

Uptake of pulmonary rehabilitation in New Zealand by people with chronic obstructive pulmonary disease in 2009

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Abstract

Aims To estimate of uptake of pulmonary rehabilitation (PR) by people with chronic obstructive pulmonary disease (COPD) in New Zealand in 2009.

Method A postal survey sent to all District Health Boards (DHBs), Primary Health Organisations (PHOs), and other non-government organisations (NGOs) identified as providers of PR. The survey requested information on the characteristics of PR programmes, estimates of the total number of people with COPD who were offered PR, entered PR, and completed PR in 2009.

Results In 2009 PR was provided in 19 of 21 DHB regions by 23 organisations (16 DHBs, five PHOs, one DHB/PHO partnership, and 1 NGO). Twenty-one of these 23 organisations (91%) responded to the survey. In total, 2569 people with COPD were offered PR, 1786 entered PR, and 1378 completed a PR programme in 2009.

Conclusions There is a marked shortfall between the national levels of provision of PR and the prevalence of COPD, with less than 1% of people with COPD participating in PR each year in New Zealand. Incentives, leadership and coordination of services are required at a national level to increase the uptake of PR.

Chronic obstructive pulmonary disease (COPD) is the fourth leading cause of death and contributes significantly to disability in New Zealand (NZ).¹ The direct health care costs for NZ of COPD in 2003 were estimated to be between \$128 million and \$192 million.² COPD presents a particular burden for Māori, who experience impairments resulting from COPD up to two decades earlier than non-Māori, have a prevalence of COPD twice as high compared to non-Māori, and have higher rates of hospitalisation and death associated with COPD.³

Estimates of the prevalence of COPD in NZ have varied widely. The 2006/2007 NZ Health Survey found that 6.6% (95%CI 5.9–7.3%) of adults over 45 years recalled being told by a doctor that they had chronic bronchitis, emphysema, or COPD.⁴ However, a more recent survey based on clinical assessment of a random sample of residential New Zealanders reported a much higher prevalence.⁵

Using the Global Initiative for Chronic Obstructive Lung Disease (GOLD) definition of COPD, the only New Zealand-based prevalence study to have done so, Shirtcliffe and colleagues reported that 14.2% (95%CI 11.0–17.0%) of adults aged over 40 years had COPD, and further that self-report of having received a doctor's diagnosis of COPD had little relationship with an objective diagnosis.⁵

Based on the figures of Shirtcliffe and colleagues⁵ and NZ population statistics,⁶ it is likely that between 213,400 and 329,800 New Zealanders over 40 years had COPD in

2009, according to the GOLD criteria. Shirtcliffe and colleagues also demonstrated however, that estimates of COPD prevalence differ depending on which clinical criteria are used.

Using a lower limit of normal (LLN) of forced expiratory volume in one second/forced vital capacity as opposed to a fixed ratio of 0.7 to diagnose airflow obstruction (the American Thoracic Society and European Respiratory Society Joint Task Force recommended criteria for diagnosis of COPD), Shirtcliffe and colleagues reported a lower prevalence of COPD: 9.0% (95%CI 6.7–11.3%) of people over 40 years.⁵ This would equate to an estimate of 129,980 to 219,220 New Zealanders over 40 years having COPD in 2009.

Pulmonary rehabilitation (PR)—a multidisciplinary programme usually comprised of 6 to 16 weeks of group-based exercise and education in outpatient or community centres—is one of the few interventions that have been consistently shown to enhance physical function and quality of life (QOL) in people with COPD.

The most recent systematic review of randomised controlled trials indicated that PR results in clinically and statistically significant improvements in quality of life, and statistically significant improvements in exercise capacity.⁷ In people receiving PR after a hospital admission for an exacerbation of COPD, evidence from a systematic review of randomised controlled trials has demonstrated that PR results in a significant reduction in risk of rehospitalisation (pooled odds ratios of 0.13 over 34 weeks) and death (pooled odds ratios of 0.3 over 107 weeks).⁸ PR is thus considered one of the key strategies for management of COPD from a public health perspective.⁹

However, despite the public and personal cost of COPD and the known benefits of PR, little information exists regarding the uptake of PR in NZ. Broad and Jackson suggested that in 2003 it was ‘doubtful if more than 2% of new COPD patients, or 10% of existing patients in New Zealand access such a programme’ (p. 30),² although the origin of these figures is unclear as no methodology was stated.

