

An Evaluation of Factors That Influence Referral to Pulmonary Rehabilitation Programs Among People With COPD

Q1 Sarah Hug, BSc; Vinicius Cavalheri, PhD; Daniel F. Gucciardi, PhD; and Kylie Hill, PhD

BACKGROUND: Pulmonary rehabilitation programs (PRP) are important for people with symptomatic COPD.

RESEARCH QUESTIONS: What proportion of people with COPD who are suitable for a PRP go on to be referred? Do clinical or sociodemographic characteristics influence the odds of whether those who are suitable for a PRP go on to be referred? What factors influence people's interest in participating in a pulmonary rehabilitation program?

STUDY DESIGN AND METHODS: People with COPD who appeared appropriate for a PRP were sequentially recruited from three tertiary hospitals in Australia. Variables such as age, sex, lung function, smoking status, and interest in participating in a PRP were collected through interviews and reviewing the medical records. Referrals to PRPs were prospectively tracked through the electronic referral system, medical records, and discussion with the participant or the physiotherapists responsible for coordinating the PRPs.

RESULTS: Six hundred eighty-two people with COPD were approached, 468 consented, and data were available on 391 (No. [%] or mean \pm SD; 215 males [55%], age 69 ± 10 years, FEV₁ 49 ± 19 %predicted). Of the 156 participants deemed suitable for a PRP, 74 (47%, 95% CI, 40-55) were referred to a PRP. Among participants who were deemed suitable for a PRP, the only variable that separated those who were from those who were not referred was interest in attending a PRP (mean difference in interest on the Visual Analog Scale [VAS]; 22 units, 95% CI, 12-32). Introverted personality traits and feelings of unworthiness reduced interest in attending a PRP.

INTERPRETATION: Among people with COPD who were suitable for a PRP, referral from the tertiary hospital setting was suboptimal. Suitable participants who were not referred showed lower interest in attending a PRP. There were novel complex individual barriers that reduced one's interest in participating in a PRP.

CHEST 2022; ■(■):■-■

KEY WORDS: behavior; COPD; exercise training; pulmonary rehabilitation; referral

ABBREVIATIONS: HCP = health care professional; IRSAD = index of relative socio-economic advantage and disadvantage; mMRC = modified Medical Research Council scale; PRP = pulmonary rehabilitation program; VAS = visual analog scale; WA = Western Australia

AFFILIATIONS: From the Curtin School of Allied Health (S. Hug, V. Cavalheri, D. F. Gucciardi, and K. Hill), Faculty of Health Sciences, Curtin University, Perth, Australia; the Department of Physiotherapy (S. Hug), Royal Perth Hospital, Perth, Australia; the Curtin eNable Institute, Faculty of Health Sciences (V. Cavalheri, D. F. Gucciardi, and K. Hill), Curtin University, Perth, Australia; Allied Health (V. Cavalheri), South Metropolitan Health Service, Perth, Western Australia,

Australia; Exercise Medicine Research Institute (V. Cavalheri), Edith Cowan University, Perth, Australia; and the Institute for Respiratory Health (K. Hill), Perth, Australia.

FUNDING/SUPPORT: This study has received funding support through the Department of Health, Western Australia (RES-HEA-SOP-CL-61482-1).

CORRESPONDENCE TO: Kylie Hill, PhD; email: k.hill@curtin.edu.au

DOI: <https://doi.org/10.1016/j.chest.2022.01.006>

Take-home Point

Study Questions: What proportion of people with COPD who are suitable for a pulmonary rehabilitation program (PRP) go on to be referred? Do clinical or sociodemographic characteristics influence the odds of whether those who are suitable for a PRP go on to be referred? What factors influence people's interest in participating in a pulmonary rehabilitation program?

Results: Among people with COPD who were suitable for a PRP, referral from the tertiary hospital setting was suboptimal. Suitable participants who were not referred showed lower interest in attending a PRP. Introverted personality traits and feelings of unworthiness were some of the individual barriers that reduced interest in attending a PRP.

Interpretation: We demonstrated that there were complex individual barriers that influenced one's interest to participate in PRPs. Collaborations among people with COPD, clinicians, and researchers presents a unique opportunity to develop novel strategies to enhance people's interest and improve referral to PRPs among people with COPD in our tertiary setting.

Robust evidence indicates that for people with COPD), pulmonary rehabilitation programs (PRPs) that include supervised exercise training produce clinically important reductions in dyspnea and fatigue, as well as improvements in exercise tolerance and health-related quality of life.¹ The editorial that accompanies the most recent Cochrane review on pulmonary rehabilitation states that "those who apply the intervention, those who receive it, and those who fund it can act with confidence,"² and therefore PRPs should be considered a standard of care for people with COPD who are limited by dyspnea during their daily life.³⁻⁵ Nevertheless, the implementation of PRPs is problematic, with earlier work showing that the proportion of people with COPD who are actually referred to a PRP from primary or tertiary care is as low as 16%.^{6,7} Addressing this implementation gap is recognized as a global priority by

Study Design and Methods

Data reported in this study were collected between August 2020 and January 2021 as part of a mixed-methods study (the OPTIMAL study) that has been described elsewhere.⁹ Approvals from the local Ethics Committees were obtained before recruitment (RGS0000003704 and HRE2020-0095). Briefly, we sequentially

international respiratory societies,^{3,8} and understanding the reasons for suboptimal referral behaviors is an important first step.

In this study, we aimed to explore referral patterns among people with COPD known to a tertiary hospital in Perth, Western Australia (WA). Our research questions were the following:

1. What proportion of people with COPD who are receiving specialist care through a tertiary hospital and appear suitable for referral to a center-based PRP go on to be referred?
2. What are the differences in characteristics between those who are suitable and referred and those who are suitable and not referred?
3. Do clinical or sociodemographic characteristics influence the odds of whether those who are suitable for a PRP go on to be referred?
4. From the patient perspective, what factors influence people's interest in participating in a PRP?

