# Barriers and facilitators to providing pulmonary rehabilitation to individuals from culturally and linguistically diverse backgrounds

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### **Abstract**

Pulmonary rehabilitation is effective in improving health outcomes in individuals with Chronic Obstructive Pulmonary Disease (COPD), as well as many other chronic respiratory diseases. It is recommended that all Australians with COPD who experience dyspnoea, or shortness of breath, should be offered pulmonary rehabilitation. However, despite growing cultural diversity within the Australian population, the impact of this diversity on access to, and participation in, pulmonary rehabilitation has not been investigated. Therefore, the aim of this study was to investigate the referral and participation rates of individuals from culturally and linguistically diverse (CALD) backgrounds in pulmonary rehabilitation programs in Sydney, Australia, as well as potential barriers and facilitators to providing pulmonary rehabilitation to these individuals.

This was a mixed methods study, using a sequential, qualitative dominant, participant-selection variant of explanatory design. Participants were coordinators of pulmonary rehabilitation programs in the Sydney metropolitan area. Stage one of the study involved a primarily quantitative web-based survey, stage two used semi-structured interviews to gain in-depth qualitative information, and stage three involved the integration of quantitative and qualitative data to provide a detailed analysis of the key outcomes.

All participants reported that their program received referrals of individuals from CALD backgrounds, including individuals from a diverse range of cultural

backgrounds, although the numbers of referrals varied between programs. Interpreters were often used for initial assessments of individuals with limited English proficiency, however were not often used for exercise classes or final assessments. Barriers identified by participants included cultural factors that programs were not able to accommodate, communication difficulties, challenges using interpreters, and resource limitations. The use of alternate methods of communication, engaging family support, and optimising utilisation of interpreters were identified as potential facilitators.

This study identified that whilst many individuals from CALD backgrounds are referred to pulmonary rehabilitation there are a number of potential barriers to providing pulmonary rehabilitation to these individuals limiting optimal participation. A greater understanding of these barriers, and the harnessing of potential facilitators, such as the development of resources and innovative service delivery models, may help to improve the participation of individuals from CALD backgrounds in pulmonary rehabilitation.

**Statement of Candidate** 

I, Elizabeth Havyatt, hereby declare that the work contained within this Thesis,

Barriers and facilitators to providing pulmonary rehabilitation to individuals from

culturally and linguistically diverse backgrounds, is my own and has not been

submitted to any other university or institution, in part or in whole, as a

requirement of a degree.

I, Elizabeth Havyatt, also hereby declare that this Thesis is an original piece of

work and it is written by me. Any assistance that I have received in the

preparation of this Thesis has been appropriately acknowledged. In addition, I also

certify that all information sources and literature used are indicated in this Thesis.

Date: 1/10/2018

E. K. Maryatt

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## **List of Abbreviations**

CALD Culturally and linguistically diverse

COPD Chronic obstructive pulmonary disease

 $FEV_1$  Forced expiratory volume in one second

 $FEV_1/FVC$  Forced expiratory volume in one second/Forced vital capacity

### **CHAPTER 1**

### Introduction

#### 1.1 Introduction

Pulmonary rehabilitation is a comprehensive program for individuals with chronic respiratory diseases, and has been shown to be effective in improving health outcomes in many respiratory diseases [1]. Pulmonary rehabilitation is one of the most important components of the management of chronic obstructive pulmonary disease (COPD), with the COPD-X Plan, the guidelines for COPD management in Australia and New Zealand, recommending that pulmonary rehabilitation be offered to individuals with COPD who experience shortness of breath on exertion, and that it can also benefit those with other chronic respiratory disorders who experience dyspnoea [2]. Additionally, it is also recommended that pulmonary rehabilitation be offered to individuals following an exacerbation of COPD requiring hospitalisation [2].

Whilst the benefits of pulmonary rehabilitation have been well documented, research to date has not considered cultural diversity, and how this may impact pulmonary rehabilitation participation. Little is known about providing pulmonary rehabilitation to individuals from culturally and linguistically diverse (CALD) backgrounds, the effectiveness of pulmonary rehabilitation for these

individuals and any potential barriers and/or facilitators to providing pulmonary rehabilitation to this group.

### 1.2 Pulmonary rehabilitation

### 1.2.1 What is pulmonary rehabilitation?

Pulmonary rehabilitation includes exercise, education and self-management support [1]. The main component of pulmonary rehabilitation is exercise training, including both endurance and resistance exercises [1]. Pulmonary rehabilitation programs in Australia typically include two supervised exercise sessions a week for a period of eight weeks [3], although there are variations to this pattern of delivery. Pulmonary rehabilitation programs may also include structured education programs covering topics such as the benefits of exercise, managing breathlessness and coping with lung disease, as well as providing individual education throughout the program as required [4].

#### 1.2.2 Efficacy of pulmonary rehabilitation

Pulmonary rehabilitation has been shown to be effective in individuals with COPD, improving an individual's sense of control over their condition, reducing symptoms of dyspnoea and fatigue, and improving exercise capacity [5]. It has also been shown to be effective in reducing hospital readmissions following an exacerbation [6]. Further, it has been shown to improve exercise capacity and quality of life in individuals with interstitial lung disease [7], and in those with bronchiectasis [8]. There is also evidence for the effectiveness of pulmonary

rehabilitation in individuals with cystic fibrosis, asthma, pulmonary hypertension, lung cancer, lung volume reduction surgery and lung transplantation [1].

#### 1.2.3 Pulmonary rehabilitation in Australia

It is estimated that the prevalence of GOLD Stage II COPD or higher (defined by an  $FEV_1/FVC$  ratio <0.70 and  $FEV_1$  <80%) in Australia is 7.5% among people aged 40 years and over, with an increase to 29.2% among people aged 75 years and over [9]. Thirty-one percent of Australians, or more than 7 million people, have a chronic lung condition including COPD, asthma, and many other conditions [10]. The high prevalence of chronic respiratory conditions means that that there is a high number of people in Australian who would be likely to benefit from pulmonary rehabilitation.

In 2017 there were 276 pulmonary rehabilitation programs in Australia listed on the Lung Foundation Australia database [11]. There were 25 pulmonary rehabilitation programs in the Sydney metropolitan area. The majority of these programs are based at public hospitals, with a small number of programs based at private hospitals [11]. Whilst the benefits of pulmonary rehabilitation and referrals guidelines are clear only 5-10% of individuals with moderate to severe COPD have accessed a pulmonary rehabilitation program [12].

# 1.3 Pulmonary rehabilitation needs in individuals from culturally and linguistically diverse backgrounds in Australia

### 1.3.1 Definition of culturally and linguistically diverse (CALD)

A high proportion of Australia's population was born overseas. In 2016 28.5% of the estimated resident population (6.9 million people) were born overseas [13]. Migrants to Australia have come from many different source countries, and as a result Australia has a highly diverse population [14]. Migrants whose cultural heritage differs from that of the Anglo-Australian culture that makes up the majority of the Australian population are often described as being from culturally and linguistically diverse (CALD) backgrounds [15]. Individuals from CALD backgrounds are, therefore, typically defined as individuals born overseas in nonmain English speaking countries [16].

#### 1.3.2 CALD populations in Australia

Individuals migrate to Australia from many different countries. In 2016 the top ten countries of birth of Australia's overseas-born population were, in order, the United Kingdom, New Zealand, China, India, Philippines, Vietnam, Italy, South Africa, Malaysia and Germany [13]. Many migrants to Australia come from non-English speaking countries and may have limited English skills. In Australia 21% of people speak a language other than English at home, with Mandarin, Arabic, Cantonese and Vietnamese being the most common languages after English [14].

People migrate for various reasons, including better educational and employment opportunities; to flee from war, persecution, terrorism or other disasters; or to join relatives who have migrated previously [17]. The main source countries of migrants to Australia have changed over time with changes to migration policies [18]. In recent years there has been an increase in migrants from Southern Asia and Chinese Asia, and a decline in the proportion of migrants from the United Kingdom [19]. In 2016-2017 the ten most common source countries of migrants (excluding New Zealand citizens who are not included in the migration program) were India, China, the United Kingdom, Philippines, Pakistan, Vietnam, South Africa, Nepal, Malaysia, and the Irish Republic [19].

The acceptance of humanitarian migrants has also influenced the patterns of migration to Australia. Over time the origins of refugees have changed, reflecting the changes in global conflicts or other crises in their home country. For example, many refugees arrived from Europe in the first two decades following World War II, whilst from 1975 to 1996 Australia resettled approximately 150,000 individuals of Indochinese origin [20]. In 2016-2017 the top five countries of birth for individuals granted visas under Australia's Humanitarian Programme were Iraq, Syria, Afghanistan, Myanmar and Bhutan [21].

Australian residents born overseas are more likely to live in major urban areas with half of all migrants living in Sydney or Melbourne [22]. Sydney has the largest migrant population in Australia; which, at the time of the 2016 Census, included over two million residents who were born overseas [23]. The most common

countries of origin of migrants residing in Sydney are China, the United Kingdom, India, New Zealand and Vietnam [23].

### 1.3.3 Health of individuals from CALD backgrounds in Australia

Migrants to Australia are commonly healthier than the Australian-born population; this is known as the healthy migrant (or immigrant) effect [24, 25]. However, the health of individuals migrating to Australia is strongly related to their visa status. Whilst many migrants are healthier than the Australian-born population humanitarian migrants and those on family stream visas have poorer health than those on skill stream visas [34].

The healthy migrant effect may be explained by the government selection process, with eligibility criteria including health requirements, as well as self-selection with those who are sick or disabled often less able to migrate [26]. This effect is even more marked in migrants from non-English speaking countries who report better health on arrival than immigrants from English speaking countries whose health is closer to that of the Australian-born population; this may be related to the migrant selection process or other factors common to migrants from non-English speaking countries [27].

Whilst on arrival migrants are healthier than the Australian-born population, their health moves towards that of the Australian-born population the longer they stay in their new country [27]. There are many potential reasons for this decline in health, including persistent difficulties in accessing healthcare services,

discrimination, and stress associated with migration and adapting to a new country [28]. Migrants also tend to be relatively young at the time of migration [29] and as they age they may experience a decline in health. With the young migrants who came to Australia following World War II now ageing the loss of this healthy migrant effect may become more evident [30]. Another possible reason for this decline in health is acculturation, through adopting behaviours of the Australian born population that negatively affect health [28]. For example, the traditional diets of some countries may be healthier and dietary changes with acculturation could have negative effects on health [31]. It may be appropriate to encourage some migrants to maintain traditional values as these can protect their health.

Social disadvantage may also contribute to poor health in migrants. Migrants to Australia are more likely to be unemployed than people born in Australia [32]. Unemployment is one example of social disadvantage that contributes to poor health, as unemployed people have more physical and mental illness than people of a similar age who are employed [33].

Refugees have poorer health status and more complex health needs [24], and chronic diseases may be undiagnosed or undertreated in refugees due to disrupted healthcare in their country of origin [35]. Migrants on humanitarian visas are more likely to have lower levels of English proficiency [29], which may lead to difficulty accessing healthcare services and understanding information when they do access these services.

Some groups of migrants may be at increased risks of poor health because of lifestyle factors, such as higher smoking rates, which are more prevalent in their home countries than in Australia [26]. For example, there are higher rates of smoking among men born in Europe, North Africa and the Middle East than men born in Australia [36], and this could increase risk of respiratory diseases within these individuals.

### 1.3.4 COPD in individuals from CALD backgrounds in Australia

According to Australian Bureau of Statistics data 2.6% of Australians across all age groups have COPD. In the Australian born population 2.7% of people have COPD, with 2.3% of those born overseas having COPD [37]. When those individuals born overseas are examined in more detail 3.2% of individuals who were born in main English speaking countries have COPD compared to 1.9% of those born in other than main English speaking countries [37]. Individuals who speak English at home have a higher proportion of COPD at 2.8%, as opposed to 1.5% of those who speak a language other than English at home. In considering this data, it is unclear whether the actual levels of COPD are lower in individuals from CALD backgrounds, or whether the level of diagnosed COPD is lower as individuals from non-English speaking backgrounds may have difficulty accessing healthcare [24].

In relation to time since arrival in Australia, 3.3% of individuals who arrived in Australia prior to 2006 have COPD, as opposed to 0.6% of those arriving between 2006-2010, and 0.2% of those arriving between 2011-2015 [37]. This reflects the insidious nature of COPD with diagnosis higher in those who are older [9] whilst

recent migrants are more likely to be younger in age [29]. However, given these statistics, it is therefore likely that there are many individuals from CALD backgrounds in Australia who would benefit from pulmonary rehabilitation, with this likely to increase the longer they live in Australia.

# 1.4 Pulmonary rehabilitation for individuals from CALD backgrounds

# 1.4.1 Evidence for pulmonary rehabilitation in individuals from CALD backgrounds

Despite the known benefits of pulmonary rehabilitation, there is currently no published research on the provision of pulmonary rehabilitation to individuals from CALD backgrounds in Australia and the efficacy of pulmonary rehabilitation in these individuals is unknown. There is, however, literature on similar programs that provide exercise for the purpose of managing chronic disease or reducing the risk of chronic disease, with or without an education component, to individuals from CALD backgrounds in English-speaking countries. For example, there is evidence that general exercise programs and cardiac rehabilitation can be effective in individuals from CALD backgrounds. This literature may give some insight into potential issues in delivering pulmonary rehabilitation to individuals from CALD backgrounds.

Exercise programs provided to individuals from CALD backgrounds have been shown to be effective, leading to improvements in health status. These programs have been designed to be culturally appropriate and may be delivered in the

participants' own language or with the use of interpreters. A program targeted at improving cardiovascular health of Greek-Australian women, which included exercise and education components, was shown to have benefits in cardiovascular fitness and weight loss in participants, with a sustained increase in exercise following completion of the program [38]. In a similar study conducted with Macedonian-Australian women participants experienced benefits cardiovascular fitness and weight loss [39], whilst in Boston, USA, participants of Chinese background who received gym memberships as well as weekly education sessions showed health benefits including weight loss, improvements in blood pressure and improvements in strength [40]. In a study conducted in Ontario, Canada, South Asian Muslim women attended 1-hour exercise sessions held at a mosque, up to three times a week over a 24-week period. The intervention resulted in improved exercise self-efficacy in participants, and a greater number of participants meeting the physical activity guidelines [41].

Individuals from CALD backgrounds who have participated in exercise programs have shown satisfaction with these programs and felt that the programs were beneficial. Individuals from CALD backgrounds who participated in cardiac rehabilitation reported satisfaction with the program, had high attendance rates and engaged in the program [42]. Cardiac rehabilitation has also been seen by participants from CALD backgrounds to be beneficial in helping them to better understand their condition, give participants an opportunity to discuss their health with healthcare professionals, and provide peer support [43].

# 1.4.2 Current participation by individuals from CALD backgrounds in pulmonary rehabilitation in Australia

The participation rate of individuals from CALD backgrounds in pulmonary rehabilitation in Australia is unknown. However, research suggests that individuals from CALD backgrounds may be less likely to participate in cardiac rehabilitation. In an Australian study, health providers reported that cardiac rehabilitation uptake was poor, and this was more so in individuals from CALD backgrounds [44].

# 1.5 Barriers and facilitators in the provision of pulmonary rehabilitation to individuals from CALD backgrounds

# 1.5.1 Barriers to individuals from CALD backgrounds participating in pulmonary rehabilitation

Barriers to accessing pulmonary rehabilitation have been documented previously and include transport difficulties, not seeing the program to be beneficial and competing demands for time [45]. Individuals may also decline to participate in pulmonary rehabilitation as they feel they are not physically capable or because they believe they are too well to need the program [46]. Whilst the barriers to accessing pulmonary rehabilitation generally have been investigated they have not been specifically researched in individuals from CALD backgrounds. Research on barriers to individuals from CALD backgrounds accessing healthcare, and particularly on barriers to these individuals from accessing chronic disease management programs, may give insight into potential barriers to providing pulmonary rehabilitation to individuals from CALD backgrounds.

Individuals from CALD backgrounds face many potential additional, different and/or amplified challenges to accessing healthcare in Australia for a variety of reasons. The most common challenge reported in accessing healthcare is language [24]. Migrants may have difficulty communicating with health providers and/or may not understand information given by healthcare providers [47, 48]. Migrants who have limited English skills benefit from the use of interpreters, however they are not always sure how to access interpreters and there may also be limited availability of interpreters [48]. Migrants may also have difficulty accessing healthcare as they do not understand the complexities of the Australian health system, which is often very different in nature to that of their country of birth [49]. This, combined with a language barrier [50], makes accessing the Australian healthcare system challenging for individuals from CALD backgrounds.

Some barriers to providing exercise programs specifically to individuals from CALD backgrounds have been identified. A common barrier to attending programs was language and a lack of resources for overcoming this. For example, a number of Punjabi-speaking individuals attending a cardiac rehabilitation program reported this to be a barrier, where finite resources limited the number of Punjabi-speaking practitioners available to participants. Punjabi-speaking participants who were not able to speak with a Punjabi-speaking practitioner reported that they were not able to fully understand the education that was provided to them in English [43]. Limitations in the availability of interpreters and a lack of translated resources were identified by health professionals as barriers in providing cardiac rehabilitation to individuals from CALD backgrounds [44].

Transportation was also identified as a barrier to attending cardiac rehabilitation [43, 51]. Whilst transportation is a common barrier to attending cardiac rehabilitation generally it was seen as a more significant barrier amongst individuals from CALD backgrounds as they are more likely to have difficulty in finding the program or using public transport due to the language barrier [44].

Cultural differences are also an important barrier to individuals from CALD backgrounds participating in exercise programs. Programs that are not designed specifically for individuals from CALD backgrounds may at times be culturally inappropriate. For example, for religious or cultural reasons it may not be appropriate for females to exercise with males, preventing these participants from attending the program [44, 51]. Cultural differences may also impact on behaviour modifications in individuals from CALD backgrounds. It may be harder for providers to give individuals education that is culturally appropriate, such as understanding an individual's dietary preferences when giving dietary advice, or understanding family and social support and how this impacts on an individual's ability and willingness to modify their behaviour [44].

