

Improving access to pulmonary rehabilitation for patients with COPD treated for substance misuse in the London Borough of Islington

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ABSTRACT

Chronic obstructive pulmonary disease (COPD) is a collection of conditions that cause permanent damage to the lungs. Among a range of treatment options, patients can benefit from pulmonary rehabilitation (PR) programmes involving physical exercises and education. The risk of developing COPD is higher for substance misusers than the general population. Substance misusers with COPD have more severe symptoms and poorer health outcomes than other COPD patients, and experience inequalities in accessing PR services.

This project aimed to work with a local substance misuse service to increase the referrals of patients with COPD with a history of drug and/or alcohol problems to a PR programme in the London Borough of Islington. Quality improvement methods were used to explore barriers to accessing PR and to identify ways of making referral to PR easier. A series of change ideas were implemented and tested sequentially through plan–do–study–act, including updating referral systems, educating staff and improving access to diagnosis.

The primary objective was to achieve 100 eligible referrals during the 14-month project period. In practice, a total of 57 patients were referred to the programme. Sustained engagement with patients was challenging, with significant attrition observed from referral to programme completion. However, there was indicative evidence of clinical improvements in dyspnoea and exercise capacity among PR completers and qualitative feedback of improved health and well-being.

Although referrals numbers were less than expected, we have established an innovative respiratory care pathway for substance misusers, founded on a holistic approach to diagnosis and treatment. There are also clear pointers as to how this approach can be sustained and developed further to maximise the benefits for this cohort of patients.

PROBLEM

Pulmonary rehabilitation (PR) for chronic obstructive pulmonary disease (COPD) is a group exercise and education programme designed for people with lung disease who experience symptoms of breathlessness. It is known to improve exercise capacity and quality of life, as well as reduce emergency healthcare use, healthcare costs and mortality.¹

WHAT IS ALREADY KNOWN ON THIS TOPIC

⇒ National clinical guidelines recommend a minimum of 12 pulmonary rehabilitation (PR) sessions, two times a week over 6–12 week period. PR referral processes for our population of interest have not been studied previously.

WHAT THIS STUDY ADDS

⇒ A collaborative approach to service innovation in this field has established a new diagnostic and referral pathway, enabling more patients with chronic obstructive pulmonary disease with a history of substance misuse to access PR.

HOW THIS STUDY MIGHT AFFECT RESEARCH, PRACTICE OR POLICY

⇒ Referrals to PR among this population can be achieved, but we conclude that the option of an abbreviated programme might be beneficial for many patients, subject to future evaluation.

Despite these benefits, only a small proportion of all eligible patients with COPD in the UK are referred for PR²; the National Health Service (NHS) long-term plan aims to improve access.³ This is especially pertinent for patients undergoing treatment for substance misuse, for whom the risk of poor respiratory health is notably high.⁴ The existing literature is limited in scope and heterogeneous, but a recent systematic review estimated pooled COPD prevalence in people who inhale illicit opioids to be 18%.⁴ Among a cohort of primary care patients in England, the prevalence of COPD was higher in methadone patients compared with non-methadone patients (12% vs 1%).⁵ Also in primary care, illicit opioid use has been associated with almost six times the risk of a COPD diagnosis.² The relationship is due largely to both the long-term effects of tobacco smoking and from inhalation of illicit drugs, which cause additional damage to the lungs.^{6,7} Disease progression is quicker in this cohort and made worse by not having



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access to the accurate diagnosis and appropriate clinical management (including PR).²

This project was led by the two North Central London PR Physiotherapists, acting as health inequality leads on behalf of Whittington Health (WH) PR team in Islington, North London, UK. Local audit data show that nine out of ten referrals to the existing PR service were from primary care. Patients with substance misuse problems tend to be more frequent users of urgent care services than the general population,⁸ but have been found not to engage well with primary care services.⁹ Systematic data on substance misuse problems among our existing PR patients (referred via primary care) were not available, but anecdotally, if referred PR staff reported that they did not attend appointments for initial assessment. Our concern, therefore, was the challenge of facilitating referrals to PR and also maintaining engagement after the initial assessment. The programme comprised of two sessions per week over a 6-week period as recommended by British Thoracic Society PR guidelines.¹

A Quality Improvement (QI) project was established in October 2022 with an aim to receive 100 referrals of eligible patients with COPD with a history of substance misuse to the WH PR programme by December 2023. This was judged to be feasible in the time available, given the better lives (BL) service caseload of approximately 2000, best available prevalence estimates⁴ and preliminary scoping described below.