Philosophical Positioning Underpinning Our Interpretation of Qualitative Data

Our study is informed by a critical realist perspective that has been described in detail elsewhere.⁹ Critical realism seeks to develop *empirically supported explanations* of phenomena via questions of how, why, and under what conditions.¹⁰ It is therefore important to appreciate our personal biases when we interpret these data to create meaning. S. H., V. C., and K. H. pay particular attention to PRPs not being prioritized in the tertiary setting, implicit biases of clinicians, and stigma and nihilism associated with COPD. These personal biases have developed from our clinical and research experience as physiotherapists. D. G. is a psychological scientist who represents "neutral ground" to ensure that our participant responses are respected, and our interpretation of these data are not clouded by these biases. The meaning we generate from the qualitative data can be appreciated as a raw, explicit, "tip of the iceberg" reflection of each participant's opinion, while accounting for our influence to cultivate implicit meanings.

screened all people with COPD who either attended an outpatient respiratory clinic appointment or were hospitalized for a suspected exacerbation of their condition across three tertiary hospitals (Fiona Stanley Hospital, Royal Perth Hospital, and Sir Charles Gairdner Hospital) in Perth, WA, for their suitability to participate in this study. Criteria were designed to find cases that appeared broadly

appropriate for referral to a physiotherapist-led PRP, in either a hospital outpatient department or a community center in Perth. That is, participants were required to have a diagnosis of COPD, be able to understand English, and have a life expectancy of more than 6 months. Those recruited as outpatients needed to be independently ambulant, and those recruited during admission needed to have been independently ambulant before admission. Potential participants were excluded if they were living in supported residential aged care or had a cognitive impairment. Those recruited as outpatients were excluded if they had participated in either a PRP within the previous 12 months or a “maintenance” PRP within the previous 8 weeks because training-related gains are known to last for up to 12 months after completion of a PRP.¹¹ People who met the study criteria were approached for written informed consent. Referrals of participants recruited as in-patients were prospectively tracked two weeks after hospital discharge and, where applicable, two weeks after their first respiratory outpatient appointment. Referrals of those recruited as outpatients were tracked 2 weeks after their first respiratory outpatient appointment. Referrals were tracked by reviewing the electronic referral system, reviewing the medical records and discussion with the participant or the physiotherapists responsible for coordinating the PRPs. All participants were asked open-ended questions to identify factors that influenced whether they were interested in attending a PRP (e-Appendix 1). Researchers were also asked to record factors that they perceived to influence each participant’s interest in attending a PRP.

In Perth, PRPs are government funded and considered to be a finite resource. For this reason, in people with COPD, suitability for and participation in these programs is reserved to those who describe dyspnea as their main symptom that limits physical activity (based on modified Medical Research Council scale [mMRC], self-reported symptoms, or exercise tolerance) and have no comorbid conditions (eg, unstable cardiovascular disease or severe neurological impairment) that would preclude safe participation in land-based exercise training. All participants who consented to participate were screened against these additional criteria to confirm their suitability. Where suitability was difficult to ascertain, decision-making was escalated to a consensus group (e-Appendix 1). Using suitability criteria and referral data, participants were then classified into one of the following discrete groups: (1) appropriate referrals (ie, deemed suitable and referred to a PRP); (2) missed referrals (ie, deemed suitable but were not referred to a PRP); (3) appropriate nonreferrals (ie, deemed unsuitable and were not referred to a PRP); or (4) inappropriate referrals (ie, deemed unsuitable but were referred to a PRP).

Results

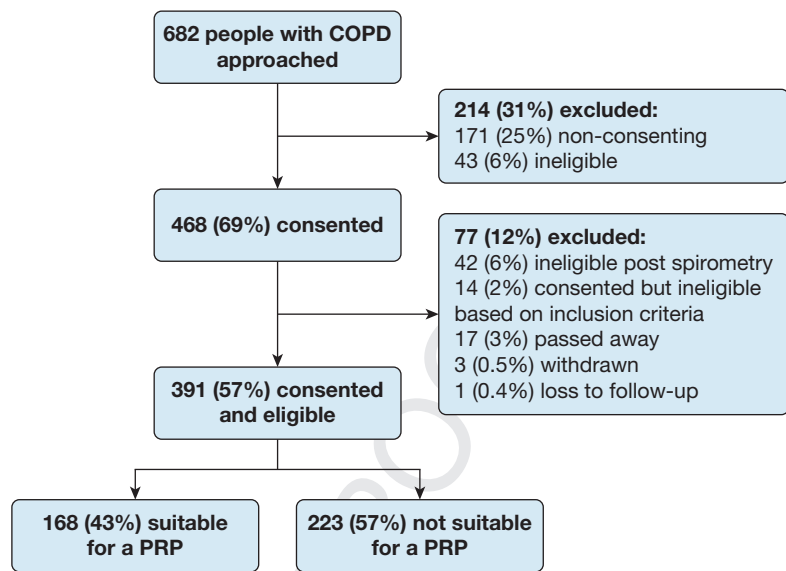
Flow of participants in the study is shown in Figure 1. Of the 682 people with COPD who were approached, 468 (69%) consented, and data were available on 391 (57%). Included participants were aged 69 ± 10 years, with a BMI of 28 ± 7 and FEV₁ of $49\% \pm 19\%$ predicted. The sample was characterized by 215 (55%) males, and 234 (60%) were recruited from outpatient respiratory clinics. A total of 12 participants who were recruited during a hospitalization were already participating in a PRP before admission, and their data were excluded from further analysis. Of the remaining 379, 156 (41%) participants were deemed suitable. Of these, 74 (47%; 95% CI, 40-55) were classified as appropriate referrals,

The primary outcomes were (1) whether participants were classified as appropriate referrals or missed referrals (expressed as a percentage of the total number who were deemed suitable for a PRP), and (2) whether participants were classified as appropriate nonreferrals or inappropriate referrals (expressed as a percentage of the total number who were deemed not suitable for a PRP). To explore differences between groups, data were extracted from the medical record and through participant interviews on age, sex, BMI, spirometric lung function, smoking status, index of relative socioeconomic advantage and disadvantage (IRSAD),¹² treating team, clinical setting, who initiated the referral, whether the participant had heard of a PRP, and whether they had previously participated in a PRP. Participants were asked to complete an mMRC score,¹³ estimate their exercise tolerance (distance walked on the level ground at their own pace before requiring a rest because of shortness of breath), and report their interest in participating in a PRP (graded using a 0 to 100 visual analog scale [VAS]¹⁴).