Overseas reports have indicated a lower uptake, with only 1–2% of all people with COPD having access to PR in Australia,¹⁰ Canada,¹¹ and the UK.¹² From a recent audit of respiratory services in NZ it is known that PR is one of the interventions most frequently highlighted by District Health Boards (DHBs) when discussing their strategies for management of chronic respiratory disorders.¹³

In 2009, 14 of 15 DHBs who completed a survey on management of COPD reported that they ran a PR programme.¹⁴ However, other than these broad indications of service provision, no empirical data exists on the exact number of New Zealanders with COPD who attend PR each year.

The primary aim of this current study was to develop a good estimate of the total uptake of PR by New Zealanders with COPD in 1 year (specifically, 2009), including the number of people who:

- Were offered a place on a PR programme,
- Entered a PR programme, and
- Completed a PR programme.

A secondary aim of this study was to gather further details regarding the characteristics of existing pulmonary rehabilitation services in NZ.

Method

Research design—A postal survey was undertaken involving all providers of pulmonary rehabilitation in NZ. The Multi-regional Ethics Committee confirmed that formal ethical approval was not required for this low risk observational study of health care providers.

Identification of providers—Services were eligible to participate in this study if they provided a PR programme in 2009 consistent with criteria in the latest Cochrane Review on PR⁷: structured exercise for people with chronic respiratory disease over a period of at least 4 weeks, delivered by a health professional in inpatient, outpatient or community settings, with or without additional education sessions or psychosocial support. Programmes that involved patient education only were excluded from the survey.

Prior to undertaking this survey, we created a database of all providers of PR in NZ. In order to identify all possible providers, we approached all DHBs and all Primary Health Organisations (PHOs) to ask about the relevant programmes, if any, they ran. We made contact with the respiratory services in all 21 DHBs (100%) and with 73 of the 81 PHOs (90%) that existed in 2009. Eight PHOs (10%) did not respond to multiple requests by phone, electronic mail or post regarding whether or not they provided PR, and, based on conversations with the DHB providers in their region, were assumed not to have been providers of PR in 2009.

We also contacted all non-government organisations (NGOs) listed by the Asthma Foundation New Zealand as providers of services for people with COPD. We asked about who, if anyone, within these organisations ran, or coordinated, a pulmonary rehabilitation programme, and their contact details. Additionally we made links with potential providers through professional networks among nurses and physiotherapists who specialised in respiratory services. Twenty three organisations were thus identified as providers of PR in 2009 (16 DHBs, five PHOs, one DHB/PHO partnership, and one NGO) and included for data collection.

Data collection—A survey was sent by mail in October 2010 to each of the 23 organisations identified as being a provider of PR in 2009. The survey consisted of a structured questionnaire seeking information about:

- The characteristics of the PR programme(s) offered (e.g. the location, frequency, duration, and design of programmes)
- The types of patient data collected (i.e. whether data was collected on age, ethnicity, lung function physiology) and how this data was collected
- The method used for establishing or confirming a diagnosis of COPD among attendees of PR programmes (if any)
- The type and timing of outcome measures used to evaluate patient progress, and
- The providers' estimates of the number of people with COPD who a) were offered, b) entered, and c) completed a PR programme in 2009.

In order to evaluate the accuracy of the providers' estimates of the provision of PR in 2009 we also sought information on what these estimates were based on (e.g. actual patient records, average PR class sizes, or a 'best guess' of patient numbers based on the respondents' recall). As definitions were likely to differ regarding what might constitute 'completion' of a PR programme, we specified that for the purpose of this survey 'completion' referred to 'the number of people who entered minus the number of people who stopped attending before finishing the PR programme'. (For a full copy of the questionnaire used please contact the corresponding author.)

The survey was piloted by respiratory services in two DHBs, and feedback from these providers was used to revise the structure of the questionnaire before the final version was mailed out. The organisations involved in the pilot also completed the final version of the survey for data collection purposes. In order to enhance the response rate for the survey, we kept the questionnaire short (concentrating on the primary aims of the study), we offered a prize draw (for a contemporary textbook on PR) for services who completed the questionnaire, and we followed up with regular reminders by electronic mail and phone to all potential respondents. Data was analysed using descriptive statistics.

