist for Extenuating Circumstances

Table 6. Conservice Checklist for extenuating circumstances

CONSERVE-CONSORT Extension:			
Item	**Item Title**	**Description**	**Page No.**
I.	Extenuating Circumstances	Describe the circumstances and how they constitute extenuating circumstances. National lockdown was implemented on 17 August due to COVID-19 pandemic.	5
II.	Important Modifications	a. Describe how the modifications are important modifications. Recruitment stopped – short of proposed sample size. Centre-based PR pivoted to telephone /VC Follow up assessments were completed via phone therefore no physical measures (6MWT + sit to stand tests) were completed.	5 5
		b. Describe the impacts and mitigating strategies, including their rationale and implications for the trial.	(see below)
		c. Provide a modification timeline. Recruitment and traditional centre-based classes stopped on 17 August. All centre-based interventions changed from 17 August Follow up assessments occurred over the phone	5 - 6 9
III.	Responsible Parties	State who planned, reviewed and approved the modifications. Research team	5
IV.	Interim data	If modifications were informed by trial data, describe how the interim data were used, including whether they were examined by study group, and whether the individuals reviewing the data were blinded to the treatment allocation.	n/a

CONSORT Number and Item		For each row, if important modifications occurred check "direct impact" and/or "mitigating strategy" and describe the changes in the trial manuscript or supplement. Check "no change" for items that are unaffected in the extenuating circumstance.			
		No Change	**Impact***	**Mitigating Strategy****	**Page No.**
1	Title and abstract	No change			
2	Introduction	No change			
3	Methods: Trial Design	No change			
4	Methods: Participants		Reduced sample size		5
5	Methods: Interventions		Usual care treatment protocols unexpectedly altered mid trial	Centre based group – forced to stop face to face classes and transition to phone or videoconferencing	6
6	Methods: Outcomes		Phone based follow up assessments No exercise tests.	Phone based follow up assessments No exercise tests.	5
7	Methods: Sample Size		Change in sample size	Reduced from 50 in smallest group to 38. Statistical model for primary outcomes is not longer powered at 80% due to reduced sample size.	14
8-10	Methods: Randomisation	No change			
11	Methods: Blinding		Change in blinding of physio at follow up assessment	No blinding possible due to phone assessment.	14
12	Methods: Statistical methods	No change			
13	Results: Participant flow				
14	Results: Recruitment		Reduced recruitment		14
15	Results: Baseline data	No change			
16	Results: Numbers analysed	No change			

CONSORT Number and Item		For each row, if important modifications occurred check “direct impact” and/or “mitigating strategy” and describe the changes in the trial manuscript or supplement. Check “no change” for items that are unaffected in the extenuating circumstance.			
		No Change	**Impact***	**Mitigating Strategy****	**Page No.**
	Results: Outcomes and estimation				
18	Results: Ancillary analyses				n/a
19	Results: Harms	No change			
20	Discussion: Limitations		Changes to centre-based intervention		14
21	Discussion: Generalisability		The change to phone calls and social circumstances may have impacted the completion rate for centre-based		11
	Other information: Registration				
24	Other information: Protocol				
25	Other information: Funding	No change			

*Aspects of the trial that are directly affected or changed by the extenuating circumstance and are not under the control of investigators, sponsor or funder.
**Aspects of the trial that are modified by the study investigators, sponsor or funder to respond to the extenuating circumstance or manage the direct impacts on the trial.