All statistical analyses were completed in Stata 17 (StataCorp 2021, StataCorp LLC) with normally distributed data expressed as mean \pm SD, skewed data expressed as median (interquartile range), and count data expressed as frequency (percentage). Rather than conduct sample size calculations to inform hypothesis testing, we planned to sequentially recruit all eligible participants across the three tertiary hospitals for 5 months. This approach was used to provide us with a rich data set to explore factors associated with referral patterns to PRPs. Exposure variables selected for simple logistic regression were those thought to influence referral. This decision was informed by earlier work,^{6,7} as well as the clinical experience of the research team. We were careful to only include exposure variables that could be easily measured by clinicians, so if we found an association with group membership, these could be used to guide clinical practice. Multiple logistic models were run to control for the possible confounders that may bias estimates of the association with the exposure variables that were significant in the simple regression models. Responses to open-ended questions that considered factors that influenced participant interest in a PRP were extracted to QDA Miner Lite for content analysis. Fourteen theoretical domains¹⁵ and 10 mechanisms of action domains¹⁶ were used as a framework to categorize open-ended responses. Quotes were coded independently by S. H., who met regularly with D. G. to explore interpretations. Where quotes did not fit an existing category, miscellaneous constructs were generated. S. H. revised coding based on time spent interacting with the data and discussions with the research team.

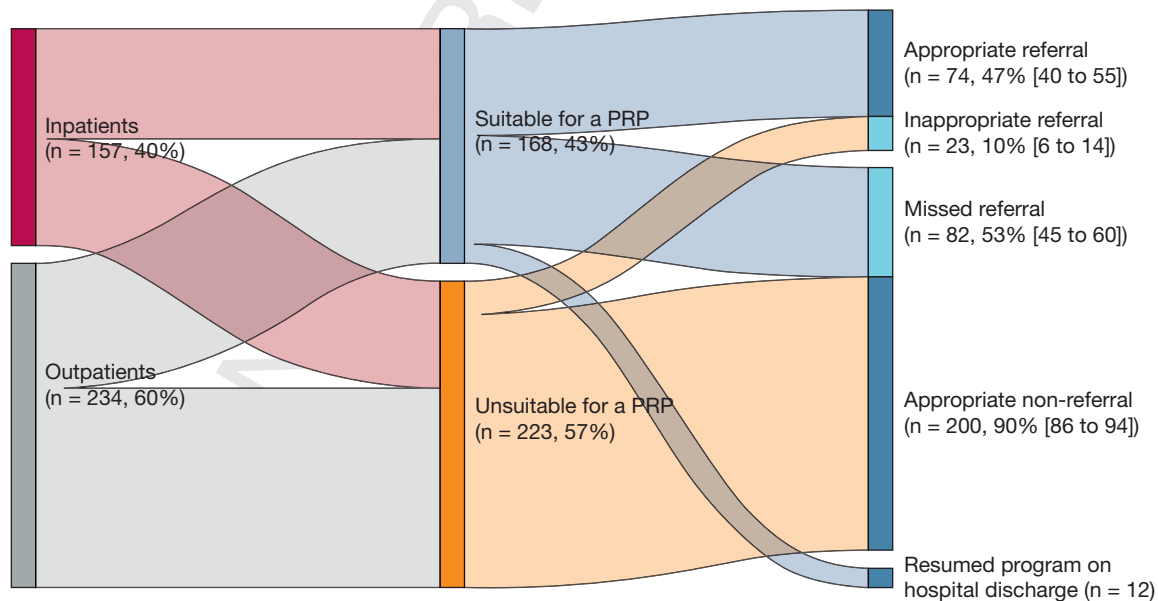
and 82 (53%; 95% CI, 45-60) were classified as missed referrals. Of the missed referrals, nine (11%) had been offered a referral but the health care professional (HCP) had not completed the referral to the PRP service providers, and 15 (18%) were offered a referral by an HCP but the participant declined. A total of 223 (59%) were deemed unsuitable for a PRP. Of these, 23 (10%; 95% CI, 6-14) were classified as inappropriate referrals and 200 (90%; 95% CI, 86-94) were classified as appropriate nonreferrals. Of the appropriate nonreferrals, 21 (11%) were offered a referral by an HCP but the participant declined. These proportions are summarized in Figure 2. Compared with those classified as missed referrals, participants classified as appropriate

331 Figure 1 – Flow of participants through the study.
 332 Reported as No. (%).



349 referrals reported greater interest in participating in a
 350 PRP (Table 1). This result was largely unchanged in a
 351 multiple logistic regression model adjusted for potential
 352 confounders of age, sex, BMI, spirometry, smoking
 353 status, treating team, mMRC, and self-report exercise
 354 tolerance (OR, 1.26; 95% CI, 1.11-1.42; Hosmer-
 355 Lemeshow $\chi^2 = 5.21$; $P = .735$).¹⁷ Sensitivity analysis
 356 showed no difference in logistic regression results when
 357 those who declined a referral were removed from the
 358 analysis (e-Table 1). Compared with those classified as