# 1.5.2 Facilitators to individuals from CALD backgrounds participating in pulmonary rehabilitation

Whilst some barriers have been identified, a number of factors that may facilitate the participation of individuals from CALD backgrounds in exercise programs have also been described. As the language barrier is commonly identified as a barrier, the use of interpreters or bilingual staff is reported to be beneficial to

individuals attending these programs [38, 40]. It is also important for the program is held at a suitable location that is easy for participants to attend [40, 52], limiting the impact of transport as a barrier.

Family and other support networks may be of greater importance in some cultures, and their experiences with these programs may help to encourage an individual to attend [42]. In some cultures advice from doctors is held in very high regard, and individuals from these cultures are more likely to participate in an exercise program when it has been recommended to them by their doctor [42]. Input from individuals from CALD backgrounds may also be beneficial to gain a greater understanding of their culture and identify changes that can be made to make programs more culturally appropriate [53]. For example, rather than simply translating information, more substantial changes to the way this information is provided may be required.

Although some potential facilitators have been identified, these may not be relevant in different locations, or in individuals from different cultural backgrounds. Effectiveness of certain facilitators may also be dependent on the structure of the program being provided. It is therefore important to gain a greater understanding of facilitators specific to location, cultural factors and the program being provided.

### 1.6 Study aims

Whilst the benefits of pulmonary rehabilitation have been well demonstrated, there is currently no research regarding pulmonary rehabilitation participation for individuals from CALD backgrounds. There is evidence that individuals from CALD backgrounds can benefit from chronic disease exercise programs, however there are also potential barriers to attending these programs. Although it may be hypothesised that similar challenges are encountered in the delivery of pulmonary rehabilitation for individuals from CALD populations, research into the barriers, and potential facilitators, of access to pulmonary rehabilitation specifically by individuals from CALD populations will help to identify the best way to deliver pulmonary rehabilitation to these individuals.

The aims of this study were to answer the following questions:

- 1. What are the referral and participation rates of individuals from CALD populations in pulmonary rehabilitation programs in Sydney, Australia?
- 2. What do health professionals working in pulmonary rehabilitation in the Sydney metropolitan area see as the barriers to providing pulmonary rehabilitation to individuals from CALD populations?
- 3. Do health professionals working in pulmonary rehabilitation in the Sydney metropolitan area recognise any potential facilitators to participation by individuals from CALD populations in pulmonary rehabilitation programs, and to what extent have these been successfully utilised?

### **CHAPTER 2**

# Methodology

### 2.1 Setting

The geographic setting of this study was the metropolitan area of Sydney, Australia. Australian residents born overseas are more likely to live in major urban areas with half of all migrants living in Sydney or Melbourne [22]. Sydney has the largest migrant population; at the time of the 2016 Census two million residents of Sydney were born overseas [23].

### 2.2 Participants and Recruitment

Coordinators from all eligible pulmonary rehabilitation programs in the Sydney metropolitan area were invited to take part in the study. To be eligible for the study the pulmonary rehabilitation program must be a non-cultural specific program that is conducted in English. Programs conducted in a language other than English were excluded from the study as they are accessible only to a very specific population group, and are not reflective of the diversity of Sydney's population, or of the majority of pulmonary rehabilitation programs. Programs were also excluded if they consisted of an unconventional format that is likely to impact on access and/or participation by specific groups. This study was approved by the Macquarie University Human Research Ethics Committee (Medicine and Health Sciences) (Reference number 5201700638).

There were 25 pulmonary rehabilitation programs in Sydney listed on the Lung Foundation Australia database of pulmonary rehabilitation programs in Australia [11]. Initial details for these programs, including the identification of each program coordinator, were obtained from this database. Program coordinators from all eligible pulmonary rehabilitation programs were then contacted by email and invited to take part in the study. Coordinators who did not respond to the initial email inviting them to participate in the survey were sent reminder emails. Consent was obtained using an electronic consent form prior to participants accessing the survey, with participants in stage two completing an additional consent form via email.

### 2.3 Study Design

This study was conducted using a mixed methods approach. A sequential, qualitative dominant, participant-selection variant of explanatory design [54] was utilised to gain both a quantitative measure of the extent of referral and participation as well as an in-depth understanding of the issues related to delivering pulmonary rehabilitation to individuals from CALD backgrounds. More specifically, this study consisted of three distinct stages: stage one consisted of a primarily quantitative survey, stage two involved qualitative interviews, and stage three involved integration of the quantitative and qualitative data.

#### 2.3.1 Stage one

In the first stage of the study, participants were surveyed using a primarily

quantitative purpose-built web-based survey. The survey was developed using *Qualtrics* Software (Qualtrics 2017, Provo, UT). This survey investigated the number of individuals from CALD backgrounds referred to, and participating in, each program, the use of interpreters, the use of family members to interpret, use of assessment tools, provision of education, barriers to participation and the development of specific resources for individuals from CALD backgrounds. Current literature on participation in pulmonary rehabilitation, and other similar rehabilitation programs, as well as discussion within the research team informed development of the survey questions. In order to enhance response rates whilst maximising the opportunity for the collection of detailed information, questions were a mixture of both closed and open-ended format. The survey was piloted with respondents similar to study participants to ensure that the wording and content of the questionnaire were appropriate to gain suitable responses [55]. The full survey can be viewed in Appendix 1.

Following the collection of the quantitative data, analysis was conducted using *IBM Statistical Package for Social Sciences (SPSS)* version 24 for Macintosh. Descriptive statistics were used to analyse all categorical variables, with presentation of frequencies, percentages and proportions. Where percentages are presented, data may not sum to exactly 100.0% due to rounding. Correlational analyses were conducted using Kendall's tau-b coefficient as this is recommended when non-parametric data is generated from a small data set with a large number of tied ranks [56]. Survey responses were not anonymous to enable the use of these responses to inform participant selection for stage two.

### 2.3.2 Stage two

The second stage of this study involved telephone interviews to gain more indepth, qualitative information from participants. Data obtained from stage one informed both the sampling and interview questions for stage two of the study. The interviews were semi-structured with a question guide (Appendix 2) to ensure desired topics were covered, but allowing the interviewer the ability to be flexible and gain more information from participants when appropriate [57]. Interview guides were developed prior to commencement of the study and reviewed by discussion amongst the investigators to assess if they remained appropriate after analysing the quantitative data with questions revised as required [58].

Participants in this stage were a nested sample of participants from the first stage of the study [57]. Purposive, intensity sampling based on the responses of the survey in the first stage of the study, was used to source participants who were likely to be able to provide more information [57]. Participants who were selected for interviews were those that had reported a higher number of referrals of individuals from CALD backgrounds to their programs in 2016, who had identified more potential barriers and/or facilitators to providing pulmonary rehabilitation to individuals from CALD backgrounds, or had reported that the referrals of individuals from CALD backgrounds to their program did not accurately reflect the area their program covered.

The sample size for this second stage was determined by data saturation when no new themes were emerging from the interviews [57]. A priority list of potential

participants for interviews was developed based on survey responses. Interviews commenced with those participants who were most likely to be able to provide more information, with further participants contacted for interviews in accordance with the priority list. Additional participants were interviewed until no new information was obtained and data saturation was achieved.

An audio recording of the interviews was made using *TapeACall Lite: Call Recorder* (Epic Enterprises), and transcribed verbatim as soon as possible following the interview. Interview transcripts were returned to the participants to check the accuracy of the transcript prior to analysis [59]. Qualitative data was analysed using *NVivo for Mac version 11.4.3*. Interview transcripts were read to develop categories for coding. The data was then coded in the appropriate categories. When there was data that did not fit a category the categories were revised and transcripts re-coded as required [57]. As data was coded into categories themes emerged, with themes altering and developing throughout the coding process. Data analysis commenced early in the interview process, to enable assessment of when no new information was being obtained from the interviews and data saturation was achieved.

### 2.3.3 Stage three

The quantitative and qualitative data were connected in the study through nested sampling [57]. Further integration occurred in stage three with the quantitative and qualitative data combined for analysis. The data was integrated by merging in domains that were explored in both stages one and two of the study [58]. These

domains included provision of education and frequency of interpreter use, which were investigated in stages one and two, and were also influenced by the themes that emerged in stage two.

Qualitative data was coded into categories using *NVivo for Mac version 11.4.3* in stage two of the study. This coding was used to identify the frequency of themes and subthemes, so that qualitative data could be transformed to quantitative data. *Microsoft Excel* was used in the integration stage to transform qualitative data to quantitative data, combine survey and interview data, and to allow side-by-side comparison of quantitative and qualitative data. Where qualitative data was transformed to quantitative form it was analysed using descriptive statistics including frequencies, percentages and proportions. Where appropriate, correlational analyses using Kendall's tau-b coefficient were conducted for deeper analysis.

### **CHAPTER 3**

### **Results – Stage 1: Quantitative Survey**

### 3.1 Participants

From the Lung Foundation database of pulmonary rehabilitation programs it was identified that there were 25 pulmonary rehabilitation programs in the Sydney metropolitan area. Of these 25 programs two were excluded from this study; one as it was delivered in Mandarin and Cantonese, and the other as it only had a water-based program and therefore did not represent a typical pulmonary rehabilitation program. Coordinators of the remaining 23 programs were invited to participate in the study. A representative from 17 of these programs participated in the study, representing a 73.9% response rate.

The demographics of the participants are outlined in Table 3.1. Fourteen (82.4%) of the participants identified their professional role as being a physiotherapist, with the remaining three (17.6%) being nurses. Fifteen (88.2%) participants achieved their qualification in Australia, with the other two (11.8%) achieving their qualification in another English speaking country. The professional experience of the participants ranged from 5 to 40 years, with a mean of 18.2 years (SD 9.9). Participants' experience in pulmonary rehabilitation ranged from 1 year to 27 years, with a mean of 12.7 years (SD 7.8). Nine (52.9%) participants had experience working in more than one pulmonary rehabilitation program. Only two (11.8%) participants spoke a language other than English to working level,

with these being Mandarin and Cantonese for one participant, and Korean for the other participant.

Table 3.1: Characteristics of participants

Characteristic	n(%) unless otherwise stated (n=17)
Professional role	
Physiotherapist	14 (82.4%)
Nurse	3 (17.6%)
Country where qualification achieved	
Australia	15 (88.2%)
Other English speaking country	2 (11.8%)
Speak a language other than English	
Yes	2 (11.8%)
No	15 (88.2%)
Years practicing (mean [range])	18.2 [5 to 40]
Years working in pulmonary rehabilitation, (mean [range])	12.7 [1 to 27]
Work in more than one pulmonary rehabilitation program	
Yes	9 (52.9%)
No	8 (47.1%)

### 3.2 Program demographics

Program demographics are displayed in Table 3.2. Fifteen participants (88.2%) reported on the number of referrals to their programs in 2016. There was a wide range in the volume of referrals, with one (5.9%) participant reporting less than 50 referrals to their program in 2016, and four (23.5%) participants reporting more than 150 referrals to their programs. Sixteen participants reported on the number of referrals of individuals from CALD backgrounds to their programs in 2016, and there was again a wide range in this with two (11.8%) programs having less than five referrals and seven (41.2%) programs having more than 30 referrals

Table 3.2: Program demographics

Table 3.2: Program demographics	
Demographic feature	n(%) unless otherwise stated (n=16)
Number of referrals in 2016 (n=15)	
Less than 50	1 (6.7%)
50-75	1 (6.7%)
76-100	2 (13.3%)
101-125	4 (26.7%)
126-150	3 (20%)
More than 150	4 (26.7%)
Number of referrals of individuals from CALD backgrounds in	
2016	
Less than 5	2 (12.5%)
5-10	5 (31.3%)
11-15	1 (6.3%)
16-20	0 (0.0%)
21-25	1 (6.3%)
26-30	0 (0.0%)
More than 30	7 (43.8%)
Number of languages other than English spoken by pulmonary	
rehab program participants	
1-5	6 (37.5%)
6-10	6 (37.5%)
More than 10	4 (25.0%)

of individuals from CALD backgrounds. Four (25.0%) out of 16 responding participants felt that the referrals of individuals from CALD backgrounds to their program did not accurately reflect the demographics of the geographical area serviced by their program. There was no significant association between the overall numbers of referrals that a program reported receiving, and the number of referrals that were for individuals from CALD backgrounds ( $r_{\pi}$  = .266, p = .231).

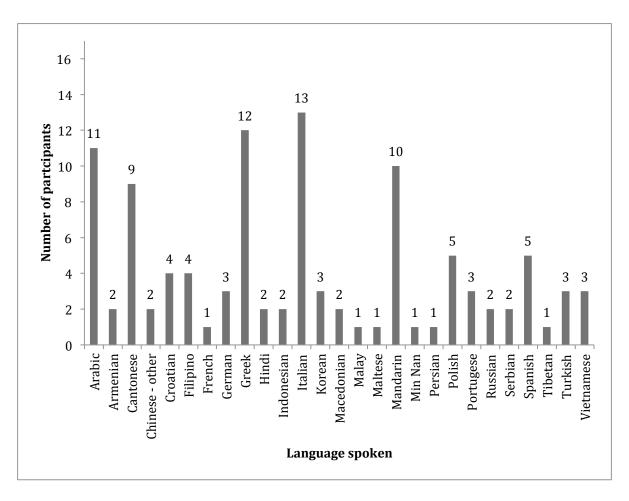


Figure 3.1: Number of participants reporting language spoken by individuals attending their pulmonary rehabilitation program

Sixteen participants reported on the languages other than English spoken by individuals referred to their pulmonary rehabilitation program in 2016; 27 different languages other than English were reported as being spoken by individuals who were referred to these programs. These are displayed in Figure 3.1. Ten (58.9%) programs reported greater than five languages other than English spoken by individuals referred to their program, as displayed in Table 3.2. The most common language reported was Italian, reported by 13 (76.5%) participants, closely followed by Greek, reported by 12 (70.6%) participants, and Arabic, reported by 11 (64.7%) participants. There was no significant association

between the number of overall referrals received to a program in 2016, and the number of languages spoken ( $r_{\pi}$  = -.011, p = .959). However, there was a statistically significant association between the number of referrals for individuals from CALD backgrounds in 2016 and the number of different languages spoken ( $r_{\pi}$  = .685, p = .001) with those programs with a higher number of referrals for individuals from CALD backgrounds in 2016 also more likely to report a greater number of different languages spoken by participants in their program.

## 3.3 Interpreter use

The use of interpreters is detailed in Table 3.3. Interpreters were frequently used for initial assessments of individuals with limited English proficiency, but less frequently for final assessments and for exercise classes. Seven (41.2%) participants reported that interpreters were always used for initial assessments and four (23.5%) reported that they were used for initial assessments most of the time. Interpreters were used less frequently for final assessments with only three (18.7%) of sixteen responding participants reporting always using interpreters for final assessments and 5 (31.3%) reporting using interpreters most of the time. The use of interpreters for initial or final assessments was not significantly associated with the number of referrals a program reported receiving for individuals from CALD backgrounds ( $r_{\pi}$  = .278, p = .204; and  $r_{\pi}$  = .037, p = .869 respectively). Interpreter use for initial or final assessments was also not associated with the number of languages spoken by program participants ( $r_{\pi}$  = .259, p = .190; and  $r_{\pi}$  = .221, p = .278 respectively).

Table 3.3: Frequency of interpreter use

Occasion	n (%)	
	unless otherwise	
	stated (n=17)	
Initial assessments		
Always	7 (41.2%)	
Most of the time	4 (23.5%)	
About half the time	2 (11.8%)	
Sometimes	3 (17.6%)	
Never	1 (5.9%)	
Final assessments (n=16)		
Always	3 (18.7%)	
Most of the time	5 (31.3%)	
About half the time	1 (6.3%)	
Sometimes	5 (31.3%)	
Never	2 (12.5%)	
Exercise classes		
For most exercise classes	3 (17.6%)	
For less than half of the exercise classes	4 (23.5%)	
For the first exercise class	3 (17.6%)	
For none of the exercise classes	7 (41.2%)	
Use of family members to interpret		
Always	2 (11.8%)	
Most of the time	5 (29.4%)	
About half the time	1 (5.9%)	
Sometimes	8 (47.1%)	
Never	1 (5.9%)	

Only three (17.6%) participants reported using interpreters with individuals with limited English proficiency for most of the exercise sessions undertaken during a pulmonary rehabilitation program. Four (23.5%) participants reported that interpreters would be used for less than half of exercise sessions. Three (17.6%) participants reported that an interpreter would be used for the first exercise session only, and seven (41.2%) participants reported that interpreters were not used for any of the exercise sessions. The use of interpreters for exercise sessions

was not significantly associated with the number of referrals a program reported receiving for individuals from CALD backgrounds ( $r_{\pi}$  = .225, p = .309), or with the number of languages spoken by program participants ( $r_{\pi}$  = .226, p = .255).

Most participants reported some level of confidence using interpreters, with eight (47.1%) reporting that they were very confident and eight (47.1%) reporting they were confident. One (5.9%) participant reported being only slightly confident using interpreters. There was no significant association between participants' reported confidence using interpreters and the number of years practicing as a health professional ( $r_{\pi}$  = .145, p = .483), or with the number of years working in pulmonary rehabilitation ( $r_{\pi}$  = .156, p = .453). Similarly, there was no significant association between participants' reported confidence using interpreters and either the number of referrals of individuals from CALD backgrounds ( $r_{\pi}$  = .025, p = .914), or the number of different languages spoken by program participants ( $r_{\pi}$  = .049, p = .814).

Participants reported frequently using family members to interpret rather than qualified interpreters, as displayed in Table 3.3. Two (11.8%) participants reported always using family members to interpret and five (29.4%) participants reported using family members to interpret most of the time, with only one (5.9%) participant reporting that they never use family members to interpret. The reasons for using family members to interpret are presented in Table 3.4, and included limitations in the availability of interpreters, the family member would be attending the appointment with the individual and using family members for exercise classes after an interpreter had already been used for some sessions.