BACKGROUND

COPD refers to a collection of conditions that cause permanent damage to the lungs. An estimated 1.2 million people in the UK are living with diagnosed COPD,¹⁰ and even more are estimated to be undiagnosed.¹⁰ The annual cost of COPD to the NHS has been calculated to be £1.9 billion.¹⁰ National policy recognises the links between deprivation and poor health, advocating localised attention to COPD among socially excluded groups, such as dependent drug and alcohol users.¹¹

Systematic review evidence indicates that, for patients with COPD in general, referral, uptake, attendance and completion of PR are influenced by environmental factors, such as travel, transport and health system resources; knowledge of referral processes (practitioners) and what PR involves (patients); and practitioner and patient beliefs about the benefits of PR.¹²

Rates of PR referral and completion are also lower for patients in more deprived geographical areas.^{13 14} Once referred, however, clinical outcomes in terms of exercise performance and health status have been found to be unrelated to deprivation.¹³ Since substance misuse is higher in more deprived areas compared with less deprived areas,¹⁵ we might expect to see a similar pattern in this specific population. To the authors' knowledge, there is no published UK research on how routine PR or similar physiotherapy programmes engage with substance misusers and how they respond.

Prior to this QI project, there was no referral pathway from BL, a substance misuse service in Islington, to the PR service. Thus, our starting point was preliminary scoping of a community respiratory clinic offered at BL, which showed that all patients reported breathlessness and half of those had Medical Research Council (MRC) dyspnoea scale scores of 4 or more. The British Thoracic Society (BTS) PR guidelines recommend that patients with MRC scale scores of 3–5 should be referred to PR.¹ Discussions with staff in team meetings revealed that they were unaware of PR or its benefits. We, therefore, concluded that linking clinical needs and awareness of PR among BL staff and service users would be core to the design of the project.

MEASUREMENT

The PR service was for people in the QI project only (ie, referred by BL). As recommended by the NHS England PR service specification,¹⁶ the following data were collected: number of patients who were offered PR (and as a percentage of referrals), number of eligible patients who completed the PR, number of eligible patients who declined PR programme following referral and the reasons, percentage of patients satisfied with the service received, attendance at PR and dropout rates at all stages.

The PR programme also routinely assesses clinical outcomes for dyspnoea (MRC dyspnoea scale), exercise capacity (6-min walk test (6MWT) or incremental shuttle walk test (ISWT)), health status (the COPD assessment test) and visual analogue scale to represent attainment of short-term goals. In addition, anxiety and depression were measured using the Hospital Anxiety and Depression scale. The intention was to compare baseline and completion data for these measures. Patient testimonials were collected throughout the course of the programme.

DESIGN

The two health inequality leads, the BL team (consultant psychiatrist, key workers and two physical health nurses), the WH PR clinical lead and people with lived experience under the addiction service formed the QI team.

The preparatory phase of the project involved initial process mapping of the proposed referral process (figure 1), carried out by the QI team to identify the key steps involved, and where barriers and bottlenecks in the system might arise (shown as red boxes). An aims statement was then established and drivers and change ideas were identified through an initial focus group with BL staff (figure 2).