Results

Survey responses—We received data from 21 of the 23 organisations that provided pulmonary rehabilitation in 2009—a 91% response rate. Two PHO providers did not respond.

Regional service delivery—PR was provided in 19 of the 21 DHB regions in 2009. Twelve DHBs (57%) were reported to be the sole providers of PR in their region. Two DHB regions (10%) had a PHO as the sole PR provider. In one DHB region (5%), PR was provided as part of a partnership project between the local DHB and PHO.

In four further DHB regions (19%) the work of providing PR was divided up between the DHB and at least one PHO, with each organisation being responsible for subpopulations within the DHB region (and one PHO providing for a subpopulation of people from two DHBs). One of these regions had three providers of PR—the DHB, a PHO, and a NGO—all providing services to separate subpopulations within the DHB region. In two DHB regions (10%) no PR was provided in 2009, although one of these DHBs had since established a PR programme in 2010.

Characteristics of PR programmes—A summary of the characteristics of the PR programmes provided by the 21 organisations responding to the survey are shown in Table 1. These 21 organisations offered PR programmes in a range of locations including hospital gyms, community gyms, community centres, marae, and individuals' homes. There was a high degree of similarity in the structure of programmes offered, with the majority of organisations (86%; 18/21) offering PR programmes consisting of 6 to 10 weeks of twice weekly exercise, plus education, with a period of assessment before and after the formal period of exercise.

All 21 providers collected data using the 6-Minute Walking Test and 81% (17/21) collected data on QOL using a disease-specific tool—either the Chronic Respiratory Disease Questionnaire or the St George Respiratory Questionnaire. Many providers also collected other forms of standardised outcome data on exercise capacity, severity of breathlessness, depression and anxiety, and body mass or weight. The majority of PR providers (86%; 18/21) collected data on patient ethnicity, and did so largely by asking patients open-ended questions about their ethnicity or by gathering information from existing patient records.

Many organisations also offered variations to the standard programme to better meet the needs of their patient populations. Examples of this included offering programmes consisting of once weekly rather than twice weekly exercise for people who struggled to adhere to more intensive programmes or offering 'rolling' programmes where patients did not need to all start at the same time but could be admitted and discharged from the programme at times that suited them.

One organisation offered an additional 4 weeks of exercise for people identified as likely to particularly benefit from an extended programme. Some incorporated transition to an ongoing community-based exercise group in a public gym or other community facility as part of discharge from the structured PR programme.

Table 1. Characteristics of PR programmes in organisations responding to the survey

Location of PR programmes	Single location only		10/21 (48%)	
	Multiple locations		11/21 (52%)	
	Group programme in a hospital gym		15/21 (71%)	
	Group programme in private or community gyms		6/21 (29%)	
	Group programme in a community centre		6/21 (29%)	
	Group programme in a Marae		2/21 (10%)	
	Individual programmes in hospital gym, home or community		12/21 (57%)	
Method for confirming a diagnosis of COPD	GOLD criteria		11/21 (52%)	
	American Thoracic Society and European Respiratory Society Joint Task Force criteria		1/21 (5%)	
	Lung function tests without specific diagnosis criteria		3/21 (14%)	
	Diagnosis of referring physician		5/21 (24%)	
Patient signs and symptoms without lung function testing		1/21 (5%)		
Structure of PR programmes	Enrolment	'Discrete' PR programme, with set start and end date for whole group	16/21 (66%)	
		'Rolling' PR programmes, with patients joining and leaving at different times	4/21 (19%)	
		Both 'rolling' and 'discrete' programmes	1/21 (5%)	
	Duration	8 weeks	15/21 (71%)	
		6–10 weeks	20/21 (95%)	
		Continuous (patients never formally discharged)	1/21 (5%)	
	Exercise	Twice weekly classes	20/21 (95%)	
		Once weekly classes	1/21 (5%)	
	Education	Run concurrently with exercise classes	21/21 (100%)	
	Outcome evaluation	Pre- and post-PR outcomes collected		18/21 (86%)
		Follow up data (1, 4, 6, or 12 months after completion of PR)		4/21 (19%)
		6-Minute Walk Test		21/21 (100%)
		Incremental Shuttle Walk Test		4/21 (19%)
		Timed Up and Go		1/21 (5%)
		Timed Sit-to-Stand		1/21 (5%)
		Borg Dyspnoea Scale		15/21 (71%)
		Medical Research Council Dyspnoea Score		7/21 (33%)
		Chronic Respiratory Disease Questionnaire		15/21 (71%)
		St. George Respiratory Questionnaire		2/21 (10%)
		Hospital Anxiety and Depression Scale		12/21 (57%)
		Chronic Disease Questionnaire		1/21 (5%)
		Body Mass Index		15/21 (71%)
Weight		2/21 (10%)		
Patient satisfaction with PR programme		18/21 (86%)		
Quality of data collection	Ethnicity	Open-ended question about ethnicity	5/21 (24%)	
		Gathered from existing clinical records	10/21 (48%)	
		Both open-ended questions and clinical records	2/21 (10%)	
		Structure questionnaire	1/21 (5%)	
	Ethnicity data not collected		3/21 (14%)	
	Basis for estimates of programme referrals	Actual patient records	7/21 (33%)	
		Informal recall supplemented by some patient records	11/21 (52%)	
		Unable to estimate referral numbers	3/21 (14%)	
	Basis for estimates of programme enrolments	Actual patient records	13/21 (62%)	
		Average PR group sizes and number of PR groups per year	4/21 (19%)	
		Informal recall supplemented by some patient records	4/21 (19%)	
	Basis for estimates of programme completions	Actual patient records	14/21 (67%)	
		Average completion rates per PR group sizes and PR groups per year	3/21 (14%)	
		Informal recall supplemented by some patient records	4/21 (19%)	