349 inappropriate referrals, there were no differences with
 350 those classified as appropriate nonreferrals (e-Appendix
 351 1, e-Table 2).
 352 Factors that influenced participant interest in a PRP
 353 were mapped as barriers or enablers to 13 (of 14)
 354 theoretical domains,¹⁵ six (of 10) mechanisms of action
 355 domains,¹⁶ and 11 miscellaneous constructs. Definitions
 356 of each domain are provided in e-Table 3. Examples of
 357 how each barrier or enabler quote was coded are
 358 provided in e-Appendix 1 and e-Appendix 3,



381 Figure 2 – Sankey diagram depicting the 391 participants and (1) the place of recruitment as either in-patients (blue), out-patients (yellow); (2) whether
 382 they were suitable for a PRP (light green) or unsuitable for a PRP (purple); and (3) those who were classified as an appropriate referral (green),
 383 inappropriate referral (red), missed referral (red), appropriate nonreferral (green), or resumed program on hospital discharge (green), reported as No.,
 384 % [95% CI].

TABLE 1] Differences in Characteristics of the Missed Referrals vs Appropriate Referrals

Variable	Missed Referrals (n = 82)	Appropriate Referrals (n = 74)		MD (95% CI) Unadjusted OR (95% CI)
Age, y	70 ± 10	68 ± 8		MD 2.02 (-0.85 to 4.89) OR 0.98 (0.94 to 1.01)
Sex, male	46 (56%)	38 (51%)		OR 0.83 (0.44 to 1.55)
BMI	28 ± 7	27 ± 7		MD 1.05 (-1.25 to 3.36) OR 0.98 (0.94 to 1.02)
FEV ₁ , % predicted ^a	48 ± 20	43 ± 19		MD 4.43 (-2.07 to 10.92) OR 0.99 (0.97 to 1.00)
Current smoker, yes	30 (38%)	27 (36%)		OR 0.96 (0.50 to 1.84)
IRSAD	3 [1 to 4] ^b	2 [2 to 4] ^b		1 Reference 2 OR 2.68 (1.08 to 6.65) 3 OR 2.38 (0.88 to 6.43) 4 OR 1.28 (0.49 to 3.39) 5 OR 1.14 (0.36 to 3.59)
Treating team, Respiratory	67 (82%)	64 (87%)		OR 1.43 (0.60 to 3.42)
Recruited from an outpatient clinic, Yes	45 (55%)	43 (58%)		OR 1.14 (0.60 to 2.15)
mMRC score	2 [1 to 2] ^b	2 [1 to 3] ^b		0 Reference 1 OR 2.35 (0.23 to 24.51) 2 OR 2.83 (0.28 to 28.57) 3 OR 3.33 (0.32 to 34.99) 4 OR 1.50 (0.06 to 40.63)
Self-report exercise tolerance (m)	200 [100 to 400] ^b	200 [75 to 500] ^b		OR 0.99 (0.99 to 1.00)
Interest in attending a PRP (VAS)	55 ± 37	77 ± 25		MD -22 (-32 to -12)^c OR 1.24 (1.11 to 1.39)^d
Who initiated the referral? ^a	NA	Consultant	22 (30%)	^e
		Physiotherapist	30 (41%)	
		Registrar	19 (26%)	
		Resident	1 (1%)	
		Other	2 (3%)	
Heard of a PRP, Yes ^a	49 (60%)	46 (62%)		OR 1.11 (0.58 to 2.11)
Previously participated in a PRP (Yes) ^a	31 (63%)	28 (62%)		OR 0.90 (0.39 to 2.07)

Data expressed as mean ± SD, median [IQR]^b or No. (%). IRSAD = Index of relative socio-economic advantage and disadvantage (a lower IRSAD score indicates relatively greater disadvantage and a lack of advantage in general)¹²; MD = mean difference; mMRC = modified Medical Research Council scale; NA = not applicable; PRP = pulmonary rehabilitation program; VAS = visual analog scale.

^aDenotes missing data for the variable.

^bIQR = interquartile range.

^cVAS, 0-100 units.

^dVAS grouped in increments of 10 units.

^eUnable to compare groups as cells with expected frequency of <5.

respectively. Barriers are presented in [Figure 3](#). Frequently reported barriers were related to environmental context and resources factors (26%), such as problems with travel distance, transport and parking, or the inflexibility of programs leading to difficulties fitting it in around work or carer commitments. Less frequently reported barriers related to miscellaneous factors, such as attitudes of already doing enough

exercise (5%), introverted personality traits (4%), and feelings of unworthiness (1%). Enablers are presented in [Figure 4](#). Those frequently reported related to environmental context and resources facilitators (13%), positive past experiences (12%), and outcome expectancies (9%). Less frequently reported enablers were social influences such as social support from family or encouragement from HCPs (2%).