Table 3.4: Reasons for using family members to interpret

#### Reasons

If there is no interpreter available

If the individual requires an urgent appointment and an interpreter cannot be arranged

If the interpreter is late or does not attend

If there is no interpreter for a specific dialect

To assist in organising appointments

To assist an individual in completing questionnaires

To advise when a class is cancelled

If it was not identified on the referral that the individual needed an interpreter resulting in an interpreter not being arranged for the first patient contact

If a family member is attending the appointment

Family are available and should be involved in the individual's management/support

After an interpreter has been used for the initial assessment and the first few exercise classes

For exercise classes

There was a non-significant association between the use of family members to interpret and both the number of referrals of individuals from CALD backgrounds, and number of different languages spoken by program participants ( $r_{\pi}$  = -.443, p = .460; and  $r_{\pi}$  = -.332, p = .098 respectively).

### 3.4 Assessment

Assessment tools used by participants are outlined in Table 3.5. The Six Minute Walk Test was used as an assessment of exercise capacity in all programs, and was consistently used for all individuals attending their program, including individuals

from CALD backgrounds. Six (35.3%) participants reported using the COPD Assessment Test, and again this was used consistently for all individuals attending their program, including individuals from CALD backgrounds. Six (35.3%) participants reported using additional questionnaires and functional assessments. However, although these additional assessments had been utilised for individuals from CALD backgrounds in some instances, they were not always used consistently in each program for this population. Sixteen (94.1%) participants reported using the St George's Respiratory Questionnaire in their program, however only 13 (76.5%) participants reported consistently using this with individuals from CALD backgrounds and one (5.9%) participant reported that it would be used with some individuals from CALD backgrounds if the individual

Table 3.5: Use of objective assessments and methods of administering questionnaires with individuals from CALD backgrounds

Assessment method	n (%) unless otherwise stated (n=17)
Assessments tools used	
Six Minute Walk Test	17 (100.0%)
St George's Respiratory Questionnaire	16 (94.1%)
COPD Assessment Test	6 (35.3%)
Hospital Anxiety and Depression Scale	13 (76.5%)
Assessments tools used with individuals from CALD backgrounds	
Six Minute Walk Test	17 (100.0%)
St George's Respiratory Questionnaire	14 (82.4%)
COPD Assessment Test	6 (35.3%)
Hospital Anxiety and Depression Scale	11 (64.7%)
Methods of administering questionnaires with individuals from	
CALD backgrounds	
Use of translated questionnaire	9 (52.9%)
Assistance of interpreter	8 (47.1%)
Assistance of family member	8 (47.1%)

had enough English literacy to be able to complete or if someone was able to assist. Thirteen (76.5%) participants reported using the Hospital Anxiety and Depression Scale in their program, however only 11 (64.7%) participants reported using this with individuals from CALD backgrounds.

Participants reported using various methods to administer questionnaires with individuals from CALD backgrounds, as shown in Table 3.5. Seven (41.2%) participants reported using more than one method to administer questionnaires to individuals from culturally and linguistically diverse backgrounds. Nine (52.9%) participants reported having some translated questionnaires available for use with individuals from CALD backgrounds.

#### 3.5 Education

The methods used to provide education to individuals participating in pulmonary rehabilitation are displayed in Table 3.6. Thirteen (76.5%) participants provided education booklets to individuals participating in pulmonary rehabilitation. Fifteen (88.2%) participants reported that their program provided group education sessions. These methods were used less frequently with individuals from CALD backgrounds, with only three (17.6%) participants reporting having translated education booklets and only one (5.9%) participant reported providing translated education sessions. Individuals from CALD backgrounds were more frequently provided with individual education sessions, with 14 (82.4%) participants in total reporting providing individual education sessions. Eight

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Table 3.6: Education	ทรงงาสคส	to individua	ils affending	niiimonari	v renanilitation
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	Number of programs	Number of programs	
	providing education in this	providing education in this	
	format	format to individuals from	
	n (%)	CALD backgrounds	
	unless otherwise stated (n=17)	n (%)	
		unless otherwise stated (n=17)	
Education	13 (76.5%)	3 (17.6%)	
booklet			
Group education	15 (88.2%)	1 (5.9%)	
session			
Individual	5 (29.4%)	14 (82.4%)	
education			

(47.1%) participants reported providing individual education using an interpreter and 13 (76.5%) participants reported using family members to interpret individual education.

### 3.6 Maintenance

All participants reported providing individuals participating in pulmonary rehabilitation with maintenance exercise programs. A variety of options were used for maintenance, as displayed in Table 3.7. The main options used for maintenance were community exercise programs (58.8%) and individual exercise programs (47.1%). Individuals from CALD backgrounds were commonly offered the same options for maintenance, with 15 (88.2%) participants reporting these individuals would always be offered the same maintenance programs and two (11.8%) participants reporting that individuals from CALD backgrounds would be offered the same maintenance programs most of the time.

Table 3.7: Provision of maintenance programs

Method	n (%) unless otherwise stated (n=17)
Ongoing classes provided by pulmonary rehabilitation program	3 (17.6%)
Community exercise program	10 (58.8%)
Individual exercise program	8 (47.1%)
Other	
Exercise DVD	1 (5.9%)
Hospital-based exercise group	1 (5.9%)
Walking group	1 (5.9%)

#### 3.7 Barriers

Participants' perceptions of the barriers to providing pulmonary rehabilitation to individuals from CALD backgrounds are displayed in Figure 3.2. Language, cultural beliefs about health and exercise, and the lack of understanding of pulmonary rehabilitation were considered by participants to be important barriers to individuals from CALD backgrounds participating in pulmonary rehabilitation. Of the 17 participants, 13 (76.5%) indicated that they somewhat or strongly agreed to language being an important barrier to participation in pulmonary rehabilitation programs. Cultural beliefs about health were seen by nine (52.9%) participants as a barrier to pulmonary rehabilitation, whilst 11 (64.7%) participants agreed that cultural beliefs about exercise were a barrier. The lack of understanding of what pulmonary rehabilitation would involve was seen as a very strong barrier with 16 (94.1%) participants somewhat or strongly agreeing to this as a barrier, and the other participant indicated that they neither agreed nor disagreed to this being a barrier. Eleven (64.7%) participants agreed that lack of perceived benefit of the program was a barrier to participation.

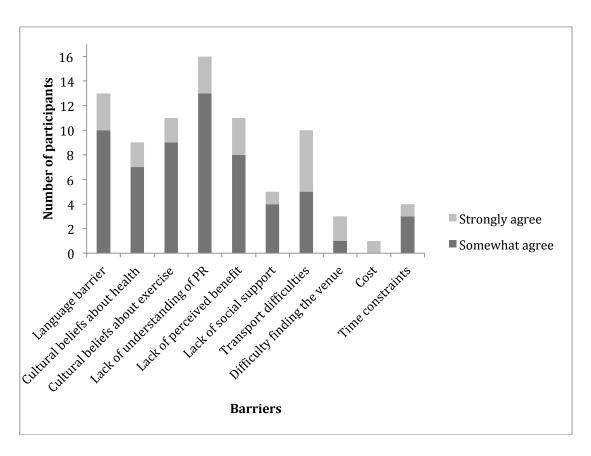


Figure 3.2: Number of participants somewhat or strongly agreeing to barriers to providing pulmonary rehabilitation to individuals from CALD backgrounds PR=pulmonary rehabilitation

Table 3.8: Other potential barriers and facilitators to providing pulmonary rehabilitation to individuals from CALD backgrounds

#### **Barriers**

Cultural factors and beliefs – families care for elders, passive approach to healthcare

Not being able to communicate with the other participants

'Too hard', 'Too SOB'

Referring doctors may not refer these clients as they are unsure how the client will manage based on their language abilities

#### **Facilitators**

ACBT and mucus clearance technique in different languages

Action plans

Medications

To educate family or family's involvement or support

Translated six-minute walk test

Participants also suggested some other potential barriers to providing pulmonary rehabilitation to individuals from CALD backgrounds, as displayed in Table 3.8. These barriers were mostly related to cultural factors or language. One participant suggested that cultural factors such as families caring for elders or individuals having a passive approach to healthcare could be barriers, whilst another participant felt that doctors may not refer individuals from CALD backgrounds as they are unsure how the individual will manage based on their language abilities.

Transport difficulties were seen by many participants as being an important barrier to individuals from CALD backgrounds participating in pulmonary rehabilitation, with ten (58.8%) participants indicating that they somewhat or strongly agreed to this barrier. However, other practicalities of attending a pulmonary rehabilitation program were not seen as important barriers. Ten (58.8%) participants reported that they somewhat or strongly disagreed to difficulty finding the venue being a barrier, with only three (17.6%) participants somewhat or strongly agreeing to this being a barrier. Time constraints were also not seen as being an important barrier, with eight (47.1%) participants indicating that they neither agreed nor disagreed to this being a barrier, five (29.4%) indicating that they somewhat or strongly disagreed to it being a barrier and only four (23.5%) either somewhat or strongly agreeing to time constraints being a barrier. A lack of social support was also not seen as being an important barrier, with only five (29.4%) participants somewhat or strongly agreeing to it being a barrier. There was no significant association between the sum of barriers identified by program coordinators and either the number of referrals of individuals from CALD backgrounds that a program reported receiving ( $r_{\pi}$  = -.060, p = .772), or the number of different languages spoken by participants within a program ( $r_{\pi}$  = -.133, p = .477).

### 3.8 Facilitators

All participants agreed that translated resources would be useful to some level in delivering pulmonary rehabilitation to individuals from CALD backgrounds, as shown in Figure 3.3. In particular translated Borg Scales were seen as likely to be useful with nine (52.9%) participants reporting they believed they would be extremely useful and seven (41.2%) reporting they believed they would be very useful. Most participants also thought translated questionnaires would be useful with ten (58.9%) reporting these would be extremely useful and five (29.4%) reporting these would be very useful, however two (11.8%) participants thought these would be not at all useful. All participants thought translated education booklets would be useful, with six (35.3%) reporting they would be very useful and seven (41.2%) reporting they would be extremely useful. Eleven (64.7%) participants rated translated written instructions as being very or extremely useful, and 13 (76.5%) participants thought that translated video instructions would be very or extremely useful.

Participants also suggested some other potential facilitators to providing pulmonary rehabilitation to individuals from CALD backgrounds, as outlined in Table 3.8. One participant thought that translated six-minute walk test instructions would be useful, and another participant suggested that translated

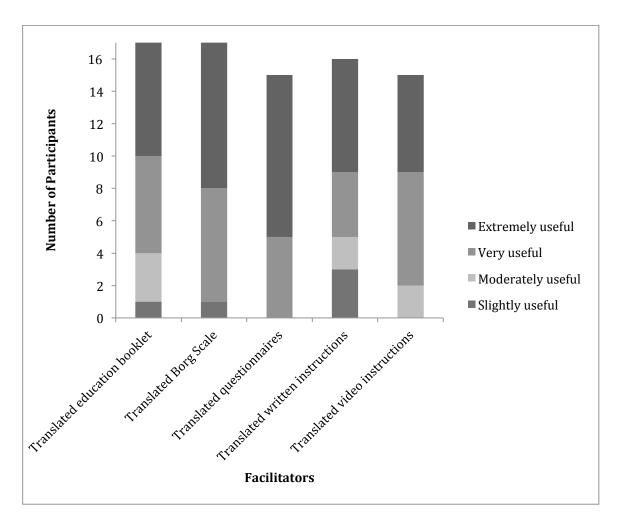


Figure 3.3: Number of participants agreeing that potential facilitators would be useful in providing pulmonary rehabilitation to individuals from CALD backgrounds

information on secretion clearance techniques would be useful. Two (11.8%) participants suggested that translated COPD Action Plans would be useful.

# 3.9 Summary

The survey results provide information on the participation of individuals from CALD backgrounds in pulmonary rehabilitation programs in the Sydney

metropolitan area, as well as some information on the methods used to facilitate communication with these patients, conduct assessments and provide education. All pulmonary rehabilitation programs included in this study received referrals for individuals from CALD backgrounds, but the number of referrals of these individuals varied between programs. Individuals from a wide range of cultural backgrounds have been referred to pulmonary rehabilitation programs in the Sydney metropolitan area. Interpreters have been used to facilitate communication with individuals with limited English proficiency, most commonly for initial assessments, but also for other stages in some programs, however participants did report using family members to assist with interpretation if interpreters were not available. The usual assessments used for participants in pulmonary rehabilitation are also used for individuals from CALD backgrounds, but interpreters may be required to assist in completing these assessments. Most pulmonary rehabilitation programs included in the study provide education to program participants using group education sessions and education booklets, however one on one education is more commonly used to provide education to individuals from CALD backgrounds. Individuals from CALD backgrounds were typically offered the same options for maintenance that were offered to other program participants.

A number of barriers to providing pulmonary rehabilitation to individuals from CALD backgrounds were identified from the survey results, with the most commonly reported barriers being language, cultural beliefs about health and exercise, and the lack of understanding of pulmonary rehabilitation. A number of potential facilitators were also identified from the survey results, including the use

of translated resources for conducting assessments and providing education, as well as translated video instructions.

# **CHAPTER 4**

# **Results – Stage 2: Qualitative Interviews**

## 4.1 Participants

Twelve (70.6%) of the 17 participants in stage one of the study consented to being contacted for interview. Interview participants were selected based on their responses in the survey stage of the study, as outlined in the methodology presented in Chapter 2. Interviews were conducted over a period of four months, between March and June 2018, with interviews transcribed and analysed throughout this process to assess for data saturation. Eight participants were interviewed to reach data saturation.

#### 4.2 Barriers

All eight participants perceived there to be barriers to individuals from CALD backgrounds attending and participating in pulmonary rehabilitation. Analysis of their comments revealed four key themes that were common to all participants. These include cultural factors that could be barriers if the program was not able to accommodate these differences, communication difficulties, challenges using interpreters, and resource limitations.

#### 4.2.1 Cultural factors

All eight participants described cultural factors that they believed could be barriers to providing pulmonary rehabilitation to individuals from CALD backgrounds when programs were not able to accommodate these differences. Participants perceived that an individual's cultural background may impact on how they view their health problems as well as how they manage their health, including that they may not accept certain treatments because of their cultural background. For example, individuals from CALD backgrounds may not see the potential health benefits of exercise, particularly when they are already unwell, or they may not participate in certain types of exercise as it may not be culturally appropriate. Because of these differing beliefs, some pulmonary rehabilitation participants reported that they had found it a challenge to provide effective education to individuals from CALD backgrounds on the benefits of exercise and to engage them in pulmonary rehabilitation:

"Challenges definitely have been explaining or putting across that point of view of a health model, especially the westernised health model and using research based models and rehabilitation models that are new to that person or not yet fully understood or appreciated by that person or that conflict with what they've been brought up with or what they believe." (Participant 8)

"When I ask them about exercise, they say, "no, I don't need to exercise" but when I ask them do you need rehab they say "yes, we need rehab". They understand in some way they need rehab but they don't understand fully the concept of rehab." (Participant 5)

Two (25.0%) participants also reported that individuals from CALD backgrounds may also have difficulty understanding the healthcare system as it differs to the healthcare system of their country of birth. The healthcare system in their country of birth may have provided more or less care than is available in Australia, which might impact on an individual's understanding of what they are able to access. Participants perceived that individuals might have difficulty accessing healthcare or might not understand what is available to them because of these differences between healthcare systems:

"There will be certain, in certain cases, cultural preconceptions of what healthcare is and how it's delivered which may be totally different to the way it's delivered in this country." (Participant 7)

"Everybody wants the best and yeah it's a matter of understanding what is out there that would benefit them." (Participant 4)

Three participants (37.5%) related that some individuals attending pulmonary rehabilitation continued to smoke despite their diagnosis of respiratory disease, as smoking was well accepted in their culture and they were fearful that they may be socially rejected if they stop smoking. They reported that they found this presents an additional barrier to educating patients on steps that they can take to improve their lung health through smoking cessation in comparison to those individuals who come from cultures where smoking is becoming increasingly socially unacceptable:

"Sometimes it's not culturally acceptable to give up smoking and we're running a pulmonary rehab exercise class so our improvements can only be so much because they're still smoking." (Participant 1)

Four (50.0%) participants identified that family members played a significant role in health management for individuals from CALD backgrounds and at times this could have a negative impact. For example, it may be more typical in some cultures for an individual who has a condition like COPD to be overprotected by their family, or to lack independence as their family are making decisions regarding their healthcare. In certain cultures family members may strongly encourage an individual who is unwell to rest, and provide them with more assistance than they require. These family members may be concerned that exercise is unsafe for the individual and they may discourage them from participating in exercise. This was seen as a challenge for pulmonary rehabilitation program coordinators as they needed to provide the family with extra education on the safety and benefits of exercise and engage family members to encourage an individual to exercise rather than discourage them:

"But on the whole I find that they tend to be over-nurturing and it's very difficult to progress the patient because the family are frightened as well so then you have that double task of trying to teach the children and teach the parents." (Participant 2)

"In some cultures you know the family member would do everything for the person who is sick you know that's why it's also important for us to teach the family member not to interfere with the daily routine too much." (Participant 3)

Some participants perceived that individuals from CALD backgrounds may have more difficulty travelling to the pulmonary rehabilitation venue. One participant felt that these individuals may have less confidence in leaving their home environment. Another participant reported that these individuals may have more dependence on family members to attend pulmonary rehabilitation classes, and that due to their language skills they may have more difficulty in using public transport to travel to classes.

