

## Referral of patients with chronic obstructive pulmonary disease to pulmonary rehabilitation

Watson, Jane; Adab, Peymane; Jordan, Rachel; Enocson, Alexandra; Greenfield, Sheila

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## **Abstract**

### **Background**

Pulmonary Rehabilitation (PR) is a cost-effective, internationally recommended intervention for patients with Chronic Obstructive Pulmonary Disease (COPD). Referral is predominately led by primary healthcare professionals (PHCP), but referral and patient uptake is poor.

### **Aim**

To understand barriers and enablers for PHCPs when considering patient referral to PR, explore the influence of patient characteristics and understand how referral rates may be increased.

### **Design & Setting**

PHCPs who care for and refer COPD patients to PR were purposively selected from General Practices across Cambridgeshire, Peterborough and the West Midlands.

### **Methods**

Semi-structured interviews were undertaken to theme saturation, exploring PR referral. Images depicting patients with varying COPD severity were used to stimulate memory and associative recall. Interviews were recorded, transcribed verbatim and analysed using Rapid Qualitative Analysis.

### **Results**

19 PHCPs were interviewed. Barriers to PR referral included limited awareness of the clinical benefits, little knowledge of local PR providers, consultation time constraints and presumed low patient motivation. Whilst practice nurses had the greatest knowledge, they still described difficulty in packaging and selling PR. PHCPs frequently described assessing patient suitability based on presumed accessibility, social and disease-specific characteristics rather than clinical benefits. Referrals were facilitated by financial incentives for the practice and positive feedback from both patients and providers.

### **Conclusion**

There were more PR referral barriers than enablers. Providers must engage better with PHCPs/COPD patients/carers and actively promote PR. Increasing PHCPs' awareness of the benefits of PR, financial incentives and alternative referral pathways should be considered.

## How this fits in:

Referral to PR is an important activity, yet it is infrequently actioned by primary health care staff. It is suggested that increasing health care professionals' PR knowledge and awareness will positively change their referral behaviour (23,26). Yet, this qualitative study highlights many complex intertwined barriers to PR referral and few enablers for primary health care staff in England. Our findings highlight some of the factors that should be addressed in addition to interventions targeting knowledge and raising awareness, in order to increase PR referral rates.

## Introduction

Chronic Obstructive Pulmonary Disease (COPD) is a chronic debilitating disease, the 5th leading cause of death in the United Kingdom (UK) (1). Emergency hospital admissions remain high (2) and annual general practice COPD consultations have risen from a mean of 6.6 in 2002 to 12.7 in 2010 (3).

Pulmonary Rehabilitation (PR) is a cost-effective, nationally and internationally recommended intervention for COPD patients (1, 4-6). It comprises structured multidisciplinary group sessions that combine individualised exercise with disease related education. Studies consistently demonstrate PR improves patients' symptoms, both in stable disease and post exacerbation (8-11).

### Box 1

In the UK, referral is largely undertaken by primary care based healthcare practitioners (PHCPs) (12) but less than 10-15% of eligible COPD patients are being referred, consequently practitioners are being asked to improve the PR 'sale' (12-14).

Qualitative studies among COPD patients repeatedly highlight barriers that impede referral acceptance, include fears around exercise and breathlessness and feelings of guilt. Functional barriers include accessibility of PR, and impacts upon family and work (15-21). Patients also report their referral acceptance is highly influenced by their Health Care Practitioner (HCP), citing information about PR, referrer's manner and professional conviction about PR as important (15-18, 21-23).

To date only two UK primary care studies (13, 24) have sought to understand PHCP's PR referral experiences. These studies suggest time-constraints, limited knowledge of PR, patient's physicality and personal culpability for COPD inhibit referral acceptance. Both suggest PHCP attitudes to PR could be important reasons for low referral numbers.

However, one study, based on five focus groups with 21 health professionals from three general practices in a limited geographical area (24) was conducted over a decade ago when PR availability was limited (25). The second (13), was based on a pre-post evaluation of multiple interventions to overcome low PR referral, using semi-structured surveys with HCPs. Whilst some potentially useful strategies were identified, the small number of

participants (9 of 22 responded to follow up), shortcomings in the survey design and data analysis process limit interpretation of the study findings.