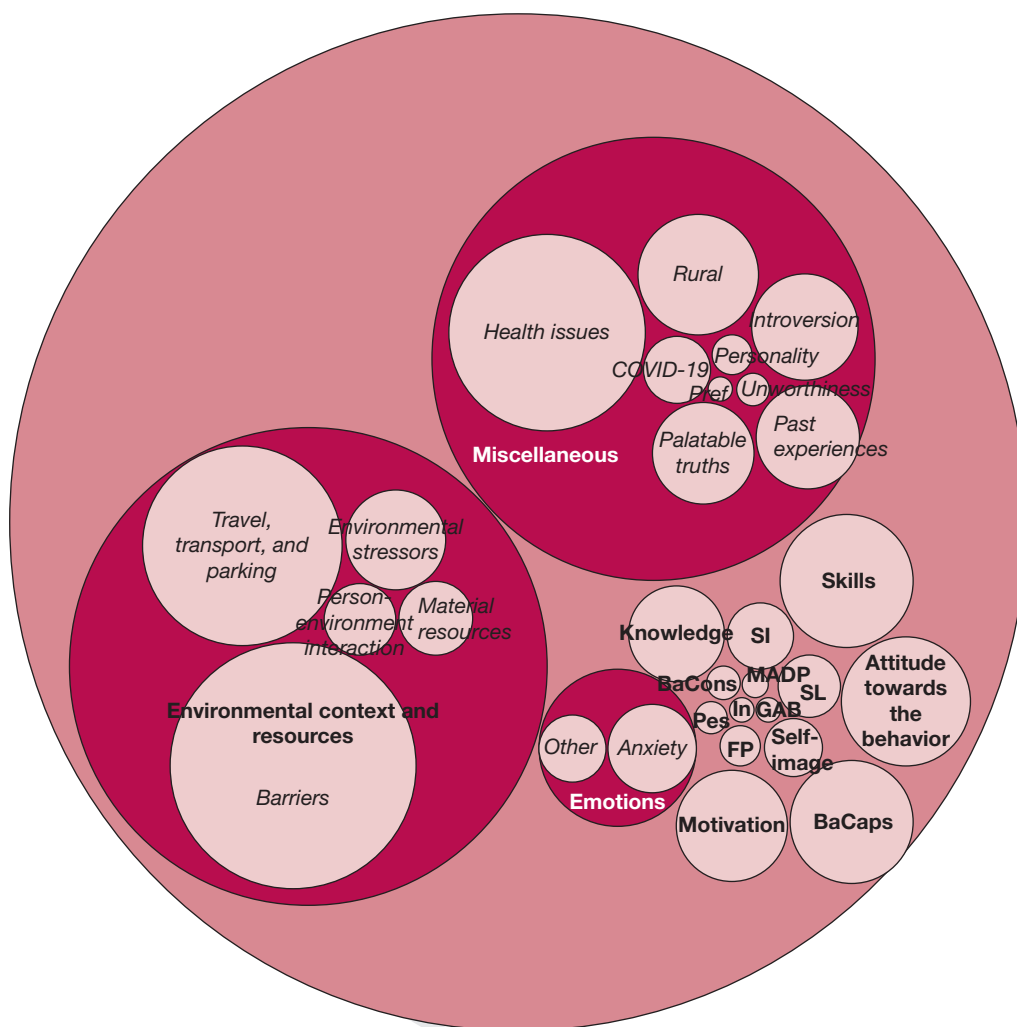


Figure 3 – Barriers to a pulmonary rehabilitation program mapped to theoretical domains framework and mechanisms of action. The size of each bubble relates to the frequency with which it was quoted. Definitions of each domain can be found in e-Table 3. BaCaps = beliefs about capabilities; BaCons = beliefs about consequences; FP = feedback processes; GAB = general attitudes and beliefs; In = intentions; Pes = pessimism; Pref = preferences; SI = social influences; SL = social learning and imitation.

Discussion

The main finding of this study was that 47% of people with COPD who were known to one of three tertiary hospitals across Perth, WA, and were suitable for referral to a PRP were actually referred. Although suboptimal, the proportion referred in our study was considerably higher than what is reported in earlier work. That is, a recent study completed in the United Kingdom reported 16% of people with COPD were referred to a PRP.⁶ However, because this earlier study did not restrict the analyses to people who were deemed suitable for a PRP, these figures do not reflect the magnitude of the implementation gap. That is, it is impossible to distinguish missed referrals (which is the implementation gap) from appropriate non-referrals (which is an appropriate outcome) without first

considering someone's suitability for a PRP. In contrast, we considered first whether someone was suitable for referral to a PRP before classifying them according to whether they were referred. This methodological difference allowed us to examine the magnitude of the implementation gap (ie, missed referrals) and to explore the characteristics of this group of participants. Notably, the only variable that differed between the participants classified as appropriate referrals and missed referrals was their interest in the program. That is, those classified as appropriate referrals expressed more interest in participating in a PRP. Although implicit biases held by clinicians (ie, sex, smoking status, or socioeconomic status) can influence referrer decision-making,⁶ no differences in these variables were found between participants classified as appropriate referrals and

661
662
663
664
665
666
667
668
669
670
671
672
673
674
675
676
677
678
679
680
681
682
683
684
685
686
687
688
689
690
691
692
693
694
695
696
697
698
699
700
701
702
703
704
705
706
707
708
709
710
711
712
713
714
715