Six (75.0%) participants reported the potential for individuals from CALD backgrounds to feel uncomfortable in a pulmonary rehabilitation group with other group members from different backgrounds to them. The mix of cultures in pulmonary rehabilitation groups was seen as a potential barrier. One participant reported that individuals from CALD backgrounds may not be well accepted by other members of the pulmonary rehabilitation group due to assumptions by these other members about other cultures, and this needed to be addressed by the pulmonary rehabilitation staff so that all members of the pulmonary rehabilitation group were treated respectfully. Participants also perceived that an individual may potentially feel excluded in a group when they are unable to communicate easily with the other members, and that they perceived that they would prefer to be in a group with individuals who speak the same language or are from a similar

cultural background. Feeling excluded in the pulmonary rehabilitation group was seen as being a possible cause of anxiety and could even potentially limit the benefit that an individual would gain from the pulmonary rehabilitation program:

"Being the only person from that language, culture or background in that group might be reported as being a barrier or intimidating and causing anxiety for clients." (Participant 8)

"Probably to get the most out of it there has to be some acceptance of that group and I suppose a feeling of comfort in that group to... gain the maximum benefit from the program." (Participant 7)

In addition to potential challenges with a mix of cultures within pulmonary rehabilitation groups, three (37.5%) participants reported that having mixed gender classes could be a barrier to individuals from CALD backgrounds participating in pulmonary rehabilitation. Some individuals may consider it inappropriate for males and females to exercise together due to religious beliefs or cultural reasons. The gender of the pulmonary rehabilitation staff was also described to be a potential barrier, as it was perceived by some participants that some individuals may have a culturally determined preference to see a healthcare professional of a specific gender:

"I think it's the healthcare belief, whether it's that you know women shouldn't exercise with men or that men shouldn't take advice from females."

(Participant 6)

## 4.2.2 Language

All participants acknowledged that language could be a barrier to providing pulmonary rehabilitation to individuals from CALD backgrounds. Two (25.0%) participants perceived that some individuals may be fearful about attending pulmonary rehabilitation when they are going to have difficulties communicating with staff. One participant also reported that it could be challenging to gain an individual's trust or build rapport with them when they were not able to communicate directly with them:

"You've got to get their confidence so they have to understand that you know what you're talking about, that you're a friendly person, that the program is individualised to them and you're not asking them to compete with anyone else but just to improve themselves." (Participant 1)

Four (50.0%) participants also thought that because of the language barrier some individuals might not fully understand what is being offered to them. Individuals may be less likely to attend pulmonary rehabilitation if they don't understand what is involved and the potential benefits of the program:

"I suppose just not understanding the benefit of the program as nobody has taken the time to explain the benefit of the program to them in their own language, then they wouldn't be able to see the point of coming." (Participant 2)

Two (25.0%) participants expressed concerns about safety due to communication difficulties with individuals from CALD backgrounds. There was concern that if an interpreter was not present individuals may not be able to inform staff if they had a problem whilst exercising. It was also reported that it was important to ensure adequate assessment prior to commencing the program to ensure individuals would be safe to participate in the program, as well as ensuring they understood how to perform exercises safely:

"I do have concerns, we just sort of screen that quite carefully I guess before bringing people into the group and into the gym area specifically. If they have issues at the initial assessment demonstrating or instructing objective measurements yeah sometimes it might be a reason to not bring them through to the gym at that moment until you can ensure they'll be safe." (Participant 8)

Three (37.5%) participants identified that some individuals from CALD backgrounds may have limited education or low literacy in their own language. They may be able to speak English but are unable to read or write in English meaning they are unable to complete questionnaires or understand written education material that is typically provided in English. Furthermore, some individuals may not be able to read and write in their own language, meaning it is also not possible to use translated written information to facilitate communication:

"It is not guaranteed they are able to read their own language... in some ways they are embarrassed to say to me I can't read my own language." (Participant 5)

## 4.2.3 Challenges with interpretation

All participants reported experiencing some challenges when using interpreters. The most commonly reported concern was interpreter availability, with participants reporting that individuals requiring an interpreter would often wait longer to be seen due to lack of interpreter availability. Only one participant reported using an interpreter for all exercise classes, with other participants reporting that they were unable to use an interpreter for all classes because interpreters would not be available for all these times. Three (37.5%) participants had also experienced problems with interpreters having difficulty finding their service, arriving late to appointments or having to cancel the appointment:

"From a practical point of view quite often the interpreters get lost trying to find a particular service and this happens to us a lot because particularly this campus is sort of um hotch potch of buildings and allied health services are strewn all over the hospital so quite often a major problem is despite giving what we think is a clear explanation of how to get here we find interpreters getting lost which is obviously not good because it means we can't do anything with the patient until they arrive." (Participant 7)

As well as difficulties with interpreter availability, three (37.5%) participants expressed difficulties using interpreters because it increased the time they needed to spend with an individual, and this further increased scheduling difficulties. Participants also reported that due to time constraints an individual who requires an interpreter may be provided with less education:

"Sometimes we modify our instructions or our education content if we're going through an interpreter because we need to cut down on our content because of time." (Participant 4)

Three (37.5%) participants reported experiencing difficulties in accessing interpreters for certain dialects. This included some specific dialects not being provided by the interpreter service, or not booking the correct interpreter for a specific dialect as they were unaware that this specific dialect was required. Another concern expressed by two (25.0%) participants was that despite interpreters speaking the correct language they may be from a different class or different religion to the individual they were interpreting for, and there were occasions when this had made an individual feel uncomfortable.

Two (25.0%) participants expressed concerns about the accuracy of translation provided by interpreters. One participant reported a friend had attended an appointment with an individual who required an interpreter, and this friend had reported that they believed the interpretation was not accurate. Another participant expressed concerns that the interpreter did not seem to be familiar with specific medical terminology, and had also experienced occasions where the

interpreter appeared to have a long discussion with an individual but did not seem to interpret the equivalent amount of information.

The use of family members to interpret when an individual had limited English was common, however all participants reported concerns with using family members to interpret. The most commonly reported concern was the potential for inaccurate interpretation, with the family member not sharing all the information with an individual or not interpreting an individual's full answer. Two (25.0%) participants also expressed concerns relating to a family member potentially not being able to accurately translate health information as they may not fully understand the information themselves or may not know the words they need to translate. It was also suggested that the interpretation could be biased by the family member's beliefs:

"Yes, so I think the main thing with family members is that they tend to answer the question and not necessarily ask the patient or you know the answer might not be one hundred percent reflective of the patient view but it may be their view." (Participant 4)

"There are times when I suspect what I'm telling the family member to communicate to the patient isn't exactly what I said but unfortunately not being multilingual at all that's just a suspicion. But you know I suspect at times that does happen." (Participant 7)

Three (37.5%) participants reported that family dynamics may limit accuracy when using family members to interpret. A family member who is interpreting may not go into enough detail because they are trying to protect an individual from information that may upset them. Conversely, an individual may also not be willing to share certain information about their health when a family member is translating, and this could result in important information not being communicated to the health professional.

One participant raised similar concerns regarding accuracy when family members were used to assist in administering questionnaires. It was perceived that the family member may not actually ask the individual the questions, or accurately articulate their responses, but instead answer the questionnaires as they think appropriate:

"We've found that again if the family interprets the questionnaires... we're just not sure who's answering the questionnaire, is it the family or the patient?" (Participant 2)

#### 4.2.4 Resource limitations

Five (62.5%) participants considered limited availability of resources as a barrier to providing pulmonary rehabilitation to individuals from CALD backgrounds. Some participants reported that there was a lack of available translated written resources, such as education booklets and questionnaires. Participants also perceived that there was a lack of coordination of translated resources, with

programs mostly trying to develop their own resources rather than programs being able to share resources. Some programs had translated resources in languages that were commonly spoken by individuals in their program but did not have resources available in languages that were less common in their program. Participants also reported that it was not always possible to have written information translated, particularly into less common languages:

"Unfortunately we don't have the funds to translate all of our educational resources into language, especially some of the more rare dialects which is a barrier I can't fix." (Participant 6)

One participant reported that individuals from CALD backgrounds may not be aware of resources that are available to assist them, such as interpreters, and because of this may not request an interpreter even though they would benefit from this. Additionally, two (25.0%) participants reported that they did not have a good awareness of resources that were available for use with individuals from CALD backgrounds and that they needed to increase their knowledge of resources:

"I suppose increasing my knowledge or our service's knowledge of any other support groups for pulmonary rehab that are specific to that culture or have been translated already for support groups." (Participant 8)

#### 4.3 Facilitators

All eight participants identified potential facilitators to providing pulmonary rehabilitation to individuals from CALD backgrounds. Participants reported already using some of these facilitators, however they also suggested additional facilitators that they thought would be useful. Analysis of their comments revealed three key themes that were common to all participants. These include using alternate methods of communication, family support, and use of interpreters.

#### 4.3.1 Alternate methods of communication

Seven (87.5%) participants identified a number of alternate methods of communication that they had either used or considered to be potentially useful in providing pulmonary rehabilitation to individuals from CALD backgrounds. Most participants reported using visual information to help in the provision of education to these individuals. This included drawing diagrams using picture cards or pictures of exercises. Some participants also suggested that having diagrams or larger signs with translated explanations could be useful in providing education and displaying information about how to perform common exercises:

"I guess enlarged diagrams with translations, especially points with the more risky pieces of equipment or yeah like the strength equipment, the technique is very important to get right with that sort of thing so that would be very useful." (Participant 8)

Translated written resources were also considered to be a facilitator by seven (87.5%) participants. Some programs were already using translated written resources, including the Modified Borg scale, St George's Respiratory Questionnaire, education booklets and home exercise booklets, or when using an interpreter they would ask them to also do some written translations. One participant reported that when they did not have their own resources available they would contact other programs to source the required translated materials. Other participants had accessed translated written resources online and used these when they had been able to confirm the accuracy of the included information. One participant reported the use of some translation pages to use if the interpreter was late, and also using warning signs with translated information that they could place around the gym. However, whilst many participants were already using translated written information, some still reported that they had inadequate translated resources and additional translated information would be beneficial:

"Translating what we have in terms of booklets and things is important, it is still very difficult to find the right language questionnaire to use for assessment and you know, different language pamphlets about proper techniques and things if they're available it will be very helpful." (Participant 3)

Four (50.0%) participants felt that a DVD would be a potential facilitator for providing the educational component of pulmonary rehabilitation. This could either be done with translated subtitles, which would enable an individual to

understand a video whilst watching it in a group education session, or with translated audio for individuals to watch at home.

Three (37.5%) participants reported they had learnt a few useful words in languages other than English that were common to participants within their program. Words that they had found helpful included 'good', 'slow' and 'pain', enabling them to encourage patients or to assist with some basic communication. As well as assisting in communication this was felt to help with building rapport with individuals from CALD backgrounds:

"I try and learn a couple of words in every language so that I can talk to the patients so after I've physically demonstrated, check they're doing it properly, mimic them into the correct position etc., then I've got a word in their own language where I can reinforce that they understand so that seems to work quite well." (Participant 1)

Two (25.0%) participants suggested using technology to aid in communication. One participant reported using *Google Translate* to effectively communicate with individuals with limited English. The other suggested that having an application on a tablet that could provide relevant translated written and audio information could be a useful communication aid.

#### 4.3.2 Family support

Participants reported that involving family members in an individual's care was a facilitator to providing pulmonary rehabilitation to individuals from CALD backgrounds. It was considered that if family members were involved in an individual's care and had a better understanding of the individual's condition and how to manage it they would be better able to provide support:

"We do encourage them to bring a family member along to their assessment so they can also understand because I do feel the education is important to the patient but also the family needs to understand what they're going through and what we're expecting of the patient to be able to help them fully."

(Participant 4)

Seven (87.5%) participants reported they frequently used family members to interpret. It was seen by these participants to be easy to organise for family members to interpret, and may allow for an appointment to be arranged earlier than it would be if waiting for a qualified interpreter. It was also considered practical to use a family member to interpret as they would often be attending with the individual anyway. Family members were encouraged to attend the exercise classes to assist with interpreting information, especially in the early stages of the program.

Family members were also commonly used to interpret education. This included family members attending group education sessions to interpret, or interpreting one on one education. One participant reported that having a family member

interpret the education session had the additional benefit of educating that family member and enabling them to better support an individual in managing their health. They may also be given written education material or exercise booklets that they could translate for the individual:

"We have booklets and exercise sheets for them to take home and if need be then the family members can translate those for the patients." (Participant 3)

## 4.3.3 Interpreter use

Six (75.0%) participants reported having used interpreters for initial assessments when required, and the need for this was often identified on the referral. It was considered important to use interpreters at this stage to gain a thorough history and ensure the individual would be safe to participate in the program:

"...their initial visit, so we need to get the background information from them.

And even if we've had a referral from a medical officer there may be great, big
gaps in the information we're getting. We need to know about comorbidities,
we need to know about past injuries, we need to know what their exercise
tolerance previously is. Are there any exercises they can't do, or culturally, or
don't want to do, do you know what I mean? Uh do they have any phobias or
fear to exercise? All this information, all their medications, it's all really
important." (Participant 1)

When an interpreter was present for the initial assessment participants would also take the opportunity to provide the individual with education, as time allowed. At this time they may also be used to provide some orientation to the pulmonary rehabilitation program and to teach individuals how to use some of the exercise equipment utilised by the program.

It was less common for interpreters to be used during the exercise program, with only one participant reporting that interpreters were used for most of the program. Four (50.0%) participants reported that interpreters may be utilised throughout the program if needed, such as when alternate methods of communication were not effective.

It was also less common for interpreters to be used for a final assessment on completion of the program, with only one participant reporting regularly using an interpreter for this. Three (37.5%) other participants reported that using interpreters at the final assessment would be beneficial, to assist in completing the assessment as well as to provide the individual with education regarding maintenance strategies.

# 4.4 Summary

The qualitative data collected from the interviews has provided in-depth information on the barriers to providing pulmonary rehabilitation to individuals from CALD backgrounds as perceived by pulmonary rehabilitation program coordinators in the Sydney metropolitan area. Barriers identified included cultural

factors, if the program was not able to accommodate these differences; communication difficulties; challenges using interpreters; and resource limitations. Interviews also revealed a number of facilitators that could potentially be used to overcome these barriers. These facilitators included the use of alternate methods of communication, such as visual aids; engaging the support of family members; and the use of qualified interpreters to facilitate communication.

# **CHAPTER 5**

# **Results – Stage 3: Integrated results**

# 5.1 Participants

Seventeen pulmonary rehabilitation coordinators from the Sydney metropolitan area participated in the first stage of this study, with eight of these participants also interviewed in the second stage of the study. The characteristics of the participants included in the second stage of the study are compared with the overall group characteristics from stage one in Table 5.1. Of those that were interviewed in depth, six (75.0%) participants were physiotherapists and two (25.0%) were nurses. Seven (87.5%) of these participants achieved their qualification in Australia, with the other participant achieving their qualification in another English speaking country. Interviewed participants' professional experience ranged from 7 to 40 years, with a mean of 18.2 years (SD 9.7), while their experience in pulmonary rehabilitation ranged from one year to 27 years, with a mean of 12.7 years (SD 7.9). Overall, the characteristics of those participants who were interviewed in the second stage of the study are similar to the features displayed by the group as a whole.

Table 5.1: Characteristics of participants in stages one and two

Characteristic	n(%) unless n(%) unless	
	otherwise	otherwise
	stated (n=17)	stated (n=8)
Professional role		
Physiotherapist	14 (82.4%)	6 (75.0%)
Nurse	3 (17.6%)	2 (25.0%)
Country where qualification achieved		
Australia	15 (88.2%)	7 (87.5%)
Other English speaking country	2 (11.8%)	1 (12.5%)
Speak a language other than English		
Yes	2 (11.8%)	2 (25.0%)
No	15 (88.2%)	6 (75.0%)
Years practicing (mean[range])	18.2 [5 to 40]	23.6 [7 to 40]
Years working in pulmonary	12.7 [1 to 27]	17 [1 to 27]
rehabilitation, (mean [range])		
Work in more than one pulmonary		
rehabilitation program		
Yes	9 (52.9%)	5 (62.5%)
No	8 (47.1%)	3 (37.5%)

## **5.2 Integration of results**

Data collected from participants in the first and second stages was combined and analysed for this third and final stage of the study. The data was integrated by merging data in the domains of education provision, frequency of interpreter use, barriers, and facilitators that were investigated in both stages one and two of the study for overall analysis and interpretation. Correlational analyses using Kendall's tau-b coefficient planned to enable deeper analysis were not conducted as the small data set would not allow for meaningful analysis.

## **5.3 Program features**

## **5.3.1 Program demographics**

Demographics of pulmonary rehabilitation programs included in the second stage of the study are compared with the overall group program demographics from stage one of the study in Table 5.2. Similarly to stage one, participants interviewed in stage two of the study reported that the number of referrals to their pulmonary

Table 5.2: Demo	aranhice of n	aragrame includ	ากก	in ctagge and an	d trazo
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Demographic feature	ographic feature n(%) n(%) unl	
	unless	otherwise
	otherwise	stated (n=8)
	stated	
	(n=16)	
Number of referrals in 2016 (n=15)		
Less than 50	1 (6.7%)	1 (12.5%)
50-75	1 (6.7%)	0 (0.0%)
76-100	2 (13.3%)	2 (25.0%)
101-125	4 (26.7%)	2 (25.0%)
126-150	3 (20%)	1 (12.5%)
More than 150	4 (26.7%)	2 (25.0%)
Number of referrals of individuals from CALD		
backgrounds in 2016		
Less than 5	2 (12.5%)	0 (0.0%)
5-10	5 (31.3%)	2 (25.0%)
11-15	1 (6.3%)	1 (12.5%)
16-20	0 (0.0%)	0 (0.0%)
21-25	1 (6.3%)	1 (12.5%)
26-30	0 (0.0%)	0 (0.0%)
More than 30	7 (43.8%)	4 (50.0%)
Number of languages other than English spoken by		
pulmonary rehab program participants		
1-5	6 (37.5%)	3 (37.5%)
6-10	6 (37.5%)	2 (25.0%)
More than 10	4 (25.0%)	3 (37.5%)

rehabilitation programs in 2016 ranged from less than 50 to more than 150. Also similarly to stage one, participants in stage two reported there to be a large range of number of referrals of individuals from CALD backgrounds in 2016, with two participants (25.0%) reporting 5-10 referrals and four participants (50.0%) reporting more than 30 referrals. Participants included in the second stage also reported a variety of different languages spoken by individuals attending their pulmonary rehabilitation programs, with three participants (37.5%) reporting more than ten different languages spoken by individuals attending their pulmonary rehabilitation program.