Uptake of PR in 2009—Data on the number of patients entering and completing PR programmes in 2009 was provided by all 21 of the responding organisations. The majority based their figures entirely on actual patient records and approximately a third reported a ‘best estimate’ based either on the average number of enrolments and completions per PR group multiplied by the number of PR groups run in 2009, or based on their and their colleagues’ recall of the total number of participants seen in 2009 (see Table 1 for details).

Three of the 21 organisations (14%) felt unable to estimate the number of people who had been offered a place on a PR programme, with the other 18 organisations (86%) providing an estimate of the number of people offered PR based on actual patient records (33%; 7/21) or a ‘best guess’ based on their recall and any other information they had available (52%; 11/21).

Overall, the 21 organisations provided 105 ‘discrete’ group PR programmes in 2009 (a ‘discrete’ programme being one where all participants begin and end at the same time) with a number of additional patients receiving PR through programmes offering ‘rolling’ admissions or through individualised programmes. The survey responses indicated that in 2009 these 21 organisations offered PR to 2498 people with COPD, enrolled 1736 people with COPD into a PR programme, and assisted 1340 people to complete a PR programme.

In order to accommodate missing data from the two PHOs known to provide PR but who did not respond to the survey, we substituted figures derived from existing data. For these two PHOs we calculated the number of people entering PR based on the mean number of PR enrolments for programmes run by PHOs who did respond to the survey. Furthermore, we estimated the number of people with COPD offered PR and completing a PR programme based on the mean ratio of referrals to enrolments and enrolments to completions in all organisations that did respond to the survey. Likewise, we substituted data on PR referrals for the three respondents to the survey who had felt unable to estimate this data.