A recent systematic scoping review which included a summary of papers exploring HCP perceived barriers and enablers to PR referral (26) identified 9 worldwide studies including 2 from the UK (13, 24). Poor PR knowledge was a commonly perceived barrier, with a need for education identified as a potential enabler. However the included studies were from diverse settings (not limited to primary care which is more relevant in the UK), included surveys which limit exploration of the full range of potential barriers, and was dominated by several studies from the same researchers (27-29). The design and contextual variations limit interpretation of PHCPs' PR referral experiences relevant to a UK primary care setting. Such understanding is critical for informing interventions to increase referral rates.

This qualitative study of PHCPs' perceptions of barriers and enablers for COPD patient referral to PR and the influence of patient characteristics on behaviour will provide an up to date exploration of the referral process, which will inform the development of potential interventions to improve primary care PR referral.

## **Methods**

### **Context**

The study was undertaken in general practices in Cambridgeshire and Peterborough and the West Midlands (NHS Birmingham South and Central CCG, NHS Birmingham Cross City CCG). It was not the intention to identify differences, but to describe practices and experiences in two contrasting regions.

COPD prevalence across the localities is broadly similar with rates for 2015-16 of 1.45%, 1.65% and 1.67% in NHS Cambridgeshire and Peterborough CCG, NHS Birmingham South Central CCG, and NHS Birmingham Cross City CCG respectively (30). However, spend per 100,000 on COPD emergency admissions in 2014/15 was higher in the West Midlands (31). Additionally, Birmingham is one of the most ethnically diverse and deprived regions in the UK (32-33) associated with which are increased primary care consultations (34).

There were 9 PR programmes available in Cambridgeshire and Peterborough and 7 in the West Midlands, but given the West Midlands' larger population (35) PR provision per head is less in this location.

### **Sampling**

53 Practice Managers from a total of 272 practices within the 2 regions were randomly selected and respiratory/COPD interested PHCPs within these practices (n=136) were identified through practice websites and invited to participate by e-mail. Invitations contained participant information sheets and reply slips which collected data on job role, estimated number of COPD patients seen weekly and referrals to PR. A follow-up email was sent to non-responders.

Adaptive sampling methods were implemented to enhance initial recruitment (36). This included JW attending 3 regional respiratory focused meetings across Birmingham and Cambridgeshire to verbally promote the study. Link-trace sampling approaches (37) were also utilised, with invited participants suggesting further potential invitees.

Purposive sampling was undertaken to ensure a fair representation of job role within each of the two locations (38). Practices were remunerated for participant time where interviews took place within working hours.

### **Data Collection Methods**

Semi structured face to face (39) or telephone interviews (40) were offered to PHCPs. All interviews were conducted by JW, audio recorded, transcribed verbatim, checked and anonymised. Validation of completed individual transcripts was requested from participants via email, to ascertain content accuracy and enhance study reliability (41).

The topic guide was informed by published literature and encompassed questions around capability, opportunity and motivation to understand influences on HCP behaviour (42). This guide was piloted and revised by JW and RJ prior to study commencement.

### **Table 1**

Photographic images depicting patients with varying COPD severity were used within each interview; to illuminate prior experiences and thoughts around PR referral (43). Data collection continued until theme saturation (44).

### **Figure 1**

### **Data analysis**

An iterative whole team two-stage approach to data analysis was undertaken using Rapid Qualitative Inquiry (RQI) (45). RQI is helpful for gaining preliminary insight into a complex phenomenon, particularly where little is known and understanding the phenomenon is key. The transcripts were initially coded to identify themes and patterns within the data. Independent coding by team members occurred following completion of the first 5 interviews. Emerging themes were then collaboratively discussed and compared to ensure team agreement and topic guide remained focused. Further independent coding and collaborative team agreement about emergent themes took place again after 14 interviews, this being the study end.

### **Results**

23 participants initially agreed to participate with 19 PHCPs from 16 practices across three CCGs (7 from Cambridgeshire and Peterborough and 9 from the West Midlands) agreeing to interviews.

## Recruitment

6 participants were recruited through email, 6 regional respiratory meeting attendance and 7 link-tracing sampling (37).