Appendix Y. TiDiER Checklist

Table 7. TiDiER Checklist

SECTION 1. BRIEF NAME	
Item 1.	Provide the name or a phrase that describes the intervention. Centre-based or mHealth delivered pulmonary rehabilitation.
SECTION 2. WHY	
Item 2.	Describe any rationale, theory, or goal of the elements essential to the intervention. PR is an evidence-based intervention which has been shown to reduce dyspnoea, dependency and hospitalisation while improving exercise capacity and health related quality of life for people living with a chronic respiratory disorder (CRD) (McCarthy et al., 2015). Despite the proven efficacy the access, uptake and completion of PR is low worldwide. Emerging models are being developed to address this and mHealth is one such model. This pragmatic trial aims to understand the patient preference for how PR is delivered and if mHealth PR can improve completion rates of PR.
SECTION 3. WHAT	
Item 3A.	Materials: Describe any physical or informational materials used in the intervention, including those provided to participants or used in intervention delivery or in training of intervention providers. Provide information on where the materials can be accessed (e.g., online appendix, URL). Patients who opted for the mPR group were required to have access to a mobile phone. The mPR-app was downloaded onto the phone by a research assistant. The participant was shown how to use the app and provided with a paper manual to take home with further information if required. Participants had the option of wearing a commercially available sensor (Fitbit or withings) which was loaned to them for the study period. If they chose this option, the research assistant linked the sensor to the app and showed the participant how to use the sensor. At the initial assessment, participants were orientated to the 8-week programme and shown the exercise programme. Each exercise was demonstrated, and the participants technique checked by the physiotherapist.

Item 3B. Procedures: Describe each of the procedures, activities, and/or processes used in the intervention, including any enabling or support activities.

Centre based PR

Participants who opted for the centre-based intervention were to attend the centre two days per week for eight weeks. The intervention included one hour of supervised exercise training in a group setting delivered by a multidisciplinary team. Exercise prescription included aerobic, resistance and balance exercises individually prescribed and completed in a circuit programme. Participants were provided with a home-based exercise programme, which they were asked to complete three times per week and record in the provided activity diary. In addition, participants were encouraged to attend a 30-minute group education session with focus on self-management education. The centre-based PR intervention follows standard clinical practise.

mPR

mPR participants were to complete an 8-week home-based PR programme delivered through mHealth (mPR). All exercises were demonstrated to participants at the baseline assessment and technique checked for safety by the PR physiotherapist. Participants had the option of an alternative exercise if one or more of the exercises were difficult or caused discomfort. Completion of the exercises was recorded in the mPR-app and participants could track their exercise completion via the 'my progress page'. Participants in the mPR group received self-management education via self-directed modules on the mPR-app and daily SMS messages. The content of the self-management education was developed and reviewed by the multi-disciplinary team who were involved in the delivery of the centre-based programme.

SECTION 4. WHEN

* Item 4. Describe the timing of the intervention in relation to the onset/stage of condition and/or other relevant events.

All participants referred to and eligible for PR were offered the opportunity to participate and given the choice of centre-based or mHealth deliver (mPR) PR. Participants with mild, moderate and severe CRD were included.

The three recruiting centres each had waiting lists of people for PR and this varied from 6 weeks to 5 months in duration.

SECTION 5. WHO PROVIDED

Item 5. For each category of intervention provider (e.g., psychologist, nursing assistant), describe their expertise, background and any specific training given.

The initial assessment was completed by a respiratory nurse specialist (minimum five years' experience) and an experienced physiotherapist (minimum 3 years' experience). Two research assistants (RA), both with prior research experience assisted in the trial.

A two-hour in person training workshop was held prior to the commencement of the trial for all staff involved in the research. This training ensured all the staff were familiar with their roles and responsibilities for the ethical and safe implementation of the study.

SECTION 6. HOW

Item 6A. Modes: Describe the modes of delivery (e.g., face-to-face or by some other mechanism, such as internet or telephone) of the intervention and whether it was provided individually or in a group.

Centre-based.

The exercise component was conducted in groups of ten to twelve participants and involved a circuit class. Exercises were individually prescribed based on initial assessment. Each group was supervised by a minimum of three staff members (physiotherapists/nurses).

mPR

The mPR group had the choice of SMS with paper manual, mPR-app and a wearable sensor. The mPR-app is a progressive web app and could be accessed on a mobile phone, tablet or computer. Participants could download the mPR-app to more than one device. All participants received a daily SMS.

* Item 6B. Strategies: Describe the strategies used to optimise the delivery of the intervention for individuals or groups.

Centre-based PR is standard practise and follows best practise guidelines.

The mPR programme included daily SMS to participants which were personalised and positively framed, aiming to encourage and support participants with their programme.

SECTION 7. WHERE

* Item 7. Describe the type(s) of environment(s) where the intervention occurred, including any necessary infrastructure or relevant features.