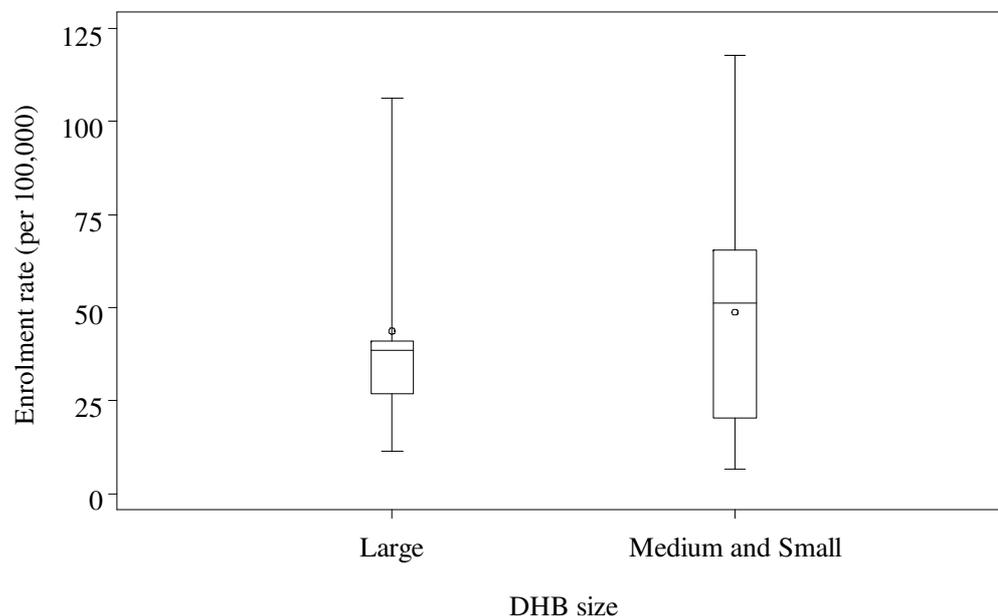
Thus in total we estimated that in 2009, 2569 people with COPD were offered PR, 1786 entered PR, and 1378 completed a PR programme. This means that based on the prevalence figures of Shirtcliffe and colleagues using GOLD criteria for diagnosis of COPD⁵ and NZ population statistics for 2009,⁶ it is likely that only 0.9% of people with COPD were offered PR, 0.7% entered PR, and 0.5% completed PR in NZ in 2009—although these estimated proportions are a little higher if different criteria are used to estimate the prevalence of COPD in NZ (see Table 2).

Sub-analysis on enrolment rates by DHB region (calculated on the basis of number of people with COPD enrolling in PR per 100,000 people in each DHB region)¹⁵ revealed no obvious differences in the number of people with COPD provided PR per capita between small (population <100,000) and medium (population 100,001—150,000) compared to large (population >150,000) DHBs (see Figure 1).

Table 2. Uptake of PR as a percentage of the estimated population of people over 40 with COPD in NZ

Variables	Figures based on data from the 2006/07 National Health Survey using self-reports of having a doctors' diagnosis of COPD ⁴	Figures based on data from Shirtcliffe et al.'s observational study using LLN-defined criteria for diagnosis of COPD ⁵	Figures based on data from Shirtcliffe et al.'s observational study using GOLD standard criteria for diagnosis of COPD ⁵
Percentage of population over 40 estimated to have COPD	6.6% (95% CI 5.9%–7.3%)	9.0% (95% CI 6.7%–11.3%)	14.2% (95% CI 11.0%–17.0%)
Total number of people over 40 estimated to have COPD in 2009 (based on New Zealand population statistics)	128,040 (95% CI 114,460–141,620)	174,600 (95% CI 129,980–219,220)	275,480 (95% CI 213,400–329,800)
Percentage of people over 40 with COPD who were offered PR in 2009	2.0% (1.8%–2.2%)	1.5% (1.2%–2.0%)	0.9% (0.8%–1.2%)
Percentage of people over 40 with COPD who entered a PR programme in 2009	1.4% (1.3%–1.6%)	1.0% (0.8%–1.4%)	0.7% (0.5%–0.8%)
Percentage of people over 40 with COPD who completed a PR in 2009	1.1% (1.1%–1.2%)	0.8% (0.6%–1.1%)	0.5% (0.4%–0.7%)

Figure 1. Box-plot of enrolment rates (number of people entering PR per year) by DHB size



Discussion

To our knowledge this is the first survey that attempts to quantify the numbers of people with COPD being referred to, entering and completing PR in NZ. Overall, this

survey has indicated that there is a marked shortfall between the national levels of provision of PR and the prevalence of COPD, with less than 1% of people who have COPD accessing it each year. This estimate of national provision of PR is lower than has been previously assumed,² despite significant levels of commitment by individual health professionals and pockets of excellence in the provision of PR at a local level around the country. While disappointing, these figures are in fact more in line with findings from similar surveys conducted in Canada¹¹ and the UK.¹²

The current level of provision of PR, in part representing a poor investment of health care resources in these programmes, is unfortunate; particularly given the sound evidence base for PR. High quality randomised controlled trials supporting the effectiveness of PR in improving exercise capacity and QOL have been published since the late 1990s. The first Cochrane review on the subject, supporting the effectiveness of PR, was published in 2003.⁷ Lack of evidence regarding the effectiveness of PR is no longer a credible reason for the low participation rates.