18 face to face and 1 telephone interview were conducted between February and November 2017. Interviews lasted 18-63 mins (mean 44.7 mins). Although all participants indicated they referred patients with COPD to PR, at interview it emerged two had no PR knowledge and had never referred, a further participant no longer reviewed COPD patients in practice but considered their respiratory knowledge relevant. All 3 participants' interview data were included in the analysis as their practice was deemed important to the study. The remainder (n-16) narratively reported infrequently referring to PR, this differed to that which had been documented on the returned self-completed reply slips as detailed in Table 2.

## Table 2

### Themes

Four main themes and eleven sub themes were derived from frequencies and patterns in the interview data, these are discussed in-depth below with quotes which reflect the range of views expressed.

Figure 2 shows there is a hierarchical structure to the themes. Awareness and understanding of PR is an important theme because awareness must be present before PHCPs can comment on other aspects. However where professionals were aware of PR, the characteristics of the PR service, perceptions about patients' ability to attend/benefit, the referral processes and personal and collective experiences impacted on the perceived value of PR and subsequent referral behaviour.

## Figure 2

### Main Theme 1. Awareness and understanding about PR.

Awareness of the exact nature of PR was variable with 17/19 reporting some understanding. A small number of PHCPs spoke about PR as a fundamental treatment for patients with COPD.

*"I, 100% feel it is a positive treatment for these patients" (PN1).*

All but one (AHP3) reported they thought PR to be an intervention that incorporated exercise for people with COPD thereby helping patients to manage their breathlessness.

*"Is all about understanding why they get breathless and how to manage that breathlessness"(PN2).*

This awareness was gained from many sources including post-graduate respiratory training and respiratory interested/specialist secondary care colleagues.

One GP shared an anecdote which he described positively influenced his view of PR and current practice.

*“GP Question -Which inhaler is best?”*

*Respiratory Consultant Answer Pulmonary Rehabilitation” (GP5).*

Local CCG interventions such as quality improvement programmes improved PR awareness.

*“We did it as part of the PDMA, Practice Development and Membership Agreement” (GP3).*

PNs appeared to know of PR’s existence more than other PHCPs, yet few were able to fully describe it. 4 /7 PNs and 1/4 ANPs described having observed PR, yet one went on to say

*“I know what pulmonary rehabilitation is, but what is it really?”(ANP2).*

One participant had previously been involved with PR delivery advocating its benefits, but reported referring few patients.

*“it’s beneficial for the right patient, expectations are different to reality” (PN1).*

This participant conveyed a perception that was echoed by several other PHCPs, suggesting that PR knowledge could itself impede referral.

Overall, irrespective of level of awareness, most PHCPs underestimated the value of PR in comparison to other interventions.

*“quite often they’re already on triple-inhaled therapy and you’re sort of thinking, what else might help and that’s when it perhaps comes to mind that maybe pulmonary rehabilitation might be suitable.” (GP6).*

Despite the sample being PHCPs with some interest in COPD, awareness and appreciation of the relative value of PR amongst all treatments, were relatively poor.

## **Main Theme 2. Characteristics of Pulmonary Rehabilitation services**

Both general features of PR and local PR service providers appeared to influence referral. An important characteristic that PHCPs frequently described as impeding the ‘sale’ of PR, is the name itself.

*“Pulmonary Rehabilitation which in itself sounds horrendously frightening” (ANP4).*

Consequently, PHCPs often pre-empted negative patient responses to PR and used alternative terms such as ‘exercise’ or ‘management’ when describing PR to patients, whilst others, described avoiding the term ‘exercise’ completely.

*“I try not to term it as an exercise programme I tend to explain it as a treatment programme” (PN1).*

And for some, particularly nurses’ greater concern existed about offering PR to patients who they perceived not to benefit.

*“If you raise patients’ hopes and say offer it....it could make the depression worse” (ANP4).*

PHCPs rarely described direct PR benefits such as improvements in depression as highlighted in Box 1.

Where PHCPs knew about PR they often described articulating it as difficult.

*I can't always put into words, you know summarise what the benefits are. you know sort of in two sentences" (PN2).*

This was linked to frequent reports of a lack of local practice PR promotional material.

The three sub-themes relative to this main theme are now discussed in further detail.

### **Provider Engagement**

Almost all participants described little engagement from PR providers, mentioning details such as wait time, and timing of provision frequently unknown.

*"there's a definite lack of understanding about when it runs, how often it runs, who the lead is, what sort of exercises they do" (PN1).*

Additionally, very few PHCPs knew if/when patients who had attended PR could re-attend.