print & web 4C/FPO

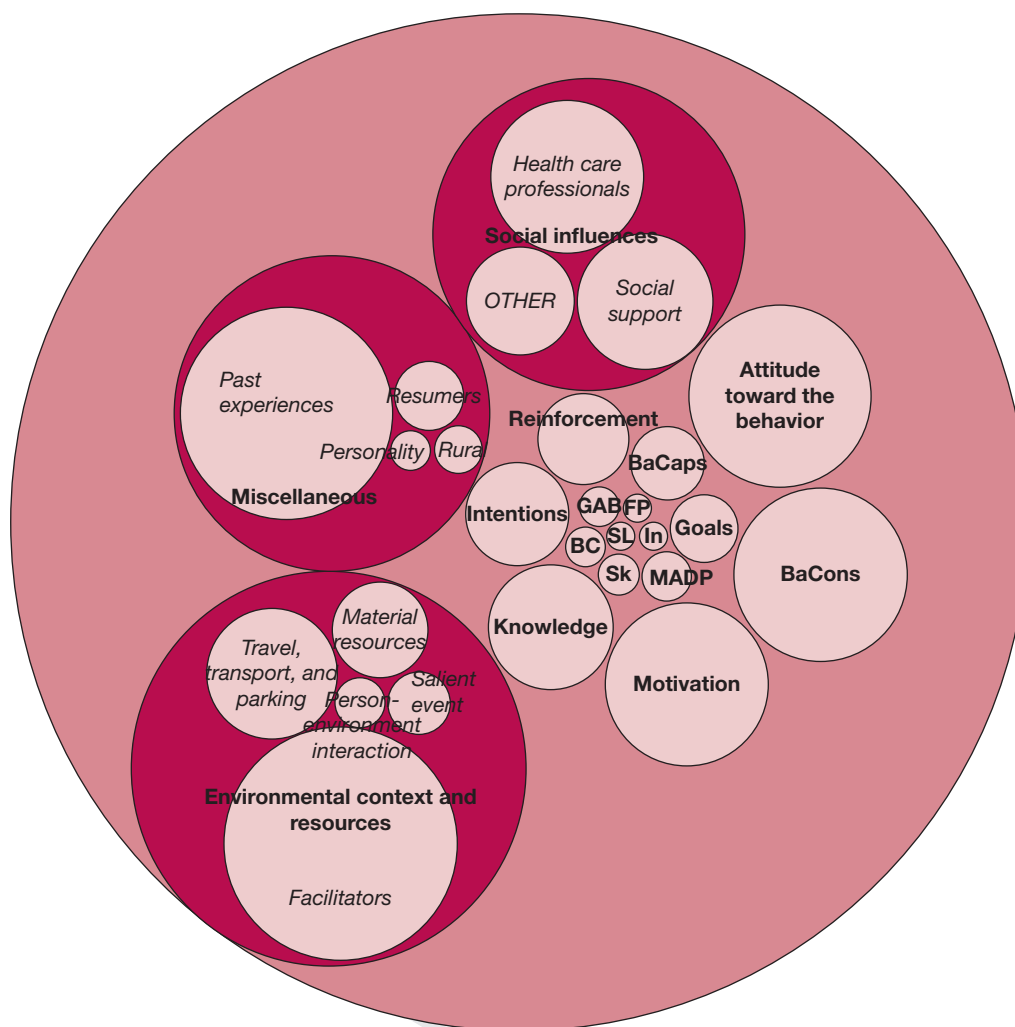
716
717
718
719
720
721
722
723
724
725
726
727
728
729
730
731
732
733
734
735
736
737
738
739
740
741
742
743
744
745
746
747
748
749
750
751
752
753
754
755
756
757
758
759
760
761
762
763
764
765
766
767
768
769
770

Figure 4 – Enablers to a pulmonary rehabilitation program mapped to theoretical domains framework and mechanisms of action. The size of each bubble relates to the frequency with which it was quoted. Definitions of each domain can be found in e-Table 3. BaCaps = beliefs about capabilities; BaCons = beliefs about consequences; BC = behavioral cueing; FP = feedback processes; GAB = general attitudes and beliefs; In = intentions; MADP = memory, attention, and decision processes; Sk = skills; SL = social learning and imitation.

missed referrals. Therefore, our data suggest that the decision to refer to a PRP was not influenced by implicit biases related to these factors.

Our data allowed us to explore the reasons why people who were suitable for referral to a PRP were not referred. That is, in our tertiary hospitals, the locus of barriers to referral are that HCPs are largely not offering referrals (71% not offered a referral when it needed to be offered, ie, missed referrals group), and for those who are offered a referral, some health care professionals do not complete the referral (11%), some patients decline (18%), and others are offered it when referral does not appear appropriate (11%). A combination of actions that optimize HCP understanding of PRPs, who is appropriate for a PRP, and prompts to complete referrals, as well as ways to

target interest among people with COPD are required to boost referral behaviors.

Understanding reasons why those classified as missed referrals expressed less interest in participating in a PRP is important, especially if the reasons are modifiable. Consistent with earlier work, frequently reported barriers included environmental context and resource factors, such as difficulties with transport and parking costs, or the inflexibility of programs leading to difficulties fitting it in around work or carer commitments.¹⁸ However, just because these factors were frequently coded as barriers, they are not necessarily the most potent. Domains frequently coded likely represent what the participant was most willing to share without further probing. It is therefore important to reflect on barriers less frequently coded

771 such as introverted personality traits and feelings of
 772 unworthiness. Our data are the first to demonstrate
 773 comments that suggest introversion being a barrier, for
 774 example: *I don't like crowds, I keep to myself. If I start*
 775 *panicking, I get breathless. I'm very much a loner, I'm*
 776 *not a people person.* Further inquiry is needed to
 777 understand whether these people have had lifelong
 778 introversion or whether their COPD, which is often
 779 coupled with underlying feelings of unworthiness¹⁹ or
 780 being told to stay “away from germs” and shield from
 781 COVID-19, has led to this personality trait. Feelings of
 782 unworthiness, such as *I felt I was taking up a place of*
 783 *someone who could benefit more*, were also noted as
 784 barriers to participating in a PRP. Perhaps society
 785 unconsciously shapes this view. COPD is a leading
 786 cause of death and disability globally,²⁰ yet respiratory
 787 diseases as whole accounted for approximately 2% of
 788 total research expenditure by funding bodies in
 789 Australia (2016-2019)²¹ and the United Kingdom
 790 (2012-2015).^{22,23} Introversion and unworthiness can
 791 cause social isolation and reduce help-seeking
 792 behaviors,²⁴ and they may contribute to lower interest
 793 levels in a PRP.