#### 5.3.2 Education

Methods used to provide education to individuals from CALD backgrounds as reported in both stages one and two of the study are displayed in Figure 5.1. In their interview responses some participants reported that using a variety of resources was important as different individuals learn in different ways, and the range of methods used to provide education reported in both stages one and two reflects this. Furthermore, in the interview stage participants also suggested additional potential resources for providing education that were not options for reporting within the survey responses, such as the use of visual information or video.

In stage one, thirteen (76.5%) participants reported using family members to interpret one to one education, however this was only mentioned by two (25.0%) participants during their interviews in stage two, with a greater focus on the use of

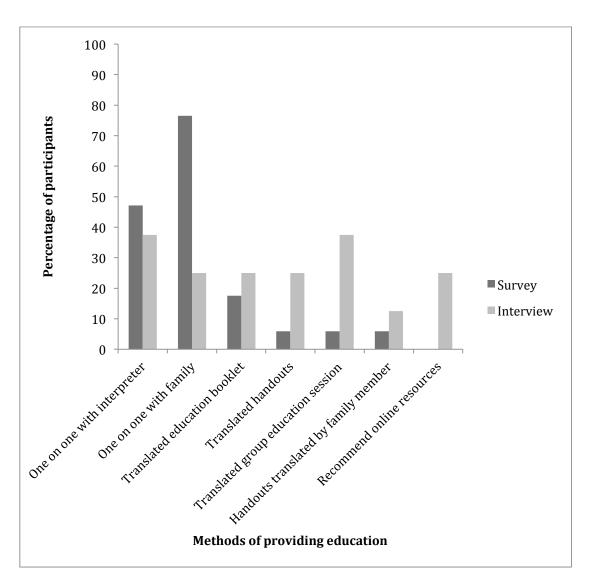


Figure 5.1: Methods used to provide education to individuals from CALD backgrounds – overall results

interpreters and translated written resources for the provision of one to one education. In stage one, one (5.9%) participant reported regularly using interpreters during group education sessions; this was reported again in the interview stage. Furthermore, two (25.0%) additional participants, who hadn't reported using interpreters during group education sessions in the survey stage, related that using interpreters during group education sessions would be of benefit and may use them if required.

In the survey stage all 17 participants agreed that translated education booklets would be beneficial in providing education to individuals from CALD backgrounds, with three (17.6%) participants reporting already providing translated education booklets. One (5.9%) participant reported having other translated handouts that were useful in providing education. In interview responses two (25.0%) participants reported providing translated education booklets, and two (25.0%) participants reported using other translated handouts to provide education. Two (25.0%) interview participants reported recommending online resources that were either already translated, or could be accessed and translated by members of an individual's family.

In interview responses participants commonly reported the need for more resources for the provision of education to individuals from CALD backgrounds, and suggested potential methods of providing this. Four (50.0%) participants reported the need for more translated written resources for the provision of education. Education videos with either translated audio or subtitles were also perceived as being beneficial for providing education, with four (50.0%) participants suggesting the use of this method in their interview responses.

#### 5.3.3 Frequency of interpreter use

In the first stage of the study participants reported using interpreters most frequently for initial assessments, with 41.2% of participants reporting they would always be used for initial assessments, 23.5% reporting they would be used most of the time and 29.4% reporting they would be used some of the time. When

interviewed, participants reported a similar pattern of interpreter use for initial assessments. Participants explained that they used interpreters most frequently for initial assessments as they believed it was important to gain accurate information from individuals to ensure they were safe to participate in the pulmonary rehabilitation program, to provide information about the program, and to provide individuals with education about their health condition.

Participants in both stages of the study also reported using interpreters for final assessments, however less frequently than they were used for initial assessments. Only three (18.8%) of sixteen responding participants reported always using interpreters for final assessments, five (31.3%) reported using them most of the time for final assessments and six (37.5%) reported using them sometimes for final assessments. The use of interpreters for final assessments was reported less frequently during interviews, however some participants did consider the use of interpreters to be important at this stage. In these instances participants reported that interpreters were used for final assessments to provide individuals with further education and to provide information on how to maintain exercise following discharge from pulmonary rehabilitation.

In stage one responses indicated that interpreters were rarely used by participants for exercise classes, with only three (17.6%) participants reporting using interpreters for most of the exercise classes, four (23.5%) reporting using interpreters for less than half of the exercise classes, and three (17.6%) using an interpreter for only the first exercise class. Despite interpreters not frequently being used during exercise classes, when interviewed some participants reported

that they believed it would be helpful to use interpreters more frequently than they did. The lack of use of interpreters during the exercise class aspect of pulmonary rehabilitation programs was explained by the interview data, with participants reporting limitations with interpreter availability as a significant barrier to greater utilisation of interpreters, particularly in trying to arrange an interpreter to attend regularly for exercise classes.

#### 5.4 Barriers

A number of potential barriers to providing pulmonary rehabilitation to individuals from CALD backgrounds were identified from both stage one and two of the study. Participants' perceptions of these barriers are displayed in Figure 5.2. Interview responses obtained in the second stage of the study provided further information on barriers reported in the initial survey stage, as well as identifying additional potential barriers that were not considered in the survey stage. Barriers that were identified by the interviews that were not considered in the survey included challenges with interpretation, family concerns, group dynamics, and resource limitations.

In the stage one survey responses 94.1% of participants agreed or strongly agreed to a lack of understanding of pulmonary rehabilitation by individuals from CALD backgrounds being a potential barrier to their participation in pulmonary rehabilitation. However this was only mentioned by 25.0% of participants when interviewed in the second stage of the program. Furthermore, eleven (64.7%) participants agreed or strongly agreed in their survey responses that the lack of

perceived benefit of pulmonary rehabilitation was a potential barrier. This was only reported by three (37.5%) participants when interviewed despite five (62.5%) of the interview participants agreeing to this as a potential barrier in their interview responses.

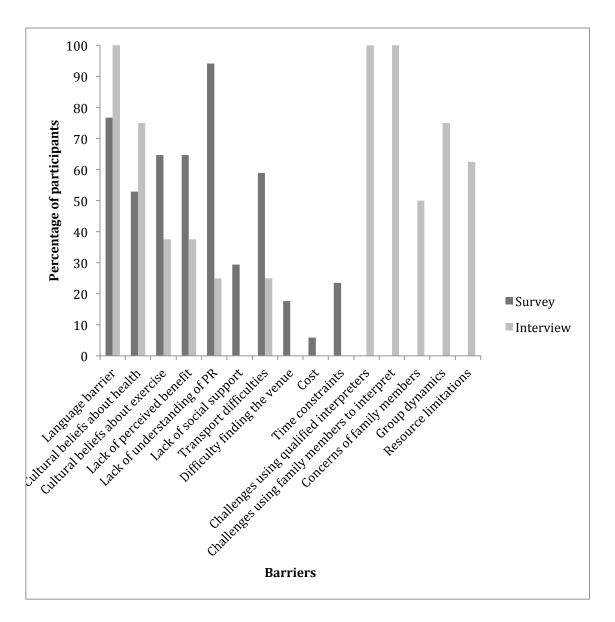


Figure 5.2: Percentage of participants agreeing to barriers to providing pulmonary rehabilitation to individuals from CALD backgrounds – overall results (PR = pulmonary rehabilitation)

When responding to the survey some participants had indicated that they agreed or strongly agreed to potential barriers to the provision of pulmonary rehabilitation to individuals from CALD backgrounds being costs involved, difficulty in finding the venue, time constraints, and a lack of social support. However, these factors were not raised as potential barriers by any of the participants in the second stage of the study during their interviews, indicating that these factors may be less frequent and/or less significant barriers.

#### 5.4.1 Cultural factors

Nine (52.9%) participants agreed to cultural beliefs about health being barriers in stage one survey responses, with this being built on by six (75.0%) participants who citied cultural beliefs about health during interviews that could be barriers to providing pulmonary rehabilitation to individuals from CALD backgrounds. Interview responses explained that it might be difficult to engage an individual in pulmonary rehabilitation due to differing health beliefs, such as not understanding the potential benefits of exercise or believing that when someone is unwell it is important for them to rest and not participate in physical activity. The challenge of family members being over-protective of an individual was not overtly considered in the survey, however 50.0% of participants reported concerns with this when interviewed. In addition, the potential for difficult group dynamics due to a mix of cultures and/or genders within pulmonary rehabilitation programs was also not specifically considered within the survey, however this was perceived as a potential barrier by 75.0% of interview participants.

#### 5.4.2 Language

Language was commonly reported as a barrier to providing pulmonary rehabilitation to individuals from CALD backgrounds in both the stage one surveys and stage two interviews. The majority of participants (76.7%) agreed or strongly agreed to language being a barrier on their survey responses. Seven (82.5%) of the eight interview participants agreed to language being a barrier in their survey responses, with all eight (100.0%) participants reporting this as a barrier when interviewed. Interview responses provided further detail regarding language as a barrier, with participants reporting that differences in language could make it more difficult to explain to individuals about what pulmonary rehabilitation involves and that individuals may be more anxious about attending pulmonary rehabilitation because of difficulties in communication. Participants also reported having concerns about safety of individuals with limited English proficiency if someone was not available to interpret for them.

#### 5.4.3 Challenges with interpretation

All participants who were interviewed in stage two reported challenges with interpretation, when using either qualified interpreters and/or family members to interpret. This was not measured in the survey stage of the study specifically, but was an important barrier identified by the interviews. In the survey stage of the study participants reported limited interpreter availability, as well as late arrival or non-attendance of interpreters as being reasons for using family members rather than qualified interpreters to interpret. These problems, as well as the time taken when using interpreters and concerns about the accuracy of interpretation,

were reported as being challenges in the interview stage of the study. Challenges using family members to interpret included concerns about the accuracy of interpretation, as well as the potential for family dynamics to influence what information was interpreted.

#### 5.4.4 Resource limitations

The lack of available resources, such as translated education material, was not specifically considered by the survey, however the limited use of translated education booklets and other translated education resources in survey responses suggests a lack of available resources. The lack of available resources was commonly reported by participants in interview responses. In the interview stage, five (62.5%) participants reported a lack of resources or limited knowledge of available resources as being a barrier to providing pulmonary rehabilitation to individuals from CALD backgrounds.

#### 5.5 Facilitators

Potential facilitators to providing pulmonary rehabilitation to individuals from CALD backgrounds, as reported in survey and interview responses, are displayed in Figure 5.3. When interviewed, participants suggested further potential facilitators that were not specifically addressed in the survey, including using translated resources for education, utilisation of visual information, the learning of words in other languages by staff, and non-verbal demonstrations.

#### 5.5.1 Alternate methods of communication

The use of translated resources to facilitate communication with individuals with limited English proficiency, including translated education booklets, assessment tools and instructions for exercises was investigated in the initial survey stage of the study. The use of written translated materials were also mentioned by participants in interview responses, however this was less frequently identified than in stage one, as demonstrated in Figure 5.3. Other alternate methods of

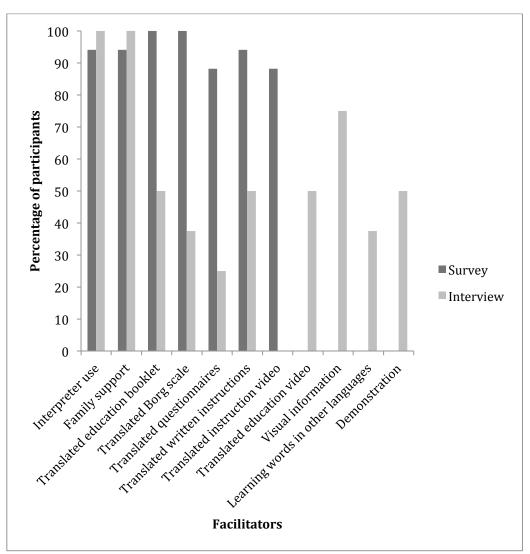


Figure 5.3: Percentage of participants agreeing to facilitators to providing pulmonary rehabilitation to individuals from CALD backgrounds – overall results

communication were more commonly mentioned in interview responses, with 75.0% of participants reporting visual information, such as diagrams for education or posters in the pulmonary rehabilitation gym, as a potential facilitator, and 50.0% of participants reporting using non-verbal demonstrations for communication.

In the survey responses fifteen (88.2%) participants reported that they believed a video with interpreted instructions for exercises would be of some use in providing pulmonary rehabilitation to individuals from CALD backgrounds. Seven (87.5%) of the eight participants who were interviewed had agreed to the usefulness of a video with interpreted instructions for exercise in their survey responses however despite this no participants suggested the use of this resource in their interview responses. Participants who were interviewed did however consider the potential benefits of using video for communication, with four (50.0%) participants suggesting that the use of video may be beneficial for providing education.

#### 5.5.2 Family support

In stage one survey responses participants reported frequently using family members to interpret, with two (11.8%) reporting always using family members to interpret, five (29.4%) reporting using them most of the time, one (5.9%) using them about half the time and eight (47.1%) participants using them sometimes, and only one (5.9%) participant reporting never using family members to interpret. At this time participants reported that family members were most

frequently used to interpret during exercise classes or when there was difficulty arranging a qualified interpreter due to availability, as outlined in table 3.4. In the interview stage 100.0% of participants reported using family members to interpret at some time, explaining that they often used family members to interpret as it was easier than organising an interpreter. Participants reported that family members were used at various stages including interpreting during assessments, interpreting education provided to individuals and also to explain written education material. Participants who reported less frequently using family members to interpret would try to use family members to interpret less important information, such as arranging appointments, and avoid using family members to interpret more complex information. Additionally, in the survey stage, one participant suggested educating family or involving the family and engaging their support as a potential facilitator. Two (25.0%) participants reported engaging the support of family members in their interview responses as a facilitator, this included providing the family members with education so that they were better able to provide support.

### 5.6 Summary

The integrated results show that participants used a variety of methods to provide education to individuals from CALD backgrounds. In stage one participants mainly reported providing one on one education using either a family member or qualified interpreter to interpret. In stage two there was a greater focus on the use of qualified interpreters for either one on one or group education, as well as the use of translated written resources and the potential benefits of other resources

such as education videos. The reported frequency of interpreter use was similar between stages one and two, with interpreters used most frequently for initial assessments, and less frequently for exercise sessions and final assessments.

In stage one a lack of understanding of pulmonary rehabilitation by individuals from CALD backgrounds and the lack of perceived benefit of pulmonary rehabilitation were frequently agreed to as barriers, however these were not commonly reported in stage two. Participants in stage one frequently agreed to cultural beliefs about heath and exercise as being barriers, and these were also frequently reported as barriers in stage two. The language barrier was commonly reported in both survey and interview responses. Challenges with interpretation were mentioned in survey responses and were also identified in interview responses as being an important barrier. Participants commonly reported a lack of translated resources in their interview responses, and a lack of available resources is suggested by survey responses, with the limited use of translated education booklets and other translated education.

A number of potential facilitators were identified by the survey and interview responses. Facilitators investigated by the survey included translated written materials for education and assessments, as well as translated written instructions for exercises and a video with instructions for exercises. Alternate methods of communication, such as the use of visual information or education videos were suggested as potential facilitators in interview responses. In survey responses participants reported frequently using family members to interpret, and this was again reported in interview responses. In interview responses participants also

reported engaging the support of family members to encourage individuals to participant in pulmonary rehabilitation.

## **CHAPTER 6**

# Discussion and concluding remarks

#### 6.1 Discussion

This mixed methods study is the first study examining barriers and facilitators to individuals from CALD backgrounds accessing and participating in pulmonary rehabilitation. It has examined this issue from the viewpoint of the coordinators of pulmonary rehabilitation programs in the Sydney metropolitan region, a region with the largest migrant population in Australia [22]. Using both quantitative and qualitative methods this study has been able to provide information on the number of individuals from CALD backgrounds referred to pulmonary rehabilitation and the barriers and facilitators to providing pulmonary rehabilitation to these individuals. This study has found that individuals participating in pulmonary rehabilitation in the Sydney metropolitan region come from a diverse range of backgrounds however a number of barriers to providing the program to these individuals exist, including cultural differences when these were not able to be accommodated by the pulmonary rehabilitation program, communication difficulties, challenges with interpretation and limited resources. Potential facilitators to overcome these barriers were identified, including using alternate methods of communication, the use of qualified interpreters and engaging the support of family members.

Participants reported on the number of referrals of individuals from CALD backgrounds to their programs in 2016, with the number of referrals ranging from less than five to more than 30. Most participants perceived that the number of referrals of individuals from CALD backgrounds to their program was reflective of the area serviced by their program, although four participants thought that the number of referrals of individuals from CALD backgrounds to their program did not reflect the area serviced by their program. Sydney has a high migrant population, with over 42% of the population of Sydney having been born overseas [23]. Whilst most participants perceived that the number of referrals of individuals from CALD backgrounds was reflective of the area serviced by their program in regards to the specific CALD populations represented within their referrals, for many programs the rates of referral of individuals from CALD backgrounds did not reflect the high proportion of overseas-born residents in Sydney. This suggests that there may be individuals from CALD backgrounds who would benefit from pulmonary rehabilitation but are not being referred. There is also large variability in the proportion of overseas-born residents in different areas of Sydney, and the range in referral numbers between programs is likely reflective of this [22].