### **Quality of local service including personal perceptions**

Wide variation in exercise type offered in PR programmes were described, including Tai-Chi and practice-based chair exercises for general populations. Variation across 'PR' programmes was more prevalent in the West Midlands than Cambridgeshire and Peterborough. However, differences in content appeared not to influence referral. Instead, factors such as intervention venue, ease of referral, patient acceptance, perception of PR providers were considered by PHCP referrers.

*"at the minute I'm probably saying .... Because its local and I think they might buy it. The referral process is really easy, I send an internal message – and it's done" (PN7).*

### **Location**

This was frequently cited by participants as a barrier to PR referral yet it is not clear if this was patient-voiced or PHCP anticipated.

*"it's 2 buses from W\*\*\* and they won't go for two buses" (PN4).*

However, not all PHCPs knew the venue, or were able to confirm to patients where providers might send them

*"We can request, but it doesn't always end up being where we say it is, and where we've asked it to be" (GP4).*

Indeed the emergence of practice-based group exercises appeared to be a solution to this problem, particularly in the West Midlands.

### **Main theme 3: Perceptions about Patients**

A further important theme that emerged from the data is the PHCP's perception of patients' physical and/or psychological ability to benefit from PR. This theme comprises four sub-themes.

## Clinical Characteristics

PHCPs largely described PR as an intervention for patients with defined clinical characteristics, particularly for deteriorating patients, measured by breathless, declining FEV<sub>1</sub> or increasing exacerbation frequency. A frequently mentioned PR referral requirement was patients having to meet MRC breathlessness score  $\geq 3$  (5).

*"I tend to base it on their MRC scores, so the people who are scoring MRC 3, 4 or 5." (GP6).*

Nevertheless, assessment of suitability was often subjective, as demonstrated through the photographic images used.

Most assumed the patient in image B did not require referral based on appearance, and without need for clinical assessment.

*"He's got his walking boots on, I mean he's quite fit." (PN7).*

On the other hand, there was reluctance in referring patients who used oxygen. This was partly based on preconceptions around potential benefit.

*"I would worry about whether she could physically participate...or actually benefit" (referring to image C) (ANP2).*

Others assumed that patients on oxygen would have already been offered PR because of likely contact with secondary care and they would be less likely to offer PR.

## Social Characteristics

PHCPs frequently described characteristics such as social isolation and employment as barriers to attendance

*"I think the majority of patients who say no to me it's because of that anxiety they've got about going out, I think it's just easier to say no" (ANP4).*

Yet, paradoxically PHCPs often viewed PR positively in terms of potential social interactions, particularly for those considered socially isolated.

Patients in work were described as being inhibited by PR programme timing, however PHCPs frequently considered them as too well to benefit.

*"The biggest thing is when they are still in work and its going, to jeopardise their work situation to take time off to go, and they're not severe yet" (ANP1)*

A small number of PHCPs also described current smokers as inappropriate for PR.

*'If a patient won't give up smoking almost what's the point in doing it.'* (PM1).

These social characteristics fed into the subtheme motivation.

## Motivation

PHCPs frequently reported patients are not motivated to attend and described having to 'push' and 'nag' patients.

*"They won't go to PR" (PN7). 'Patients don't want it' (PN5)*

*"the main hurdle is convincing people to go." (GP5).*

This described lack of patient motivation can lead to variation in PR introduction approaches

*"you sort of need to trickle feed it" (PN4)*

which further links to the subtheme "relationships".

### **Relationships**

Relationships between PHCPs and patients were seen as important, but could result in differing patient reactions. Long-term contact with PHCPs resulted in trust for some:

*"I've seen patients for many many years ... they've confidence in you and will say well if you think that's its good for me I will go to it" (PN3).*

In contrast others found familiarity a barrier

*'not again, don't start, not again' (PN7).*

The relationship also impacted on PHCPs' reactions, with some describing caring for COPD patients as challenging, captured by the term

*'heart sink patients' (PN2 & GP5)*

### **Main theme 4: Working environment and Referral processes.**

This final theme included four sub-themes.

Discussions about PR referral were largely seen as most appropriately undertaken by PNs, at COPD annual review.

*"When they're doing the routine review.....that's probably the ideal time" (GP5).*

GPs largely reported infrequently referring.