All participants completed an initial assessment at a location provided by the recruiting centre. For the centre-based group the intervention occurred at the same site as the assessment and included community sports facilities, community gym and hospital outpatient departments.

The mPR group completed all the intervention at home.

The follow-up assessment was completed at the same site as initial assessment for both groups until COVID-19 restrictions were implemented and were completed via telephone during this period.

SECTION 8. HOW MUCH

* Item 8A. Session(s) duration: provide the planned session(s) duration of the intervention.

For both groups the intervention was 8 weeks in duration.

The centre-based group attended twice per week and each session was 90 minutes in duration. This included 60 minutes of exercise and 30 minutes of education. Participants were asked to complete a home-based programme on another three days per week and the programme took approx. 30 minutes to complete.

The mPR group exercise programme took between 45 to 60 minutes to complete. This was to be completed on five days of the week. Participants could complete the exercise on any day or time which suited their schedule. They were encouraged to view all the modules on the tips and tools page but advised they could do this at any time over the 8 weeks.

During the COVID-19 restrictions, centre-based participants were offered telephone or videoconference (zoom) based options. The telephone calls were once weekly and lasted between 20 and 40 minutes. The zoom exercise class was twice weekly for 60 – 90 minutes in duration.

* Item 8B. Essential element(s) duration: provide the planned duration for engaging with essential element(s) of the intervention.

The intervention was 8-weeks in duration but could be paused if unwell. Therefore, participants had up to 12-weeks to complete in both groups.

* Item 8C. Frequency: provide the planned frequency of the intervention.

Twice weekly to centre-based, with 3 home-based exercise sessions encouraged.

Five times per week for mPR.

* Item 8D. Intervention length: provide the planned overall length of the intervention.

SECTION 9. HOW CHALLENGING

* Item 9. Describe the method used to measure and set the intervention challenge. Provide information on the reliability and validity of the method used.

For the centre-based group intensity of exercise is prescribed based on the modified BORG breathlessness scale with all participants encouraged to progress exercise to maintain a breathlessness score of 3 – 4 (Crisafulli & Clini, 2010)

The mPR group also used the BORG breathlessness scale as a guide of intensity. This was taught to participants in the initial assessment and further information on the scale was provided in the paper manual provided and on the mPR-app tips and tools page.

SECTION 10. REGRESSION/PROGRESSION

* Item 10. Describe <u>when</u> and <u>how</u> the planned regression or progression of dosage parameter(s) was implemented.

<u>Centre-based</u>

The centre-based programme was reviewed and progressed at midway point by the site physiotherapist.

<u>mPR</u>

Participants were sent a SMS at the end of each week asking them if they were ready to progress their exercise programme. If they answered Yes, a progressed exercise plan was sent, if they replied NO the same exercise plan was sent via SMS and available on the mPR-app. The exercise progression was duration of aerobic exercise one week and number of resistance exercises the alternate week. At the midway point, the exercises changed, and new exercises were prescribed.

SECTION 11. PERSONALISATION

* Item 11. Describe the way(s) in which the intervention was planned to be adapted for personal preferences.

<u>mPR</u>

Each participant enrolled in the mPR programme received a personally tailored package of text messages over the 8-week period, in addition to mPR-app. The programme consisted of different modules to allow content to be tailored to individual clinical characteristics, preferences and demographics. All participants received a core programme. In addition, optional modules were available for smokers, participants with low BMI and participants with retained or excess respiratory secretions.

SECTION 12. PROTOCOL DEVIATION

* Item 12. If there were deviation(s) in the intervention protocol during the course of the study, describe the changes (what, why, when, and how).

Sample size.

Due to COVID-19 restrictions recruitment was stopped early. The target sample size was 50 in the smallest group and at recruitment end there were 67 centre-based and 38 mPR.