There was diversity of CALD backgrounds observed within individuals attending pulmonary rehabilitation programs in the Sydney metropolitan region, with ten participants reporting six or more languages other than English spoken by individuals participating in their pulmonary rehabilitation program. Just as there is variation in overall numbers of individuals of CALD backgrounds in different areas of Sydney, there is also variability in the source countries of migrants

represented in different areas [22], and this can also have an impact on the nature of referrals to different programs. Italian and Greek were the two most common languages other than English spoken by individuals participating in pulmonary rehabilitation in the Sydney metropolitan area. Italy was a common source country for migrants to Australian in the 1950s and early 1960s, with Greece also being a common source country in the early 1960s [60], and this may suggest that as the migrants from Italy and Greece have aged they have had deterioration in their health. These individuals may have also had more time to become accustomed to the Australian healthcare system, have more assimilated beliefs about their health, and therefore may be more comfortable in attending pulmonary rehabilitation programs despite their differences in culture and language. Arabic, Mandarin and Cantonese were the next most common languages other than English spoken by pulmonary rehabilitation participants, however these three languages are the most common languages other than English spoken by Australians [14]. It is possible that the reason these languages are not the most commonly spoken among pulmonary rehabilitation participants as migrants from these backgrounds have migrated more recently [61], and may be younger or less assimilated.

Barriers to participation in pulmonary rehabilitation have been documented previously, and it is known that access to pulmonary rehabilitation programs generally is poor [12]. This study adds potential barriers specific to providing pulmonary rehabilitation to individuals from CALD backgrounds. Some individuals may face greater barriers to participating in pulmonary rehabilitation, and it is important to consider this to improve access to pulmonary rehabilitation.

There were some similarities between barriers identified in this study and previously documented barriers. The lack of perceived benefit has been identified as a barrier to participating in pulmonary rehabilitation generally [45]. Participants in this study reported that it may be even more challenging to explain the benefits of pulmonary rehabilitation to individuals from CALD backgrounds due to the language barrier and differing cultural beliefs regarding health. Transport difficulties have also previously been identified as a barrier to participating in pulmonary rehabilitation [45] [62]. Some participants in this study reported that transport may be even more difficult for individuals from CALD backgrounds as they may be more reliant on family members to provide transport or may have greater difficulties using public transport because of the language barrier. Transportation has similarly been seen as a more important barrier for individuals from CALD backgrounds attending cardiac rehabilitation programs [44].

Some cultural factors, including cultural differences that could not be accommodated by the pulmonary rehabilitation program, were identified as being potential barriers for individuals from CALD backgrounds. This included the impact of culture on an individual's beliefs about health and exercise, expectations of health care, the roles of family members in different cultures, and potential discomfort when they are the only one from their cultural background in the pulmonary rehabilitation group. Whilst culture may impact on an individual's beliefs about health, there may also be large variations within cultures, and individuals may have beliefs about health that differ to those of other individuals from the same backgrounds [63]. The delivery of pulmonary rehabilitation may be

enhanced by an improved understanding of the impact of these differing beliefs by health professionals, however it is also important that health professionals remember that each individual has different needs and preferences, as well as different perspectives of what their own cultural background means to them specifically. Individuals also may present with a complex mix of cultural backgrounds, and may identify with these different backgrounds in different ways. Therefore it is always imperative that health care, including pulmonary rehabilitation, is tailored to suit each individual specifically.

Some participants reported that some individuals from CALD backgrounds attending pulmonary rehabilitation continued to smoke, as smoking was common in some cultures, and participants believed that this could limit the benefits they could gain from pulmonary rehabilitation. They may also be less compliant to the pulmonary rehabilitation program, as individuals who continue to smoke have been shown to be less likely to attend pulmonary rehabilitation, as well as less likely to complete the program [62, 64]. Despite these limitations, it is still recommended that pulmonary rehabilitation be offered to individuals who are current smokers, however smokers should be referred for assistance with smoking cessation [65].

Language was one of the most commonly reported barriers in this study, suggesting that it is one of the most important barriers to providing pulmonary rehabilitation to individuals from CALD backgrounds. This is consistent with previous research which identifies a language barrier as being one of the primary

challenges in providing health care to individuals from CALD backgrounds [24]. As well as difficulty communicating with individuals with limited English proficiency, participants in this study identified that a language barrier could also result in difficulties building rapport and engaging individuals optimally in pulmonary rehabilitation, as well as concerns with the safety of these individuals. Adverse events associated with language as a barrier have previously been recognised in hospitalised paediatric patients [66], as well as in other clinical settings [67]. Individuals who are unable to communicate with their health care professional may have feelings of fear or frustration [68], and participants in this study perceived that individuals with limited English proficiency may be fearful of attending pulmonary rehabilitation because of difficulties communicating with program staff.

The use of qualified interpreters was seen as a facilitator to providing pulmonary rehabilitation to individuals from CALD backgrounds, as this could enhance communication between program staff and individuals with limited English proficiency. The use of qualified interpreters has previously been shown to improve care for individuals with limited English proficiency in other clinical settings, including improving communication accuracy and comprehension, and increasing satisfaction with communication [69]. However, whilst the use of interpreters was seen as a facilitator to individuals from CALD backgrounds participating in pulmonary rehabilitation, participants also reported many challenges with using interpreters. Participants reported difficulties with the availability of qualified interpreters including difficulties in booking interpreters who may be booked out well in advance. Additionally there were particular

limitations with the availability of interpreters for certain dialects. It was also reported that more time was required when interpreters were used, and this could make it more difficult to schedule appointments or to cover the required content within a standard appointment time. Participants reported qualified interpreters being used most frequently for initial assessments, but their use for other stages of the pulmonary rehabilitation program, including education sessions, exercise classes and final assessments, was limited. The limited use of interpreters reported by participants in this study is consistent with previous research on the use of interpreters conducted at Liverpool Hospital in Sydney, in which over half of individuals who had limited English proficiency reported that they had not been offered an interpreter during their hospital stay and only about a third reported using an interpreter during their hospital stay [68]. All pulmonary rehabilitation programs included in this study are provided by NSW Health facilities. NSW Ministry of Health policy states that when an individual is not fluent in English "health care interpreters are to be engaged in all health situations where communication is essential", with interpreters available from the Health Care Interpreter Services or Commonwealth Translation and Interpreting Service [70]. The limited use of interpreters despite this policy, and concerns raised regarding the availability of interpreter services, suggests a lack of resources that needs to be addressed to improve access to interpreters and provision of health care to individuals from CALD backgrounds.

Participants also expressed some concerns with accuracy of interpretation when using qualified interpreters, and the literature does provide some evidence of errors in interpretation including omission or alteration of content [71]. Despite

these reports, errors in interpretation are less likely when using qualified interpreters [69]. Translators and interpreters provided by health care interpreting services in New South Wales (NSW) are accredited by the National Accreditation Authority for translators and interpreters (NAATI) [70], a non-government body which assures the quality of translating and interpreting services [72]. Whilst errors in interpretation may occur, health care professionals should therefore have confidence that qualified interpreters can provide the most accurate interpretation.

The support of family members was identified by participants to be both a barrier and facilitator to the provision of pulmonary rehabilitation to individuals from CALD backgrounds. Some participants reported that family members may be concerned about the safety of exercise and an individual may be discouraged from exercise because of this. Family members discouraging individuals from CALD backgrounds from exercising has been documented previously where there are concerns that exercise is not safe for them [73, 74]. Participants in this study reported they needed to provide additional education to family members to engage their support of an individual in pulmonary rehabilitation.

Family members were commonly used to interpret for individuals with limited English proficiency. Participants also reported asking family members to translate written information. Reasons for using family members to interpret included the fact that they were often attending with the individual anyway, providing an easier option for interpretation given the difficulties with interpreter availability

and the limitations that this may pose to appointment times. However, participants also saw this as an opportunity to engage family support and enhance the education of the family members themselves, as well as the individual attending for pulmonary rehabilitation.

Whilst family members were frequently used to interpret, participants did identify a number of problems with this, including the possibility of inaccurate interpretation or the interpretation being biased by the perspective of the family member. These issues are well supported by the literature. Whilst many individuals may feel comfortable using family members to interpret, some individuals have identified problems with using family members such as concerns about the language skills of family members in interpreting complex information, or feeling disadvantaged by needing to use their family members to interpret [68]. Individuals may not always be comfortable using family members to interpret, and may not disclose some information to their health professions as they do not want their family members to know this information [48]. There may also be cultural factors that impact on what information is translated. For example, in some cultures it is not acceptable to share bad news with an individual [21], and this could be a potential reason for a family member to omit information when translating. Adverse clinical consequences may also occur when unqualified interpreters, including family members, have inaccurately interpreted information [75]. The problems that may arise when using family members or other nonqualified interpreters support the need for greater use of qualified interpreters, and greater availability of qualified interpreters to facilitate this.

As language and challenges with interpretation were seen as barriers to providing pulmonary rehabilitation to individuals from CALD backgrounds, participants suggested a number of alternate methods of communication for facilitating general communication and providing education. These included the use of non-verbal demonstrations, assistive technology, the learning of important key words in other languages, and additional translated written resources.

Two participants in the study suggested the use of applications such as *Google Translate* to translate information. Due to the unquantified accuracy of such methods of translation NSW Ministry of Health policy does not support their use [70]. Despite this, advances in technology have made portable devices, such as tablets, easily available, and using such technology for translation could assist with the problem of limited formal interpreter availability. The use of technology to translate information could be a potential facilitator if applications, or alternate utilities, that could reliably accurately translate information, were available and accepted by relevant policy.

Learning some key words in other languages that are important within the context of pulmonary rehabilitation was also reported as being a potential facilitator to providing pulmonary rehabilitation. This was useful in facilitating some basic communication as well as helping to build rapport with individuals from CALD backgrounds. Health professionals may use "small talk" to help build rapport with individuals however this is often lost when communicating through an interpreter [71], so it is beneficial to utilise other methods of building rapport.

The use of translated written information was well supported by participants as being a potential facilitator as a means of providing education as well as administering questionnaires. However, a number of participants also related that some individuals from CALD backgrounds may also have poor literacy in their first language, and translated written information would not be suitable for these individuals. The use of pictures in addition to text has been shown to improve comprehension of health information, such as medication information [76], in individuals with low literacy levels. Therefore, the use of infographics may be beneficial in providing education to individuals from CALD backgrounds with low literacy, however prior to their use they should be piloted to ensure they are culturally appropriate and effectively communicate the information presented [77].

Participants in this study reported using various methods to provide education to individuals from CALD backgrounds. These included using translated written education materials, and using qualified interpreters or family members to verbally interpret education sessions, both within one to one and group settings. A number of potential additional facilitators for providing education were suggested, including improved availability of education booklets as well as other translated handouts that could be useful in providing specific education, translated videos and visual information. The use of video, either in a different language or with translated subtitles, was commonly suggested as a method to provide education. Video with interpreted audio information could be particularly beneficial for individuals who have poor literacy in their first language. The use of video to provide education on health for individuals from CALD backgrounds has

previously been shown to be effective. For example, education videos developed for Cantonese and Mandarin speaking individuals with COPD living in Canada was found to improve inhaler technique as well as the ability to manage exacerbations of COPD [78]. Access to resources for providing education to individuals from CALD backgrounds could be enhanced through the development of useful and effective resources, such as videos and other translated materials, which could be shared between pulmonary rehabilitation programs.

Pulmonary rehabilitation programs included in this study commonly provided education booklets as well as group education sessions to individuals attending their programs, however these were not frequently provided for individuals from CALD backgrounds. Individuals from CALD backgrounds typically received one to one education, interpreted by either a qualified interpreter or a family member, however it was unclear whether they received as much education as other Education is commonly included in pulmonary program participants. rehabilitation programs however there is evidence to suggest that in individuals with COPD there are no additional improvements in functional capacity and health-related quality of life gained from exercise training combined with education compared with exercise training alone [79]. Given this, it is likely that individuals from CALD backgrounds will still gain improvements in functional capacity and health-related quality of life from exercise training in pulmonary rehabilitation even if there is limited education provision. This is consistent with the Australia and New Zealand Pulmonary Rehabilitation Clinical Practice Guidelines which recommend that pulmonary rehabilitation be offered to all individuals with COPD even if education is not able to be provided [80]. However, whilst individuals from CALD backgrounds may gain benefits from exercise training in pulmonary rehabilitation without accompanying education, there remains a lack of equity in service delivery if other participants are receiving education and individuals from CALD backgrounds are not. It is also unclear whether a reduction in education provision impacts on the long-term self-management of their COPD, resulting in less optimal health outcomes from pulmonary rehabilitation for individuals from CALD backgrounds.

Participants commonly reported the need for translated resources, however did not mention that information might have to otherwise be altered to ensure that the information provided was culturally appropriate. Whilst translating resources might help to mitigate the language barrier, the information may not be provided in a way that is culturally sensitive or that considers the needs of individuals from a particular cultural background, or mix of cultural backgrounds. Information may also need to be altered to make it more appropriate for individuals from different cultural backgrounds, such as considering the particular impact of a health issue on that group or presenting it within the context of cultural values [81]. Therefore, simply translating the words from English to a different language may not be providing a culturally responsive solution. Additionally, individuals may have different needs to others from the same cultural background and this should be considered when developing resources, with flexibility to tailor resources to each individual.

#### 6.1.1 Study strengths

This study used a mixed methods approach, collecting both quantitative and qualitative data to gain a greater depth of understanding of the barriers and facilitators to providing pulmonary rehabilitation to individuals from CALD backgrounds. The quantitative data examined the number of individuals from CALD backgrounds referred to pulmonary rehabilitation, and the diversity within pulmonary rehabilitation, as well as gaining important information on provision of education, interpreter use, and potential barriers and facilitators. Combining this with a qualitative stage enabled the collection of more in-depth information explaining methods of provision of education and frequency of interpreter use, exploring identified barriers and the reasons for these, as well as identifying a greater range of potential facilitators. A nested sample of participants from stage one of the study was used for the second stage of the study, with participants selected based on their responses from the first stage of the study. The use of the nested sample ensured that participants who were interviewed were able to provide in-depth information, as it was already known that these participants had experience providing pulmonary rehabilitation to individuals from CALD backgrounds and had identified potential barriers and facilitators to providing pulmonary rehabilitation to these individuals. There was good consensus between the quantitative and qualitative sections of this study, with domains investigated in both stages of the study including provision of education, frequency of interpreter use, barriers and facilitators. This consensus improves confidence in the information gained by this study.

The study focused on the Sydney metropolitan area, which has the largest migrant population in Australia [22]. Many programs represented in this study had a high number of referrals of individuals from CALD backgrounds, with individuals coming from many different backgrounds. As a result, many of the participants in this study had substantial experience working with individuals from CALD backgrounds and were able to provide a great depth of information from their experience. Across the Sydney metropolitan area different pulmonary rehabilitation programs had participants from different cultural backgrounds, and this cultural diversity has also informed the participants' experiences. Additionally, participants in this study were mostly quite experienced, both in years of working as a health professional and in years working in pulmonary rehabilitation. This experience has also added to the participants' ability to provide in-depth information.

#### **6.1.2 Study limitations**

This study used a small sample size as it focused on the coordinators of pulmonary rehabilitation programs within the Sydney metropolitan area. Despite the small sample size it should be noted that the participants in this study represented 73.9% of pulmonary rehabilitation programs in the Sydney metropolitan area. However, the small sample size did limit the use of statistical analyses, particularly when the quantitative and qualitative results were integrated in the third and final stage of the study. In addition, the barriers and facilitators identified by program coordinators in Sydney may be different to those experienced by individuals in other parts of Australia, including other metropolitan cities, regional areas and

areas that are rural or remote. It should also be noted that the personal and professional experiences of participants in interacting with individuals from other cultures may have influenced their responses in this study. For example, a participant who is less familiar with a particular culture may perceive greater barriers in providing pulmonary rehabilitation to an individual from that culture than someone else may.

Results in this study are from the perspective of pulmonary rehabilitation coordinators. There are many other stakeholders whose viewpoints should be considered when discussing the provision of pulmonary rehabilitation to individuals from CALD backgrounds, including these individuals themselves, as well other program participants, additional program staff, referrers, family members, interpreters and the policy makers responsible for the health care services delivering pulmonary rehabilitation programs. Whilst this study has identified many potential barriers and facilitators the perspectives of these other stakeholders were not considered by this study.

## 6.2 Implications

#### **6.2.1 Clinical Implications**

Participants in this study identified a number of potential facilitators for improving the provision of pulmonary rehabilitation to individuals from CALD backgrounds, as well as identifying resources that had already successfully been implemented in a number of programs. Most participants agreed that translated education booklets, Modified Borg Dyspnoea Scale, questionnaires and written

instructions for exercise would be beneficial resources. The development of translated resources could improve provision of pulmonary rehabilitation to individuals from CALD backgrounds with limited English proficiency. Furthermore, some participants reported contacting coordinators of other pulmonary rehabilitation programs to ask for resources that they could use with individuals of particular cultural backgrounds. Greater sharing of resources amongst pulmonary rehabilitation programs, or the collective development of resources that are not currently available, could be facilitated by program coordinators resulting in an enhanced availability of resources for use with individuals from CALD backgrounds.

Participants in this study identified many potential barriers to providing pulmonary rehabilitation to individuals from CALD backgrounds. An increased awareness of potential barriers and the experiences that other pulmonary rehabilitation coordinators have had in providing pulmonary rehabilitation to individuals from CALD backgrounds may help clinicians in developing solutions to overcome barriers experienced by their specific program. Understanding cultural factors that may present as a barrier to optimal access or participation by individuals from CALD backgrounds in pulmonary rehabilitation may guide program coordinators in efforts to make their program more culturally responsive. Additionally, awareness of challenges with interpretation may help in planning for use of interpreters, and may encourage the use of qualified interpreters rather than using family members to interpret to improve the accuracy of interpretation.

#### 6.2.2 Implications for service delivery

The use of interpreters, and its associated challenges, was examined extensively in this study with participants reporting using family members to interpret more frequently than they used qualified interpreters. Many barriers to interpreter use were identified, including interpreter availability, concerns regarding accuracy of information, and the time taken to use interpreters; and this in part may explain the limited use of interpreters. Enhanced interpreter services, including improving the availability of interpreters and enabling interpreters to be booked for regular exercise classes throughout the program, are likely to improve the provision of pulmonary rehabilitation to individuals from CALD backgrounds. Additionally, providing training for interpreters regularly booked for pulmonary rehabilitation in order to improve their understanding of the program and common terminology used in providing education, as well as explaining the importance of accurate interpretation for safety in the program, could be beneficial in improving the quality of interpretation as well as enhancing the integration of interpreters as important members of the health care team.