Using the drivers for change as a framework, BL staff (key workers, and medical and nursing staff) and the wider community respiratory team (nurses, rehab support workers and physiotherapists) were then invited to complete an online survey to understand more about their awareness of each other's expert field. Questions included relevant clinical experience to date, knowledge and confidence in the respective areas (PR for addiction

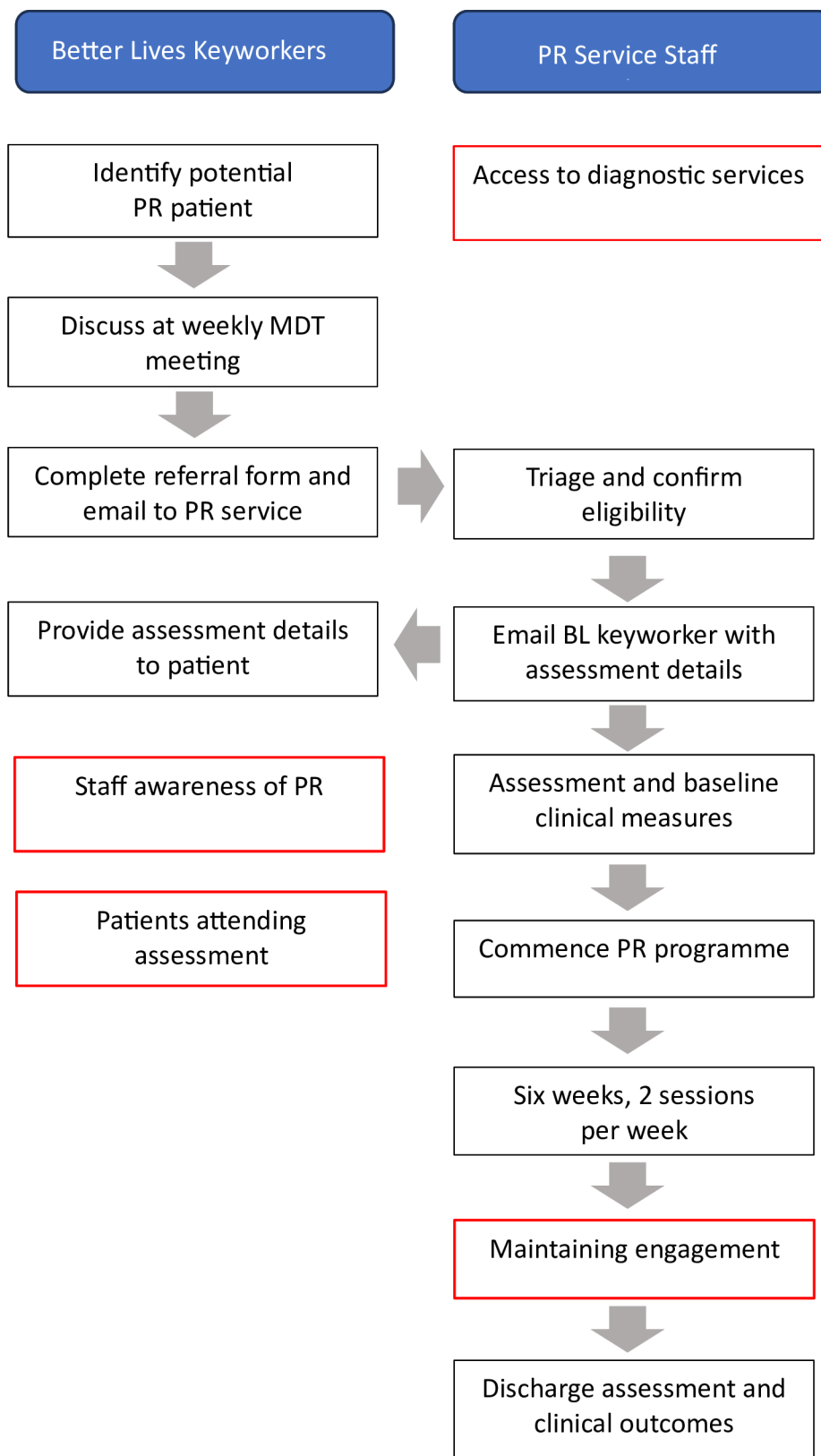


Figure 1 Proposed referrals process map. BL, better lives; PR, pulmonary rehabilitation; MDT, Multi-Disciplinary Team.

staff and drug and alcohol addiction for respiratory teams). Each was asked for suggestions for any specific learning needs.