Intervention

Part way through the study period, National restrictions were imposed due to the COVID-19 pandemic meaning face-to-face research and all centre-based services were required to pivot to telehealth options. Following consultation with the primary research team (DT, JR, RW, RD, EU SC) the following deviations from the protocol were implemented:

- Centre-based PR (standard care): all participants were contacted and offered whatever home-based options their study centre provided, which were either via weekly telephone calls or twice weekly teleconference class. These interventions continued until participants had completed their eight-week PR programme. The video conference classes were 60 minutes in duration and included warm up and cool downs plus, aerobic, resistance and balance exercises. The intensity of exercises was based on BORG dyspnoea scale as had been used in the centre-based programme. Telephone calls were made by a member of the PR team and included a review of home-based exercise programme and discussion around the self-management education topics. Additional information was sent to patients in paper copy or via email.
- mPR: An additional ad hoc SMS message was sent to all participants during the national restrictions. There were no others changes to the mPR intervention.

Outcome Measures

The follow-up assessment was completed over the telephone which meant the exercise capacity (6-minute walk test and one minute sit to stand) could not be assessed.

SECTION 13. HOW WELL

* Item 13A. Plan: If intervention engagement, adherence and/or fidelity was assessed, describe how and by whom, and if any strategies were used to maintain or improve fidelity, describe them.

Centre-based PR

If a participant was unwell or unable to attend the programme, they could pause the programme. They had a maximum of 12 weeks to complete the programme. The number of sessions they attended was recorded (out of a maximum of 16) and the number of sessions they missed (DNA). After 12 weeks the reassessment was completed independent of the number of sessions attended.

If a participant did not attend two sessions in a row without pausing the programme, they were called by a staff member. If they did not attend a further two sessions, a second phone call was made.

If the participant did not attend, they were still called at the end of the eight weeks and invited to complete a follow-up assessment. If the participant declined the follow up assessment or was unable to be contacted, they were considered lost to follow up.

mPR

If participants were unwell or unable to complete the programme, they could pause the intervention. They had a maximum of 12 weeks to complete the programme. Attendance in the mPR programme was recorded as the number of messages participants replied to during the 8-week intervention (out of a maximum of 16). Participants were advised they are to reply to TWO question messages per week (number of times they have completed exercises, and ready to progress exercise programme).

If the participant did not reply to either of the SMS messages which require response in week ONE they received an ad hoc SMS reminding them to reply. If the participant was unwell, they were reminded they can pause the programme.

If they still did not reply to the SMS a second ad-hoc message was sent.

If the participant replied to the messages at week one but did not reply to two consecutive messages on a later week, they received one ad-hoc SMS reminding them to reply. If the participant still did not reply they were called at the end of the eight weeks and invited to complete a follow up assessment.

If the participant declined the follow up assessment or was unable to be contacted the participant was considered lost to follow up.

* Item 13B. Actual: If intervention engagement, adherence and/or fidelity was assessed, describe the extent to which the intervention was delivered as planned.

SECTION 14. ADVERSE EVENTS

* Item 14A. Plan: Describe the monitoring and reporting of adverse events.

All participating centres and staff were advised of the adverse events reporting process. This required immediate communication with the principal investigator and documentation of the incident. An adverse events register was set up in the trial manual.

* Item 14B. Actual: Describe the number and seriousness of adverse events that occurred, and their relatedness to the intervention.

One serious adverse event occurred during the trial period. One participant from the mPR group fell while out walking and injured her shoulder. The participant was unable to complete the intervention but was able to complete the follow-up assessment.

Appendix Z. Sampling Framework

Characteristic	**Levels**			
Age	<50	50 -80	> 80	
Ethnicity	Māori	Pacific	Asian	Euro/
Working status	Working	Not working		
Smoking status	Current	Ex	Never	
MMRC	4	3	2	1-0
Exercise tolerance	<200m	200 – 400	> 400m	
Distance travelled	> 40 min	40 – 20	< 20 mi	

Appendix AA. Semi-Structured Interview Guide

Semi structured interview question guide

The questions below serve as examples of the kinds of prompts we might use to encourage the participant to talk about their experiences and opinions. These prompts will only be used as required. The interview will focus on participant reports of perceptions of the pulmonary rehabilitation programme and their experience attending in using mPR.

The following interviews will be audio recorded and transcribed verbatim.

1. Please describe why you choose to do the mobile version of PR (mPR)?

   Access, cost, transport, time of day, I don't like groups.