The low uptake in NZ is more likely to reflect a lack of direction and financial incentives provided at a public policy level. A recent audit of respiratory services in NZ concluded that there is a 'lack of national leadership and insufficient regional organisation leading to large gaps in service provision of even basic respiratory services' (page 1).¹³ The findings from this survey of PR in NZ are symptomatic of this wider problem.

Some may perhaps consider provision of PR less important than smoking cessation programmes, which have featured highly in both the media and public policy discussions—particularly following recent suggestions to make NZ 'Smokefree' by 2025.¹⁶ While smoking cessation is probably the single most important action a smoker with COPD could take to improve their health and wellbeing¹⁷, it is important to note that even if the ambitious goal of a 'Smokefree' NZ was achieved by 2025, there would still be a further 20–30 years where smoking-related respiratory illnesses continued to be a financial burden for the country because of the insidious nature of these conditions. Furthermore, smoking is not the only (or, some have argued, even the most significant) cause of COPD.¹⁸ Other factors such as childhood respiratory illnesses, socioeconomic status, and air pollution have been also identified as significant contributors to COPD.¹⁸ Smoking cessation, while highly important, will not eradicate the need for PR.

On the positive side, data from this survey have indicated that when PR is provided, it is done so in line with evidence-based guidelines, and as part of publicly funded health services in the large majority of DHB regions. This is a finding worth celebrating.

There are important limitations of this survey. Firstly, just over a third of the respondents were unable to base their reported enrolment and completion rates on actual patient records, relying instead on other sources of information, including informal recall. Secondly, almost half of all respondents did not confirm the diagnosis of people entering their PR programmes using standard diagnostic criteria for COPD and used instead the diagnosis of the referring physician or non-standard diagnostic criteria. This means that we cannot be entirely confident that all people counted in this survey as receiving PR did in fact have COPD.

Thirdly, our survey did not account for people who might have attended more than one PR programme. Fourthly, the survey did not account for people who might have been referred to PR by a general practitioner or hospital physician, but who did not enter a PR programme—potentially resulting in an underestimate of the percentage of people who decline an offer to enrol in a PR programme.

Furthermore, we are aware that there are a handful of community-based exercise groups, attended by people with COPD, which did not meet our definition of a PR programme. Potentially these programmes may also be effective in improving health outcomes for people with COPD, but were not included in our review. Nevertheless, even if our figures on the uptake of PR in NZ in 2009 were doubled the conclusions from this survey would remain the same.

Finally, we did not specifically gather data on the number of participants in each PR programme by ethnicity. Previous research has implied that Māori appear to be under-represented in PR classes nationally, with it being estimated that Māori comprise 11% of PR classes in DHBs¹⁴, despite Māori representing 15% of the NZ population and experience COPD at over twice the rate of non-Māori.³ However, the exact uptake of PR by Māori with COPD still needs to be established empirically.

Some might argue that another limitation of this study was that we did not distinguish between people based on severity of COPD, and that perhaps a restricted resource such as PR could be best utilised if targeted at the group of people most like to benefit. However, given that the current best evidence has indicated that people with moderate, severe and very severe COPD benefit equally from involvement in PR (and insufficient evidence exists to draw firm conclusions about the relative benefit to people with mild COPD)¹⁹ we suggest that interpretation of our survey data on the basis of severity of disease would be misleading.

There is a strong need for continued research into PR in the future. Such research should include investigations of the barriers and facilitators to access and completion of PR programmes. Arguably, given that COPD appears significantly underdiagnosed,⁵ the greatest barrier to improved uptake of PR is lack of identification of people who could benefit from it.

Interventions to increase screening for COPD, such as offering lung function testing in primary care settings as a routine part of the management of smokers and other people at risk of respiratory disease, would be worth investigating. However, data from our survey indicates that even when PR is offered, at least 30% of people with COPD do not subsequently enrol in a PR programme. In order to maximise the known benefits of this intervention, research needs to be conducted to better understand the reasons why people with COPD do not take up an opportunity to participate in PR when it is offered.

Any such future research ought to focus in particular on addressing the needs of Māori, who are inequitably burdened by COPD.³ Finally, future research should also investigate, in a NZ context, the cost-utility of PR in comparison to other medical management strategies in order to further strengthen arguments regarding the importance of this intervention in NZ.

Competing interests: None declared.

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