*"I can't remember the last time I referred anyone" (GP3).*

Few PHCPs considered PR discussion appropriate in an acute exacerbation consultation, given clinical priority and consultation time constraints.

*'It doesn't form any part of my acutely unwell consultation.' (GP4),*

However, post-exacerbation review in primary care is an emerging practice, particularly in the West Midlands, this was described to offer an additional referral opportunity.

*"it may get better now we're trying to do these post-exacerbation reviews because then you've got that second opportunity to look and say" (GP6).*

### **Consultation time & priorities**

PHCPs often reported clinical time constraints inhibit PR referral and described rationalising organisational priorities.

*'The biggest barrier to any referral is time.... (on PR) it's almost like an optional thing you can consider, not something you have to do" (ANP2)*

*"there are lots of calls on prioritisation" (GP2).*

### **Ease of referral**

The majority of PHCPs knew how to refer, describing the process as straightforward, despite some variations. The PR referral on COPD templates was frequently described as a valuable reminder.

*“the template would always prompt” (HCA1).*

### **Patient & Provider Feedback**

Positive patient feedback motivated PHCPs to discuss PR with subsequent COPD patients.

*“I have seen patients who ...have been suitable for PR but haven't agreed to be referred in the past ....I would mention ...the experience of other patients..... have found it helpful so that might motivate them to kind of agree” (GP1)*

PR provider feedback was largely described as very poor.

*“I don't know what's happened to my patients that I've referred, whether they've actually gone, what their outcome is” (ANP4).*

Additionally where referred patients had been deemed ineligible for PR by providers it appeared to be patients rather than providers that fed that back. PHCPs described feeling frustrated in these circumstances, demotivating them from future referrals.

*“I was a bit annoyed because I felt quite strongly that he would benefit” (PN3).*

Public PR awareness appeared very low with only 2/19 participants reporting patient/carers to have asked about PR. PR awareness within some general practices also appeared to be low.

*“it's very rarely talked about, I've never heard it mentioned” (ANP3).*

### **Practice Incentives**

Financial incentives, appeared to differ between the locations and influence PHCPs' views. In Cambridgeshire and Peterborough there was no financial incentive for PR referral.

*“I'm not saying it should be but if pulmonary COPD was a QoF priority, money attached we would do it” (GP2),*

In the West Midlands there were financial incentives, which were deemed as helpful in terms of reminders

*“maybe triggers other people's brains.... it's part of a thing you need to do” (GP6).*

and also in raising PRs profile and authorising referrals

*“It makes it okay” (GP6).*

### **Suggested Enablers**

All participants were invited to suggest possible PR referral enablers. Table 3 demonstrates all 12 suggestions that were proposed and their alignment to the main themes.

### **Table 3**

### **Discussion**

## Summary

This is the first in depth qualitative study to look at a range of PHCPs' experiences of referring or considering PR referral for COPD patients in England. It highlights a hierarchical approach to PR discussion and referral by PHCPs, that has not previously been reported. This is dominated initially by PHCPs' individual awareness and understanding of PR, which is subsequently strongly influenced by three further factors: characteristics of PR services, perceptions about patient motivation and characteristics, the working environment and referral process.

PR referral is a highly complex phenomenon which was influenced by the PHCP's knowledge and awareness of the benefits of PR, and contextual factors such as perceived quality of the PR service, engagement with providers, consultation time, referral prompts, ease of referral, PHCP/patient relationship, perceptions of the patient's needs and abilities and practical considerations such as PR accessibility. Whilst detailed awareness of PR's clinical benefits was generally low, it is the totality of these factors that appeared to greatly inhibit PR referral by PHCPs. As such increasing PHCP knowledge alone will not necessarily translate to increased referral rates, indeed some PR knowledge appears to impede referral as patient assessment and suitability was analysed in greater detail by knowledgeable PHCPs.

PHCPs described referral to be considered largely at COPD annual review, yet frequent subjective evaluation of patient characteristics rather than clinical assessment dominated decisions. This subjective assessment led to referral opportunities being considerably narrowed.

PHCPs frequently reported patients were unmotivated and perceived patient-based difficulties in attending PR as important barriers to referral. In response, a commonly utilised lever was to offer PR when COPD symptom burden such as exacerbation rate and dyspnoea is increasing and where pharmacological treatments have been maximised. PR was therefore frequently viewed as an end of the road treatment at a time where patients with COPD often have high symptom burden. PHCPs were aware of this and not always certain how best to support patients, although described introducing PR gradually as one approach.