796 Data from this study can be used to inform approaches
 797 to optimize people's interest in participating in a PRP.
 798 For example, inflexibility of the program times and
 799 locations, or the attitude of not needing the program
 800 because they are *already doing enough* were reported as
 801 barriers to participation. These barriers have a negative
 802 influence on interest but are modifiable. For example,
 803 offering a “suite” of alternative models of delivery to
 804 choose from outside the traditional “group” format,⁸
 805 offering programs outside usual business hours, and
 806 framing people's expectations²⁵ are some ways to
 807 modify participant-reported barriers and increase their
 808 interest. Participants frequently reported outcome
 809 expectancies as an enabler to participating in a PRP, for
 810 example *To get me better, even a small improvement*
 811 *would be nice.* Another frequently coded enabler was
 812 positive past experiences among those who had
 813 previously completed a PRP: *I thought it was a brilliant*
 814 *program and would do it again.* Using testimonials can
 815 be a powerful tool to attest to the benefits of a PRP and
 816 empower potential PRP candidates to participate.²⁶
 817 Because earlier work has demonstrated that showing
 818 inpatients co-designed video testimonials had no clear
 819 effect on referral or completion of PRPs on hospital
 820 discharge,²⁷ a more interactive approach seems
 821 required. This might involve asking people with COPD
 822 who are recent class participants to champion PRPs in

the hospital setting and share their lived experience
 with others.²⁸ Perhaps offering social support and
 giving potential PRP candidates the opportunity to ask
 questions of someone with program experience, factors
 that were coded less frequently as enablers, may
 activate intrinsic motivation and regulate interest in
 participating in a PRP.^{29,30} Encouragement from HCPs
 was another less frequently coded enabler that has been
 previously reported,¹⁸ and although we collected data
 on who initiated the referral (Table 1), we did not have
 data on which HCPs missed referrals. Future research
 on referral behaviors should aim to capture such
 information, which could inform areas to target
 interventions.

Strengths and Limitations

A strength of this study is that we classified our
 participants according to their suitability for a referral to
 a PRP. This allowed us to accurately reflect the size of
 the implementation gap of PRPs in Perth. Possibly PRPs
 in other jurisdictions apply different suitability criteria,
 but to optimize the generalizability of our results,
 decision-making was escalated to a consensus group
 that involved PRP clinicians, and we were liberal with
 our decision-making (ie, if in doubt, deem them suitable
 for a referral). A further strength of this study is that
 data were collected prospectively, through face-to-face
 interviews with participants either during their
 hospitalization or after their outpatient clinic
 appointment. This contrasts with earlier work
 investigating the implementation gap of PRPs, which
 has used surveys or retrospective audits of notes,^{6,7}
 giving a superficial understanding of complex
 implementation barriers. Prospective data collection
 also minimized missing data and loss to follow-up.
 Approximately 25% of people with COPD who met the
 study criteria and were approached chose not to
 participate in our study. This finding was somewhat
 surprising, because this study was observational,
 required very little active participation (10 minutes),
 and had negligible burden or risk. Nonparticipation in
 research could be associated with nonparticipation in a
 PRP, so our cohort may have been influenced by a
 selection bias. Perhaps considering novel approaches to
 involve people with COPD in research for whom
 altruism alone is insufficient motivation is important.
 Engaging consumers as colleagues, whose expertise is
 their lived experience, is a novel approach to this
 limitation.³¹

881
882
883
884
885
886
887
888
889
890
891
892
893
894
895
896
897
898
899
900
901
902
903
904
905
906
907
908
909
910
911
912
913
914
915
916
917
918
919
920
921
922
923
924
925
926
927
928
929
930
931
932
933
934
935

Interpretation

From our prospective observational study, we found that just under half of people with COPD known to one of three tertiary hospitals in Perth, WA, who were suitable for a PRP were actually referred. The only characteristic that differed between the appropriate referrals and missed referrals was their interest in participating in a PRP.

Factors that negatively influenced our participant's

interest in PRPs included environmental context and resource factors (ie, issues with travel, transport, parking, or program inflexibilities), introverted personality traits, and feelings of unworthiness. Collaborations among people with COPD, clinicians, and researchers present a unique opportunity to develop novel strategies to enhance people's interest and improve referral to PRPs among people with COPD in our tertiary setting.

Acknowledgments

Authors' contributions: Kylie Hill assumes responsibility for being guarantor, taking responsibility for the integrity of the work as a whole, from inception to published article. All authors have made a significant contribution to this body of work reported across study design, data collection, analysis and interpretation. Each author has contributed to the drafting of this manuscript and has approved the final version.

Financial/nonfinancial disclosures: None declared.

Other contributions: The authors thank the Department of Health, Western Australia (Research Translation Projects—2019; Round 13) for support in the form of a research grant. We also acknowledge Nola Cecins for her involvement in our consensus group, Dr Anne Smith for her meticulous statistical support, our steering committee (Carol Watson, Jade Larsson, Nola Cecins, Peta Winship, Tamara Hatton and Tenae Cowie), and research assistants (Brooke Loxton, Emma Koenig, Hollie Lawson-Smith, Jo Cockram, Pip Windsor and Tamara Hatton).

Additional information: The e-Appendix and e-Tables can be found in the Supplemental Materials section of the online article.