Participants also reported the potential for problems with group dynamics, such as individuals from CALD backgrounds not feeling comfortable in a group when they were the only one from their specific cultural background, as well as the mix of genders within pulmonary rehabilitation groups presenting a problem for individuals of some cultural backgrounds. The design of services that can provide culturally responsive health care and adapt to differing needs, such as providing gender-specific classes, will help to address these factors.

It was identified from the Lung Foundation Australia database of pulmonary rehabilitation programs that there was a pulmonary rehabilitation program in Sydney that was delivered in Mandarin and Cantonese. The development of further pulmonary rehabilitation programs for particular cultural groups, using either bilingual health care professionals or qualified interpreters to facilitate communication, may be of benefit in improving efficiency of resources. However it was identified that programs with a higher number of referrals for individuals from CALD backgrounds were also more likely to report a greater number of different languages spoken by participants in their program, which may make it difficult to target specific cultural groups for such programs.

Whilst there was a high level of diversity in individuals participating in pulmonary rehabilitation, only two participants in this study reported speaking a language other than English, suggesting there is lower diversity amongst health care professionals. The use of multicultural health workers, members of CALD communities who are bilingual or multilingual and have received training in health promotion, has been shown to improve knowledge and behaviour change outcomes in chronic disease management [82]. The use of multicultural health workers in pulmonary rehabilitation could potentially improve the engagement of individuals from CALD backgrounds in pulmonary rehabilitation, as well as assist in providing education to these individuals. It is also worth considering how to better support individuals from CALD backgrounds to successfully undertake university level studies and become health professionals, enhancing the cultural diversity of the health care team.

Development of innovative new service models that help to address the barriers identified in this study, and harness potential facilitators may be useful in enhancing the delivery of pulmonary rehabilitation to individuals from CALD backgrounds. This may include developing groups for individuals from specific cultural backgrounds, enhancing both the training of interpreters and staff working with interpreters, and the development of models that optimise interpreter use. Similarly, different models of education provision could be considered, such as education days in specific languages. This would be more efficient than having numerous interpreters attending multiple education sessions to interpret for one individual at a time.

Participants in this study suggested a number of alternate methods of communication, however at present some methods are not available and other methods do not meet policy requirements. In particular, new assistive technology may provide opportunities for alternate solutions to the significant barriers of language and available interpretation. With the continual advancement of technology there is likelihood for this to provide strong future solutions to these barriers. Therefore, it is important that policy makers ensure policy and procedures are in place to facilitate these advancements and new opportunities, and that they don't stifle the utilisation of innovative solutions.

#### 6.2.3 Research Implications

This study considers barriers and facilitators from the perspective of pulmonary rehabilitation program coordinators, but not those of other stakeholders who are

likely to offer alternate perspectives. Therefore, further research is required to examine whether there are alternate perspectives. These may include some barriers that have not been considered here, as well as additional facilitators that could be utilised to enhance access and service provision. The highest priority for further research should be with individuals from CALD backgrounds who are eligible for pulmonary rehabilitation, to identify their perceptions of barriers and potential facilitators, maintaining a person-centred approach with the co-creation of potential solutions, such as the development of suitable resources. Family members of individuals from CALD backgrounds with chronic respiratory diseases are also important stakeholders. Research investigating their beliefs about health and exercise, as well as their understanding of the management of their family member's lung disease may identify methods to better engage the support of family members and encourage an individual to participate in pulmonary rehabilitation.

Four participants in this study perceived that the referrals of individuals from CALD backgrounds to their program did not reflect the demographics of the area that their program covered, however participants were not clear on why this was the case. Further research with health professionals who refer individuals to pulmonary rehabilitation programs, such as respiratory specialists, general practitioners and physiotherapists, should be conducted to identify if there are any reasons that individuals from CALD backgrounds are not referred to pulmonary rehabilitation programs.

This study highlighted a number of potential solutions for barriers identified by program coordinators, particularly in regards to the language barrier. The use of technology for translation was suggested. Research could be conducted to identify potential uses of technology, such as applications with translations of keywords, phrases or useful information, and assess if a valid and acceptable tool can be developed. The use of education videos in different languages were also suggested, and these could be developed and tested for appropriateness, acceptability and effectiveness in achieving learning outcomes.

Development and testing of different service models to address the barriers identified, and harness potential facilitators, will help to identify if there are better methods of delivering pulmonary rehabilitation to individuals from CALD backgrounds, or if the current model with additional support is most appropriate. Engaging various stakeholders in the co-creation of innovative solutions to this complex issue will provide an opportunity to develop feasible, acceptable and effective solutions that are not only culturally responsive, but pragmatic and implementable.

# 6.3 Conclusion

All participants reported that the pulmonary rehabilitation program they coordinate receives referrals of individuals from CALD backgrounds, with a range in number of referrals. Individuals participating in pulmonary rehabilitation programs in the Sydney metropolitan area come from a variety of cultural backgrounds.

This study identified barriers to providing pulmonary rehabilitation as perceived by pulmonary rehabilitation coordinators in the Sydney Metropolitan area. Communication difficulties, including language and challenges with interpretation, were the most commonly identified barriers, as well as those reported to have the greatest impact. Cultural factors such as differing beliefs about health and exercise were a barrier when not able to be accommodated by the pulmonary rehabilitation program. Limited resources were also identified as a potential barrier.

Potential facilitators to providing pulmonary rehabilitation to individuals from CALD backgrounds were also identified. Most of the facilitators identified were aimed at overcoming difficulties communicating with individuals with low levels of English proficiency. Facilitators included using qualified interpreters, as well as utilising alternate methods of communication such as translated written resources, visual information and video. Family support was also identified as a potential facilitator, both for interpreting information and encouraging individuals in the management of their condition.

The outcomes of this study suggest that there is a need for new and innovative solutions to enhance the provision of pulmonary rehabilitation to individuals from CALD backgrounds. Further research with other stakeholders involving the cocreation of innovative solutions to overcome the barriers and improve service delivery models is urgently needed. In the interim, the development of more effective and shared resources, will help to overcome the barriers identified in this

study, and improve the provision of pulmonary rehabilitation to the many individuals from CALD backgrounds who would benefit this program.

# References

- 1. Spruit, M., et al., *ATS/ERS task force on pulmonary rehabilitation. An official American Thoracic Society/European Respiratory Society statement: key concepts and advances in pulmonary rehabilitation.* Am J Respir Crit Care Med, 2013. **188**(8): p. e13-64.
- 2. Yang, I.A, Brown J.L., George J, Jenkins S, McDonald CF, McDonald V, Smith B, Zwar N, and Dabscheck E, *The COPD-X Plan: Australian and New Zealand Guidelines for the management of Chronic Obstructive Pulmonary Disease 2018*, Versiom 2.54, 2018.
- 3. Johnston, C.L., L.J. Maxwell, and J.A. Alison, *Pulmonary rehabilitation in Australia: a national survey.* Physiotherapy, 2011. **97**(4): p. 284-290.
- 4. Jenkins, S., K. Hill, and N.M. Cecins, *State of the art: how to set up a pulmonary rehabilitation program.* Respirology, 2010. **15**(8): p. 1157-1173.
- 5. McCarthy, B., et al., *Pulmonary rehabilitation for chronic obstructive pulmonary disease.* Cochrane Database Syst Rev. 2015;2. The Cochrane Collaboration.
- 6. Puhan, M.A., et al., *Pulmonary rehabilitation following exacerbations of chronic obstructive pulmonary disease.* Cochrane Database Syst Rev. 2016;12. The Cochrane Collaboration.
- 7. Dowman, L., C.J. Hill, and A.E. Holland, *Pulmonary rehabilitation for interstitial lung disease*. Cochrane Database Syst Rev. 2014;10. The Cochrane Collaboration.
- 8. Lee, A.L., et al., *Pulmonary Rehabilitation in Individuals With Non-Cystic Fibrosis Bronchiectasis: A Systematic Review.* Archives of Physical Medicine and Rehabilitation, 2017. **98**(4): p. 774-782.e1.
- 9. Toelle, B.G., et al., Respiratory symptoms and illness in older Australians: the Burden of Obstructive Lung Disease (BOLD) study. Med J Aust, 2013. **198**(3): p. 144-8.
- 10. Australian Bureau of Statistics, *National Health Survey: First Results, 2014–15*, Doc. No. 4364.0.55.001, ABS, Canberra, 2015.
- 11. Lung Foundation Australia. *Pulmonary Rehabilitation Program Locations*. Viewed 24 May 2017.
  - http://lungfoundation.com.au/patient-support/living-with-a-lung-condition/pulmonary-rehabilitation-2/pulmonary-rehabilitation-programs-2/.
- 12. Marks, G., et al., Monitoring pulmonary rehabilitation and long-term oxygen therapy for people with chronic obstructive pulmonary disease (COPD) in Australia. Australian Institute of Health and Welfare: Canberra, 2013; pp. 38.

- 13. Australian Bureau of Statistics, *Migration, Australia, 2015-16*, Doc. No. 3412.0, ABS, Canberra, 2017.
- 14. Australian Bureau of Statistics, 2016 Census: Multicultural [media release], 2017. Viewed 3 August 2017. http://www.abs.gov.au/ausstats/abs@.nsf/lookup/Media%20Release3
- 15. Queensland Government, *Practice Paper: Working with people from culturally and linguistically diverse backgrounds*, 2010; pp. 28.
- 16. Ethnic Communities' Council of Victoria, *ECCV Glossary of Terms*, 2012; pp. 4.
- 17. Bhugra, D. and M.A. Becker, *Migration, cultural bereavement and cultural identity.* World psychiatry, 2005. **4**(1): p. 18-24.
- 18. Jupp, J., From 'White Australia' to 'Part of Asia': recent shifts in Australian immigration policy towards the region. International Migration Review, 1995: p. 207-228.
- 19. Department of Immigration and Border Protection, *2016-2017 Migration Programme Report*; pp. 15.
- 20. Australian Government Department of Immigration and Citizenship, *Refugee and Humanitarian Issues Australia's Response*, 2009; pp. 52.
- 21. Kaufert, J.M. and R.W. Putsch, *Communication through interpreters in healthcare: ethical dilemmas arising from differences in class, culture, language, and power.* Journal of Clinical Ethics, 1997. **8**: p. 71-87.
- 22. Australian Bureau of Statistics, *Australian Social Trends, 2014*, Doc. No. 4102.0, ABS, Canberra, 2014.
- 23. Australian Bureau of Statistics, 2016 Census QuickStats, 2018. Viewed 29 September 2018. http://quickstats.censusdata.abs.gov.au/census\_services/getproduct/census/2016/quickstat/1GSYD?opendocument.
- 24. Australian Institute of Health and Welfare, *Australia's Health 2010*. Australia's health series no. 12. Cat. No. AUS 122, AIHW, Canberra, 2010; pp. 567.
- 25. Kennedy, S., et al., *The healthy immigrant effect: patterns and evidence from four countries.* Journal of International Migration and Integration, 2015. **16**(2): p. 317-332.
- 26. Australian Institute of. Australian Institute of Health and Welfare, *Australia's Health 2008.* Cat. No. AUS 99, AIHW, Canberra, 2008; pp. 610.
- 27. Biddle, N., S. Kennedy, and J.T. McDonald, *Health assimilation patterns amongst Australian immigrants.* Economic Record, 2007. **83**(260): p. 16-30.
- 28. Jatrana, S., S.S.R. Pasupuleti, and K. Richardson, *Nativity, duration of residence and chronic health conditions in Australia: Do trends converge towards the native-born population?* Social science & medicine, 2014. **119**: p. 53-63.

- 29. Australian Bureau of Statistics, *Understanding Migrant Outcomes Enhancing the Value of Census Data, Australia, 2011,* Doc. No. 3417.0, ABS, Canberra, 2013.
- 30. Australian Institute of Health and Welfare, *Australia's Health 2004.* Cat. No. AUS 44, AIHW, Canberra, 2004; pp. 528.
- 31. Anikeeva, O., et al., *The health status of migrants in Australia: a review.* Asia Pacific Journal of Public Health, 2010. **22**(2): p. 159-193.
- 32. Australian Bureau of Statistics, *Characteristics of Recent Migrants, Australia, November 2016*. Doc No. 6250.0, ABS, Canberra, 2017.
- 33. Mathers, C.D. and D.J. Schofield, *The health consequences of unemployment: the evidence.* The Medical Journal of Australia, 1998. **168**(4): p. 178-182.
- 34. Chiswick, B.R., Y.L. Lee, and P.W. Miller, *Immigrant selection systems and immigrant health*. Contemporary Economic Policy, 2008. **26**(4): p. 555-578.
- 35. Johnston, V., L. Smith, and H. Roydhouse, *The health of newly arrived refugees to the Top End of Australia: results of a clinical audit at the Darwin Refugee Health Service.* Australian Journal of Primary Health, 2012. **18**(3): p. 242-247.
- 36. Weber, M.F., E. Banks, and F. Sitas, *Smoking in migrants in New South Wales, Australia: report on data from over 100 000 participants in The 45 and Up Study.* Drug and alcohol review, 2011. **30**(6): p. 597-605.
- 37. Australian Bureau of Statistics, *National Health Survey: First Results, 2014–15 Australia,* 'Table 4.3 Long-term health conditions by population characteristics, Proportion of persons(a)', data cube: Excel spreadsheet, cat. No. 4364055001D0004\_20142015, 2018. Viewed 7 August 2018. http://www.abs.gov.au/AUSSTATS/abs@.nsf/DetailsPage/4364.0.55.0012 014-15?OpenDocument
- 38. Brown, W.J., C. Lee, and R. Oyomopito, *Effectiveness of a bilingual heart health program for Greek-Australian women.* Health Promotion International, 1996. **11**(2): p. 117-125.
- 39. Brown, W.J., C. Lee, and Y.N. Nasstasia, *Heart health for migrant women: A short intervention with Macedonian Australian Women.* Health Promotion Journal of Australia, 1997. **7**(2): p. 134-137.
- 40. Lu, Y., et al., *The evaluation of a culturally appropriate, community-based lifestyle intervention program for elderly Chinese immigrants with chronic diseases: a pilot study.* Journal of public health, 2013: p. 149-155.
- 41. Banerjee, A.T., et al., *A Pilot Examination of a Mosque-Based Physical Activity Intervention for South Asian Muslim Women in Ontario, Canada.* Journal of immigrant and minority health, 2017. **19**(2): p. 349-357.
- 42. Banerjee, A.T., et al., *Cultural factors facilitating cardiac rehabilitation participation among Canadian South Asians: a qualitative study.* Heart & Lung: The Journal of Acute and Critical Care, 2010. **39**(6): p. 494-503.

- 43. Galdas, P.M. and H.B.K. Kang, *Punjabi Sikh patients' cardiac rehabilitation experiences following myocardial infarction: a qualitative analysis.* Journal of clinical nursing, 2010. **19**(21 22): p. 3134-3142.
- 44. Haghshenas, A. and P.M. Davidson, *Quality service delivery in cardiac rehabilitation: cross-cultural challenges in an Australian setting.* Quality in primary care, 2011. **19**(4).
- 45. Keating, A., A.L. Lee, and A.E. Holland, *Lack of perceived benefit and inadequate transport influence uptake and completion of pulmonary rehabilitation in people with chronic obstructive pulmonary disease: a qualitative study.* Journal of Physiotherapy, 2011. **57**(3): p. 183-190.
- 46. Mathar, H., et al., *Why do patients decline participation in offered pulmonary rehabilitation? A qualitative study.* Clinical rehabilitation, 2017. **31**(12): p. 1674-1683.
- 47. Vatcharavongvan, P., et al., What are the health needs, familial and social problems of Thai migrants in a local community in Australia? A focus group study. Journal of immigrant and minority health, 2014. **16**(1): p. 143-149.
- 48. Garrett, P.W., et al., What do non-English-speaking patients value in acute care? Cultural competency from the patient's perspective: a qualitative study. Ethnicity & health, 2008. **13**(5): p. 479-496.
- 49. Radermacher, H. and S. Feldman, 'Health is their heart, their legs, their back': understanding ageing well in ethnically diverse older men in rural Australia. Ageing & Society, 2015. **35**(5): p. 1011-1031.
- 50. Blignault, I., et al., A qualitative study of barriers to mental health services utilisation among migrants from mainland China in South-East Sydney. International Journal of Social Psychiatry, 2008. **54**(2): p. 180-190.
- 51. Chauhan, U., et al., Exploring uptake of cardiac rehabilitation in a minority ethnic population in England: a qualitative study. European Journal of Cardiovascular Nursing, 2010. **9**(1): p. 68-74.
- 52. Brunk, D.R., et al., *A Culturally Appropriate Self-Management Program for Hispanic Adults With Type 2 Diabetes and Low Health Literacy Skills.* Journal of Transcultural Nursing, 2017. **28**(2): p. 187-194.
- 53. Caperchione, C.M., G.S. Kolt, and W.K. Mummery, *Examining physical activity service provision to culturally and linguistically diverse (CALD) communities in Australia: a qualitative evaluation.* PloS one, 2013. **8**(4): p. e62777.
- 54. Creswell, J.W. and V.L. Plano Clark, *Designing and conducting mixed methods research*. 2<sup>nd</sup> ed., Sage Publications, 2011; pp. 457.
- 55. Rattray, J. and M.C. Jones, *Essential elements of questionnaire design and development*. Journal of clinical nursing, 2007. **16**(2): p. 234-243.
- 56. Field, A., *Discovering Statistics Using IBM SPSS Statistics.* 4<sup>th</sup> ed., London: Sage Publications, 2013; pp 952.
- 57. Polit, D.F. and C.T. Beck, *Nursing research: Generating and assessing evidence for nursing practice*. Lippincott Williams & Wilkins, 2008; pp. 802.