   Were there any other factors / reasons …

2. What did you think about the mPR programme?

   Why did you think …. tell me a bit more about that …

   What did you think about the content of mPR, information, vidoes…

   What did you think about the exercises, progression...?

   Why did you think about using your phone/computer/sensor etc…?

   2a What did you like about the programme?

   Content… Exercise, education, suitability, support, effectiveness

   Technology… sensor (tracking), having it on my phone (accessibility)

   Family/whānau being able to do it with me

   2b What did you dislike about the programme?

   Content…. Topics

   Exercise... too easy/hard

   Technology…

   Lack of social support

   Did you have any technical issues?

   2c How easy or challenging was the PR programme to do .

   a. *content – doing the exercises, (progressions) watching the videos,*
   b. *technology – finding your way around the app / progress page? Step count? answering the weekly questions.*

1. How did you use the mPR –
    a. *What parts of the programme did you use (sms, app sensor) ** explore why they did not use it ….*
    b. *When did you use it ? how often? What parts did you use the most? Did you read the messages when they came through or go back to them later?*
2. Do you have any suggestions of how we could improve the programme?
3. Can you describe the things that made it easier for you to complete PR?

4. Can you describe the things that made it harder to complete PR?
5. Would these factors still have impacted if you had done PR at the centre? Why/why not?
6. How do you think that COVID 19 and associated lockdowns have impacted your experiences with PR?
    a. *Wait times, referrals, motivated, fear of group activity, avoided previously…*
    b. *Did you engage less or more with mPR because of COVID?*
    c. *Did the lockdown impact on how you were able to do mPR, the exercise /education?*
7. *How confident are you using digital technology for your health?*

    Has mPR made you more or less confident to use technology

    Have you used health portals? COVID sites …

    Are you motivated to engage with other technology / tools…?

    Do you plan to continue to use fit bit / apps to manage your health …?

Appendix BB. Sample Coding of Qualitative Interviews

Table 8. Coding framework

Code	Description	Example
Flexibility	Being able to fit in around work commitments	*Being able to do exercise in own time when suits…. Break up the exercises rather than doing all at once to fit in with own timetable*… F 87
	Being able to break into chunks and do when fits in with schedule	
	Liked being able to do at home when it suits me and to do all the exercises with my husband –	F 9
Motivation	Bridging the gap between thinking and doing	
	SMS provided reminders and motivation	M 59 SMS helped me keep my mind on the job, when I got a message it reminded me to do my exercise
	Some people get motivation from going to the centre, others can be motivated at home with the encouragement from SMS	M
	Motivated – pushed me	F 87 Made me exercise cant stop now, cant go back to where I was F Broke exercises up… some at work and some at home
	F 100 When I open it up and get the little message this is such a great incentive….	
Family / whanua	Doing exercises with husband	
	Family learning about condition and how to help/support	
	Wanted to do the exercises with daughter and then when she got a job and could not do them, he was unable to complete the intervention	
Improved mood	Helped me psychologically	F 87 Feel a bit more alive

Code	Description	Example
Improved fitness		F 87 Feel fitter … and I can do more now …
	Maggie 100 Not one for exercise before … had all this equipment… but I just could not be bothered.	
Connected Supported		
Clinician touch points	Would have been good to know I was doing the exercises correctly	F 100
	The exercises progressed too hard… so stopped doing it After I came out of hospital, I was not sure…	
		M 59 Thought the text messages were great, but maybe the odd phone call, once a week would have been beneficial…. F Did not need HCP to contact me … I was happy with doing it on my own …
	A phone call at the end of the week to talk about how you have done and progressed… More personal interaction	M35 … more interaction from HCP would either give incentve for doing it or why have you not done it …
	More personal contact for mpR would be good. Phone calls or home visits would be encouraging	Its up to the individual F 52
Engagement		F Did the exercises, not every day
Impacts of COVID	Feeling vulnerable, “fearful”	M 59
	Uncertain times	M59 F 92 – could not make plans…. Would like to go see son or niece in whangamata… can’t make plans…
	Less active	F 92 Less active – less walking, not able to go to shopping mall and walk like I used to…