Through synthesis of these exercises, potential challenges to supporting patient engagement with PR services were identified: limited awareness of available services, lack of trust due to previous negative experiences with

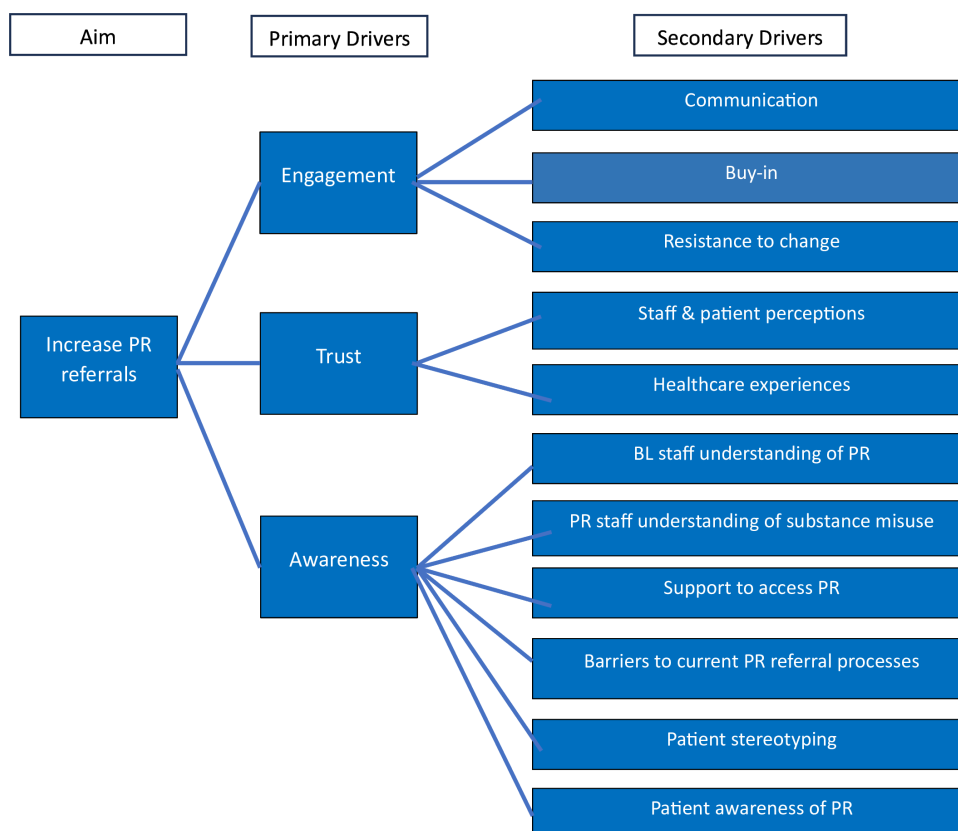


Figure 2 Driver diagram. PR, pulmonary rehabilitation.

healthcare services, complex and deteriorating physical and mental health needs, poor health literacy, lack of flexibility in the referral and diagnosis pathways, priorities differing daily and lack of social autonomy.

STRATEGY

The project used a plan, do, study and act (PDSA) cycle approach¹⁷ to test different approaches to improving the referral process, informed by the earlier identified drivers for change.

PDSA cycle 1: enhancing engagement

Our initial change was to enhance stakeholder engagement by updating referral systems across the two services. BL was added as referral source on the WH electronic patient records and also given direct access to PR referral form. BL staff were informed of these changes (communication) and encouraged to use the new system (staff buy-in). Ensuring that appropriate and eligible referrals were recorded properly was a prerequisite for the project. We also hoped enabling referrals in this way would have knock on the effects on staff awareness of the PR service, and thus reduce resistance to change, as well as increasing the flow of patients.

The number of referrals received in the first 16 weeks was lower than expected (n=18). Discussion in meetings between health inequality leads and the BL team clarified that responsibility for identifying potentially eligible patients for the PR service was delegated to key workers

and they requested guidance on how to explain the benefits of PR to patients.