Relationships with PR providers and environmental factors, such as having the time to refer and practical accessibility of PR service for patients influenced referral behaviours. PHCPs often described lack of familiarity with their local PR providers contributing to lower referral. Indeed the most frequent suggested enablers to improve PR referral (table 3) were related to PR providers.

Whilst it was not intended to make comparisons between the geographical areas, some differences were noted. In some West Midlands practices, PR incentive funding appeared to increase PHCP PR awareness and increased reported referral rates. However, higher non-elective COPD emergency admissions in this location (31) may also contribute.

## Strengths and limitations

The study was able to recruit a wide range of general practice based participants, with knowledge of PR, in all but 2/19. Gaining insight into PHCPs' real experiences of current PR referral barriers and enablers is important

Only PHCPs who had an interest in PR and/or COPD may have agreed to take part and had the study been undertaken in different geographical regions, findings may have differed. All PNs and 16% of GPs interviewed had a post qualifying respiratory qualification which may not be reflective of the general practice workforce. Despite this, awareness and appreciation of the relative value of PR amongst treatment options for COPD was limited.

JW is an experienced respiratory specialist nurse, whose experiences may have influenced data collection and analysis (38).

### **Comparison with existing literature.**

HCP knowledge of PR has previously been reported as being low (23, 26). Whilst general HCP awareness may have increased since the implementation of secondary care COPD discharge bundles, PR referral and uptake remains low (49,50).

The current study found most PHCPs had a general PR awareness, but few had detailed PR knowledge. Whilst knowledge is a key factor to referral, this is highly influenced by additional factors which must be addressed if PR referral rates are to increase and PHCPs are to improve its 'sale'.

An early qualitative study (24) and a practice-based service evaluation (13) postulate that PHCP attitude may contribute to low PR referral numbers, a factor reported by patients themselves (19,21). Conversely, this study found PHCPs frequently described patients as having little motivation for PR, also reported elsewhere (24, 26). Participants described maximal pharmacological therapy and worsening COPD symptoms as opportunities for motivating patients to accept PR. This approach has important implications firstly; patients with high COPD symptoms live with high levels of fear and panic (20,46) and have concerns about functional abilities, including beliefs that shortness of breath is detrimental to lung capacity (20), these are highly likely to influence patients' referral acceptance and may explain 'low motivation'. Secondly, many patients with COPD are frequently inappropriately prescribed triple therapy (Price et al, 2015). Referring patients earlier to PR, where symptom burden is less may increase patient acceptance and may reduce prescribing behaviours.

Patients themselves have reported key factors to referral acceptance are their understanding of the content and benefits of participation in PR programs (17). Our findings highlight that PHCPs struggle to articulate both content and clinical benefit of PR. HCPs are highly influential in a patient's PR referral acceptance (15-18), yet those interviewed had little awareness of this and subsequently no plans to address it.

Financial incentives appeared to facilitate likelihood of referral in this study and elsewhere (47). It is likely the implementation of financial reward for PR referral instilled by the new GP

contract changes in England and Wales (48) will yield some positive changes, but it is important to acknowledge that increased GP PR referral rates do not necessarily translate to greater PR completion as has been reported by Hogg et al, 2012 (51) . As such, adopting a system based approach at the point of referral that incorporates the three key parties (PHCP, patient and PR provider) is likely to be more successful in overcoming the multiple barriers than isolated interventions.

### **Implications for research and/or practice.**

PR is a nationally and internationally recommended intervention for COPD patients, yet it remains poorly accessed. Primary care consultations for COPD are increasing as is the COPD population. Increasing PR referral and likely uptake will reduce patient symptom burden and potentially reduce primary care contacts.

The PR referrer is very important to referral acceptance, uptake and completion. PHCPs reported large numbers of barriers and very few enablers. This appears to indicate a multi-pronged approach to enhancing referral is likely to be valuable. This goes beyond education and awareness raising for PCHPs, and includes engagement of PR providers and system level changes. Identifying the frequency and generalisability of these findings are important next steps. These current findings have been mapped to a national PHCP survey for which data collection is ongoing.

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