- 58. Curry, L. and M. Nunez-Smith, *Mixed methods in health sciences research: A practical primer*. Vol. 1, Sage Publications, 2014; pp. 394.
- 59. Thomas, E. and J.K. Magilvy, *Qualitative rigor or research validity in qualitative research.* Journal for specialists in pediatric nursing, 2011. **16**(2): p. 151-155.
- 60. Krupinski, J., Changing patterns of migration to Australia and their influence on the health of migrants. Social Science & Medicine, 1984. **18**(11): p. 927-937.
- 61. Phillips, J., M. Klapdor, and J. Simon-Davies, *Migration to Australia since federation: a guide to the statistics.* Migration, 2010; pp. 25.
- 62. Hayton, C., et al., *Barriers to pulmonary rehabilitation: characteristics that predict patient attendance and adherence.* Respiratory medicine, 2013. **107**(3): p. 401-407.
- 63. Kelaher, M. and L. Manderson, *Migration and mainstreaming: matching health services to immigrants' needs in Australia.* Health Policy, 2000. **54**(1): p. 1-11.
- 64. Selzler, A.-M., et al., *Pulmonary rehabilitation in chronic obstructive pulmonary disease: predictors of program completion and success.* COPD: Journal of Chronic Obstructive Pulmonary Disease, 2012. **9**(5): p. 538-545.
- 65. Alison, J., et al., *The pulmonary rehabilitation toolkit on behalf of the Australian Lung Foundation*, 2016. Viewed 9 September 2018. https://pulmonaryrehab.com.au
- 66. Cohen, A.L., et al., *Are language barriers associated with serious medical events in hospitalized pediatric patients?* Pediatrics, 2005. **116**(3): p. 575-579.
- 67. Johnstone, M.-J. and O. Kanitsaki, *Culture, language, and patient safety: making the link.* International journal for quality in health care, 2006. **18**(5): p. 383-388.
- 68. Garrett, P.W., et al., *How are language barriers bridged in acute hospital care? The tale of two methods of data collection.* Australian Health Review, 2008. **32**(4): p. 755-764.
- 69. Karliner, L.S., et al., *Do professional interpreters improve clinical care for patients with limited English proficiency? A systematic review of the literature.* Health services research, 2007. **42**(2): p. 727-754.
- 70. NSW Ministry of Health (2017) *Interpreters Standard Procedures for Working with Health Care Interpreters*, Doc. No PD2017\_044; pp. 38.
- 71. Aranguri, C., B. Davidson, and R. Ramirez, *Patterns of communication through interpreters: a detailed sociolinguistic analysis.* Journal of general internal medicine, 2006. **21**(6): p. 623-629.
- 72. National Accreditation Authority for Translators and Interpreters, *What We Do*, 2017. Viewed: 9 September 2018. https://www.naati.com.au/about/what-we-do/

- 73. Koo, F.K., A case study on the perception of aging and participation in physical activities of older Chinese immigrants in Australia. Journal of aging and physical activity, 2011. **19**(4): p. 388-417.
- 74. Kolt, G.S., J.E. Paterson, and V.Y. Cheung, *Barriers to physical activity* participation in older Tongan adults living in New Zealand. Australasian Journal on Ageing, 2006. **25**(3): p. 119-125.
- 75. Flores, G., *Language barriers to health care in the United States.* New England Journal of Medicine, 2006. **355**(3): p. 229-231.
- 76. Mansoor, L.E. and R. Dowse, *Effect of pictograms on readability of patient information materials*. Annals of Pharmacotherapy, 2003. **37**(7-8): p. 1003-1009.
- 77. Arcia, A., et al., Sometimes more is more: iterative participatory design of infographics for engagement of community members with varying levels of health literacy. Journal of the American Medical Informatics Association, 2015. **23**(1): p. 174-183.
- 78. Poureslami, I., et al., Assessing the effect of culturally specific audiovisual educational interventions on attaining self-management skills for chronic obstructive pulmonary disease in Mandarin- and Cantonese-speaking patients: a randomized controlled trial. International Journal Of Chronic Obstructive Pulmonary Disease, 2016. 11: p. 1811-1822.
- 79. Blackstock, F.C., et al., Comparable improvements achieved in chronic obstructive pulmonary disease through pulmonary rehabilitation with and without a structured educational intervention: a randomized controlled trial. Respirology, 2014. **19**(2): p. 193-202.
- 80. Alison, J.A., et al., *Australian and New Zealand Pulmonary Rehabilitation Guidelines*. Respirology, 2017. **22**(4): p. 800-819.
- 81. Kreuter, M.W., et al., *Achieving cultural appropriateness in health promotion programs: targeted and tailored approaches.* Health Education & Behavior, 2003. **30**(2): p. 133-146.
- 82. Goris, J., et al., *Effectiveness of multicultural health workers in chronic disease prevention and self-management in culturally and linguistically diverse populations: a systematic literature review.* Australian journal of primary health, 2013. **19**(1): p. 14-37.

# **Appendices**

**Appendix 1: Survey** 

# Pulmonary rehabilitation for individuals from CALD backgrounds

# Barriers and facilitators to providing pulmonary rehabilitation to individuals from culturally and linguistically diverse backgrounds

Thank you for taking the time to visit this site. This page provides detailed information about this survey. Please take the time to read this information carefully.

### What does the survey aim to do?

We are interested in the thoughts and beliefs of pulmonary rehabilitation coordinators in the Sydney metropolitan area regarding the barriers and facilitators to providing pulmonary rehabilitation to individuals from culturally and linguistically diverse (CALD) backgrounds.

Individuals from CALD backgrounds are those born overseas, in non-main English speaking countries, whose cultural heritage differs from that of the Anglo-Australian culture.

# What is involved?

If you decide to participate, you will be asked to complete a brief questionnaire that will involve answering questions regarding your thoughts and beliefs regarding the provision of pulmonary rehabilitation to individuals from CALD backgrounds. We estimate that this survey will take **approximately 10 minutes**.

The second stage of our study will involve telephone interviews to gain more indepth information on the thoughts and beliefs you may have regarding the provision of pulmonary rehabilitation to individuals from culturally and linguistically diverse backgrounds, and you may be contacted to request participation in this stage. Interviews are expected to take place in early 2018.

# Who can participate in this survey?

Anyone who is the primary coordinator of a pulmonary rehabilitation program in the Sydney metropolitan area. Where there is more than one person involved in coordinating the program the person who is best able to answer questions about referral rates and involvement of individuals from CALD backgrounds participating in the program should complete the survey.

### Are there any risks?

There are no anticipated risks associated with undertaking this questionnaire. Participation in this study is entirely voluntary. You are not obliged to participate in or to complete this questionnaire.

# What are the expected benefits of this research?

There are no direct benefits from participating in this research study, however it is expected that identifying barriers and facilitators to providing pulmonary rehabilitation to individuals from CALD backgrounds will assist in improving services to better provide for these individuals. This will improve access to pulmonary rehabilitation for individuals from CALD backgrounds and facilitate improvements in health and quality of life.

# What about privacy and confidentiality?

Any identifiable information collected about you will remain entirely confidential, and will not be disclosed without your expressed permission unless we are required to do so by law. All data will be stored in password protected computer files that can be accessed only by study investigators at Macquarie University. Any data generated from this survey used in future research studies will only be done so in non-identifiable form. Dissemination of study results in any form will be only done in a manner that does not allow for identification.

# Who is conducting this survey?

This study is being carried out by physiotherapist, Liz Havyatt, to meet the requirements of Masters of Research. Liz is working under the supervision of Associate Professor Taryn Jones and Professor Catherine Dean from Macquarie University, and in conjunction with Mr Tim Noblet.

The ethical aspects of this questionnaire have been approved by the Macquarie University Human Research Ethics Committee (Medical Sciences) (Ref no 5201700638). If you have any complaints or reservations about any ethical aspect of your participation in this research, you may contact the Committee through the Director, Macquarie University Research Ethics (Ph: +61 2 9850 7854; email: ethics@mq.edu.au).

#### Can I contact the researchers?

The researchers can be contacted by email on taryn.jones@mq.edu.au or elizabeth.havyatt@hdr.mq.edu.au or by phone on 02 9850 2796.

#### Am I able to obtain a summary of the study results?

Yes, a short summary of the overall study results will be available once the study has been completed. Should you be interested in obtaining a copy of this summary please email Liz Havyatt at elizabeth.havyatt@hdr.mq.edu.au.

# What do I do now?

If you have read and understood the above information and would like to participate in the study please select "yes" below, knowing you can withdraw from the study at any stage. Should you not wish to participate in the study please select

participation in this study is entirely voluntary; you are not obliged to participate and if you decide to participate, you are free to withdraw at any time, even after completing the questionnaire, without giving a reason and without consequence.
<ul><li>Yes, I have read the above information and agree to participate in the study</li><li>(1)</li></ul>
<ul><li>No, I do not want to participate at this time (2)</li></ul>
Skip To: End of Survey If Barriers and facilitators to providing pulmonary rehabilitation to individuals from culturally = No, I do not want to participate at this time
What is your name?
○ First name (1)
O Last name (2)
What is your email address and/or contact phone number?
O Email (1)
O Phone number (2)
O Alternative phone number (3)
What is the postcode of your pulmonary rehabilitation program?
NB: If your program covers more than one site, please provide the postcode of the primary site.
O Postcode (1)

What is your professional role?
O Physiotherapist (1)
O Nurse (2)
Other (please specify) (3)
How long have you been practicing as a health professional? (Answer in years)
Where did you receive your qualification?
O Australia (1)
Other English speaking country (2)
O Non-English speaking country (3)
Have you ever practiced overseas?
O Yes (please specify where) (1)
O No (2)
Page Break
How long have you been coordinating your pulmonary rehabilitation program? (Answer in years)

Have you worked in any other pulmonary rehabilitation programs?
○ Yes (1)
O No (2)
Display This Question:
If Have you worked in any other pulmonary rehabilitation programs? = Yes
How long have you worked in pulmonary rehabilitation in total? (Answer in years)
<del></del>
Do you speak any languages other than English? (To a level sufficient to use at work)
O Yes (please specify) (1)
O No (2)

rehabilitation program in 2016?
C Less than 50 (1)
O 50-75 (2)
O 76-100 (3)
O 101-125 (4)
O 126-150 (5)
O More than 150 (6)
Approximately how many individuals from CALD backgrounds were referred to your program in 2016?  Less than 5 (1)  5-10 (2)  11-15 (3)  16-20 (4)  21-25 (5)  26-30 (6)  Greater than 30 (7)

What languages other than English did individuals from CALD backgrounds referred to your program in 2016 speak?
Please select all languages that apply.
NB: languages are listed in order of most prevalent in Sydney based on data from the 2011 Census.
Mandarin (1)
Cantonese (2)
Thai (3)
Indonesian (4)
Korean (5)
Spanish (6)
Greek (7)
Vietnamese (8)
Russian (9)
French (10)
Arabic (11)
Italian (12)
Japanese (13)
German (14)
Filipino/Tagalong (15)
Hindi (16)

Chinese (other) (17)
Portuguese (18)
Turkish (19)
Polish (20)
Persian/Dari (21)
Nepali (22)
Serbian (23)
Bengali (24)
Dutch (25)
Min Nan (incl Hokkien) (26)
Croatian (27)
Hungarian (28)
Czech (29)
Swedish (30)
Tamil (31)
Malay (32)
Macedonian (33)
Other (please specify) (34)

Do the referrals to your program of individuals from CALD backgrounds accurately reflect the area your program covers?

O No (2)					
When you have a patient with limited English how often do you use an interpreter for?					
	Always (1)	Most of the time (2)	About half the time (3)	Sometimes (4)	Never (5)
Initial assessments (1)	0	$\circ$	$\circ$	$\circ$	$\circ$
Final assessments (2)	0	$\circ$	$\circ$	$\circ$	$\circ$
Do you use an	interpreter fo	r exercise ses	sions?		
O For all	exercise classe	es (1)			
O For mo	st exercise cla	sses (2)			
O For hal	f of the exercis	se classes (3)			
O For les	s than half of t	he exercise cl	asses (4)		
O For the	e first exercise	class (5)			
O For not	ne of the exerc	rise classes (6	5)		

O Yes (1)

How confident are you using interpreters?
O Not at all confident (1)
Slightly confident (2)
○ Confident (3)
O Very confident (4)
Do you ever use family members to interpret?
O Always (9)
O Most of the time (10)
O About half the time (11)
O Sometimes (12)
O Never (13)
Skip To: Q21 If Do you ever use family members to interpret? = Never
Under what circumstances are you more likely to use family members to interpret?

program? (Select all that apply)	
Six-Minute Walk Test (1)	
Incremental Shuttle Walk Test (2)	
Endurance Shuttle Walk Test (8)	
Chronic Respiratory Disease Questionnaire (3)	
St George's Respiratory Questionnaire (4)	
COPD Assessment Test (5)	
Hospital Anxiety and Depression Scale (6)	
Other (please specify) (7)	
Which assessments do you use for individuals from CALD backgrounds participating in your pulmonary rehabilitation program? (Select all that apply)	
Six-Minute Walk Test (1)	
Incremental Shuttle Walk Test (2)	
Endurance Shuttle Walk Test (8)	
Chronic Respiratory Disease Questionnaire (3)	
St George's Respiratory Questionnaire (4)	
COPD Assessment Test (5)	
Hospital Anxiety and Depression Scale (6)	
Other (please specify) (7)	

How do you administer questionnaires with individuals from CALD backgrounds? (Select all that apply)
Translated questionnaire (1)
Assisted by interpreter (2)
Assisted by family member (3)
Other (please specify) (4)

What education do you provide to participants in your pulmonary rehabilitation program? (Select all that apply)
Education booklet (1)
Group education session/s (2)
Other (please specify) (3)
How do you provide education to individuals from CALD backgrounds participating in your pulmonary rehabilitation program? (Select all that apply)
Translated education booklet (1)
Translated group education session/s (2)
One-on-one education with interpreter (3)
One-on-one education with family member interpreting (4)
Nil education provided (5)
Other (please specify) (6)

What do you offer participants for maintenance following completion of your pulmonary rehabilitation program? (Select all that apply)
Regular supervised exercise sessions provided by your program (1)
Lungs in Action (2)
Community exercise programs (3)
Individual exercise program (4)
No maintenance (5)
Other (please specify) (6)
Are individuals from CALD backgrounds offered the same maintenance options?
O Always (17)
O Most of the time (14)
O About half the time (15)
O Rarely (16)
Skip To: Barriers If Are individuals from CALD backgrounds offered the same maintenance options? = Always
For what reasons would an individual from a CALD background not be offered the same maintenance options?
<del></del>

How strongly do you agree that these are barriers to individuals from CALD backgrounds participating in pulmonary rehabilitation?

	Strongly disagree (11)	Somewhat disagree (12)	Neither agree nor disagree (13)	Somewhat agree (14)	Strongly agree (15)
Language barrier (1)	0	0	0	0	0
Lack of understanding of what pulmonary rehabilitation will involve (2)	0	0	0	0	0
Lack of perceived benefit of pulmonary rehabilitation (3)	0	0	0	0	0
Lack of social support (4)	$\circ$	$\circ$	$\circ$	$\circ$	$\circ$
Cultural beliefs about health (5)	0	$\circ$	$\circ$	$\circ$	$\circ$
Cultural beliefs about exercise (10)	0	0	$\circ$	$\circ$	$\circ$
Transport difficulties (6)	0	0	$\circ$	$\circ$	$\circ$
Difficulty finding the venue (7)	0	$\circ$	$\circ$	0	0
Cost (e.g. costs involved with transport) (8)	0	$\circ$	0	$\circ$	0
Time constraints (9)	0	0	$\circ$	$\circ$	$\circ$

Translated education booklet (1)	useful (1)	useful (2)	useful (3)	(4)	useful (5)
Translated Borg Scale of Breathlessness (2)	0	0	$\circ$	0	0
Translated questionnaires (3)	0	0	$\circ$	$\circ$	0
Translated written instructions for exercise equipment (4)	0	0	0	0	0
Translated instruction video for exercise equipment on tablet (5)	0	0	0	0	0

Are there any other factors that you believe may be barriers to individuals from CALD backgrounds participating in pulmonary rehabilitation?

Thank you for taking the time to complete this survey.

The second stage of this study will involve telephone interviews to further explore thoughts and beliefs on providing pulmonary rehabilitation to individuals from CALD backgrounds. Do you consent to being contacted to participate in a telephone interview at a time convenient to you?

- Yes (1)
- O No (2)

# **Appendix 2: Interview Guide**

Individuals from culturally and linguistically diverse backgrounds are individuals born in countries other than those classified as main English speaking countries by the Australian Bureau of Statistics. It is a broad descriptor for communities with diverse language, ethnic background, nationality, traditions and religion.

How do you think cultural and linguistic diversity may influence an individual's views towards their health and healthcare?

# **Barriers**

Many barriers to participating in pulmonary rehabilitation have been identified in the literature.

What do you think might be barriers to participating in pulmonary rehabilitation for individuals from CALD backgrounds?

What challenges have you faced in delivering pulmonary rehabilitation to individuals from CALD backgrounds?

How do you prescribe/progress exercises for CALD individuals?

Do you have any concerns about safety with CALD individuals attending your program?

# <u>Interpreter Use</u>

Individuals from CALD populations may have limited English and require the use of an interpreter to effectively communicate with health professionals.

When do you consider it important to use interpreters for individuals from CALD backgrounds?

(Prompts if needed – at initial assessment, at final assessment, throughout program)

Have you experienced any challenges using interpreters?

Have you experienced any challenges when using family members to interpret?

# Education

How do you provide education to individuals from CALD backgrounds?

What resources do you think could be helpful in providing education to individuals from CALD backgrounds?

### Resources

What resources have you used to assist in delivering pulmonary rehabilitation to CALD individuals?

Are there any resources that you think could be beneficial in providing pulmonary rehabilitation to individuals from CALD backgrounds?