References

- McCarthy B, Casey D, Devane D, et al. Pulmonary rehabilitation for chronic obstructive pulmonary disease. *Cochrane Database Syst Rev*. 2015;2:CD003793.
- Lacasse Y, Cates CJ, McCarthy B, Welsh EJ. This Cochrane Review is closed: deciding what constitutes enough research and where next for pulmonary rehabilitation in COPD. *Cochrane Database Syst Rev*. 2015;(11)Ed000107.
- Rochester CL, Vogiatzis I, Holland AE, et al. An Official American Thoracic Society/European Respiratory Society Policy Statement: Enhancing implementation, use, and delivery of pulmonary rehabilitation. *Am J Respir Crit Care Med*. 2015;192(11):1373-1386.
- Alison JA, McKeough ZJ, Johnston K, et al. Australian and New Zealand pulmonary rehabilitation guidelines. *Respirology*. 2017;22(4):800-819.
- Bolton CE, Bevan-Smith EF, Blakey JD, et al. British Thoracic Society guideline on pulmonary rehabilitation in adults: accredited by NICE. *Thorax*. 2013;68(Suppl 2):ii1-ii30.
- Stone PW, Hickman K, Steiner MC, et al. Predictors of referral to pulmonary rehabilitation from UK primary care. *Int J Chron Obstruct Pulmon Dis*. 2020;15:2941-2952.
- Johnston K, Young M, Grimmer K, et al. Frequency of referral to and attendance at a pulmonary rehabilitation programme amongst patients admitted to a tertiary hospital with chronic obstructive pulmonary disease. *Respirology*. 2013;18(7):1089-1094.
- Holland AE, Cox NS, Houchen-Wolloff L, et al. Defining modern pulmonary rehabilitation: an official American Thoracic Society workshop report. *Ann Am Thorac Soc*. 2021;18(5):e12-e29.
- Hug S, Cavalheri V, Gucciardi DF, et al. OPTImising the implementation of pulmonary rehAbiLitation in people with chronic obstructive pulmonary disease (the OPTIMAL study): mixed methods study protocol. *BMC Pulmon Med*. 2020;20(1):286.
- Wiltshire G. A case for critical realism in the pursuit of interdisciplinarity and impact. *Qual Res Sport Exerc Health*. 2018;10(5):525-542.
- Ries AL, Kaplan RM, Myers R, Prewitt LM. Maintenance after pulmonary rehabilitation in chronic lung disease: a randomized trial. *Am J Respir Crit Care Med*. 2003;167(6):880-888.
- Australian Bureau of Statistics. Census of Population and Housing: Socio-Economic Indexes for Areas (SIEFA)—The Index of Relative Socio-economic Advantage and Disadvantage (SA1); 2016. 2020. Accessed May 12, 2021. <https://www.abs.gov.au/AUSSTATS/abs@.nsf/Lookup/2033.0.55.001Main+Features12016?OpenDocument>
- Celli BR, Cote CG, Marin JM, et al. The body-mass index, airflow obstruction, dyspnea, and exercise capacity index in chronic obstructive pulmonary disease. *N Engl J Med*. 2004;350(10):1005-1012.
- Wewers ME, Lowe NK. A critical review of visual analogue scales in the measurement of clinical phenomena. *Res Nurs Health*. 1990;13(4):227-236.
- Cane J, O'Connor D, Michie S. Validation of the theoretical domains framework for use in

- behaviour change and implementation research. *Implementation Science*. 2012;7:37.
- Connell LE, Carey RN, de Bruin M, et al. Links Between Behavior Change Techniques and Mechanisms of Action: An Expert Consensus Study. *Annals of Behavioral Medicine*. 2018;53(8):708-720. <https://doi.org/10.1093/tbm/ibaa050>
 - Archer KJ, Lemeshow S. Goodness-of-fit test for a logistic regression model fitted using survey sample data. *The Stata Journal*. 2006;6(1):97-105.
 - Cox NS, Oliveira CC, Lahham A, et al. Pulmonary rehabilitation referral and participation are commonly influenced by environment, knowledge, and beliefs about consequences: a systematic review using the Theoretical Domains Framework. *J Physiother*. 2017;63(2):84-93.
 - Berger BE, Kapella MC, Larson JL. The experience of stigma in chronic obstructive pulmonary disease. *West J Nurs Res*. 2011;33(7):916-932.
 - Soriano JB, Kendrick PJ, Paulson KR, et al. Prevalence and attributable health burden of chronic respiratory diseases, 1990-2017: a systematic analysis for the Global Burden of Disease Study 2017. *Lancet Respir Med*. 2020;8(6):585-596.
 - Gilbert SE, Buchbinder R, Harris IA, et al. A comparison of the distribution of Medical Research Future Fund grants with disease burden in Aust. *Med J Australia*. 2021;214(3):111-113.e1.
 - MRC annual report and accounts 2017 to 2018. Accessed September 10, 2021. <https://mrc.ukri.org/publications/browse/annual-report-and-accounts-2017-18/>
 - Snell N, Jarrold I, Holgate S. The current state of respiratory research in the UK. *Thorax*. 2015;70(11):1011-1013.
 - Harrison SL, Robertson N, Apps L, et al. "We are not worthy": understanding why patients decline pulmonary rehabilitation following an acute exacerbation of COPD. *Disabil Rehabil*. 2015;37(9):750-756.
 - Harrison SL, PP, Lahham A. Patient experiences. In: Holland AEDS, Spruit MA, eds. *Pulmonary Rehabilitation (ERS Monograph)*. Sheffield: European Respiratory Society; 2021:11-22.
 - McNamara RJ, Dale M, McKeough ZJ. Innovative strategies to improve the reach and engagement in pulmonary

- 991 rehabilitation. *J Thorac Dis.* 2019;11(Suppl
992 17):S2192-S2199.
- 993 27. Barker RE, Jones SE, Banya W, et al. The
994 effects of a video intervention on post-
995 hospitalization pulmonary rehabilitation
996 uptake: a randomized controlled trial. *Am
997 J Respir Crit Care Med.* 2020;201(12):
998 1517-1524.
28. White P, Gilworth G, Lewin S, et al.
Improving uptake and completion of
pulmonary rehabilitation in COPD with
lay health workers: feasibility of a clinical
trial. *Int J Chron Obstruct Pulmon Dis.*
2019;14:631-643.
29. Deci EL, Eghrari H, Patrick BC, et al.
Facilitating internalization: the self-
determination theory perspective.
J Personality. 1994;62(1):119-142.
30. Ryan RM, Deci EL. Intrinsic and
extrinsic motivation from a self-
determination theory perspective:
definitions, theory, practices, and future
directions. *Contemp Educ Psychol.*
2020;61:101860.
31. Dahm MR, Brown A, Martin D, et al.
Interaction and innovation:
practical strategies for inclusive
consumer-driven research in
health services. *BMJ Open.* 2019;9(12):
e031555.
- 999
1000
1001
1002
1003
1004
1005
1006

UNCORRECTED PROOF