Code	Description	Example
	Lonely	F 92
Managing condition		M59, "Its put me in a good space as far as my health goes…. Wish I had done it earlier" Vanessa Handy, informative, keeps me on track with what I was doing
Staff		
Exercise is hard		F liked the exercises, not too easy or too hard.
Exercises broken up …		F Some at home and some at work
Usability of mPR app	Easy to use	F 92 Pretty easy to use… able to work out to do it…
Digital literacy	Used computer at work	F 92
	Not really interested in technology – prefer paper works and paper herald	F 92
	Used computer… little bits and pieces, basics / beginner	F87
	Could not reply to the txt messages	M105
	Confident with technology and interested in it … that is why he wanted to do mPR along with the convenience	M 35
SMS	Dosage	
	Helped with physical and mental	F 87
	The text messages were not linked to what I was doing, if I was being monitored and you could see my activity levels then you would not have sent some of the messages	M 35
	Questions came at the wrong time - before the week was finished	M 35
	Being able to do after hours, messages reminded me, flexibility to do in my own time	F 29
		F Wore it all the time… motivated by step counter and checked heart rate.

Code	Description	Example
Tips and tricks		Watched videos as well as read the information…
Why mPR	*Access, cost, transport, time of day*, I don't like groups.	F 52
	I thought I would do the programme at home with my daughter and that she would be able to help me. She got a job and was not at home and I could not work out how to send a text message or to open the app.	M24

Appendix BC Consolidated criteria for report qualitative research (COREQ) Guidelines

Item no.	**Topic**	**Guide Questions/Description**	**Reported on page no.**
Domain One Research team and reflexivity			
1.	Interviewer/facilitator	Which author conducted the interview or focus group?	136
2.	Credentials	What were the researchers credentials?	136
3.	Occupation	What was their occupation at the time of the study?	136
4.	Gender	Was the researcher male or female	136
5.	Experience and training	What experience or training did the researcher have?	136
6.	Relationship established	Was the relationship established prior to the study commencement?	136
7.	Participant knowledge of the interviewer	What did the participant know about the research? Eg. Personal goals, reasons for doing the research?	138
8.	Interviewers characteristics	What characteristics were reported about the interviewer/facilitator? Bias,	138

		assumptions, reasons and interests in the research topic.	
Domain Two Study Design			
9.	Methodological orientation and theory	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	139
10.	Sampling	How were participants selected? e.g. purposive, convenience, consecutive, snowball	136, 137
11.	Method of approach	How were participants approached? e.g. face-to-face, telephone, mail, email	136
12.	Sample size	How many participants were in the study?	138
13.	Non-participation	How many people refused to participate or dropped out? Reasons?	138

14.	Setting of data collection	Where was the data collected? e.g. home, clinic, workplace	136
15.	Presence of non-participants	Was anyone else present besides the participants and researchers?	n/a
16.	Description of sample	What are the important characteristics of the sample? e.g. demographic data, date	137
17.	Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested?	136
18.	Repeat interviews	Were repeat inter views carried out? If yes, how many?	n/a
19	Audio/visual recordings	Did the research use audio or visual recording to collect the data?	137
20.	Field notes	Were field notes made during and/or after the interview or focus group?	n/a
21.	Duration	What was the duration of the inter views or focus group?	136
22.	Data saturation	Was data saturation discussed?	

23.	Transcripts returned	Were transcripts returned to participants for comment and/or correction?	
Domain Three Analysis and findings			
24.	Number of data codes	How many data coders coded the data?	137
25.	Description of coding tree	Did authors provide a description of the coding tree?	137
26.	Derivation of themes	Were themes identified in advance or derived from the data?	137
27.	Software	What software, if applicable, was used to manage the data?	137
28.	Participant checking	Did participants provide feedback on the findings?	
29.	Quotations present	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	140
30.	Data and findings consistent	Was there consistency between the data presented and the findings?	142

31.	Clarity of major themes	Were major themes clearly presented in the findings?	142
32.	Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?	145

Developed from; Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (CREQ): a 32 item checklist for interviews and focus groups. *International Journal for Quality in Health Care.* 2007. Volume 19, Number 6: pp 349-357.