PDSA cycle 2: improving awareness

This cycle addressed multiple drivers we had identified as potential contributors to improvement. Training material was created, based on needs identified at a BL team meeting. Training was provided in the form of a 2 hour online interactive educational session, designed and presented by community respiratory specialists specifically for BL key workers. The session was recorded to allow access to the training at a later date and delivered to improve PR awareness and knowledge among the BL key workers.

A shorter presentation at a BL team meeting in April 2023 aimed to equip key workers with knowledge about PR, the programme structure and its benefits to patients. Testimonials from WH PR service patients were shared to support BL key workers' confidence in speaking to patients about PR. After the presentation, BL staff completed a brief questionnaire, which indicated improvements in knowledge and ability to describe PR and its benefits to potential patients. This again did not improve the referral rate, with 14 referrals in the following 16 weeks (May–August 2023).

Using the five whys technique,¹⁸ discussion between the BL and PR teams suggested that, despite expecting a high proportion of patients with long-term respiratory conditions in this cohort, key worker identification of potential

cases was hampered by lack of a formal COPD diagnosis for many patients. Those who had been diagnosed were sometimes judged to be unsuitable for referral due to complex physical and mental health presentation. We, therefore, turned our attention to improving access to the COPD diagnostic pathway.

PDSA cycle 3: accessing diagnosis

This cycle further addressed awareness but also trust in the service. In the London Borough of Islington, diagnostic spirometry is provided in primary care or by respiratory consultant-led outpatient clinics. To enhance the appeal and accessibility for BL patients, we worked with the diagnostic project manager to provide a drop-in diagnostic clinic provided on three separate days over a 6-week period. The clinic was led by a respiratory consultant and supported by WH and Camden community respiratory teams. The sessions were held at Arsenal football club, which was regarded as an attractive and familiar local venue. Posters were prepared and BL staff were responsible for advertising and for organising transport for those who needed it.

In total, 66 patients were screened, of whom 10 had normal lung function. The remaining patients were either given a formal diagnosis or referred on for further investigation. 13 patients were identified to be suitable for PR, of whom 2 consented to PR referral. The remaining 11 patients were to discuss referral with their key workers before committing. While making significant improvements to the diagnostic pathway, the observed complexities of diagnosis and referral for this patient population meant that our expectations for the number of PR referrals would not be met.

RESULTS

During the 14-month QI period, 57 referrals to the PR service were received directly from BL. As [figure 3](#) shows, improving the mechanics of the referral process (PDSA cycle 1) and the diagnostic pathway (PDSA cycle 3) led to modest improvements in referrals. Most of the patients referred (n=51; 89%) were offered PR for the first time. The characteristics of the 57 referrals and their journey through the assessment and treatment process are shown in [table 1](#).

After triage, 12 (21%) patients were not offered an initial assessment. One of the main reasons was that patients had not had diagnostics to confirm their lung condition, despite being on the COPD register.

Of the 45 (79%) patients offered an initial assessment, 38 (84%) attended the PR clinic set up at BL. Following assessment, 31/38 patients (82%; 54% of referrals) were offered enrolment on the PR programme and 21 (68%) commenced the programme. On average, patients attended 6 out of the 12 allocated sessions and 7 of them attended 10 or more of the allocated sessions. Reasons for non-completion included worsening mental health (n=4), becoming unwell with chest infections (n=4), hospital admissions (n=3), conflict with other patients (n=1) and homelessness (n=1).

Four patients completed the discharge assessment. Three attained minimal clinically important difference in exercise capacity using either the ISWT or the 6MWT. Two showed improvements in the MRC dyspnoea scale and in depression and anxiety. Three improved in health status. On average, patients scored 7 out of 10 for achieving their self-defined short-term goal.

Testimonials commended the sessions. Patients reported improvement in exercise tolerance (eg, 'able to walk further and less breathless') and better symptom management (eg, 'I do not reach out for the inhaler

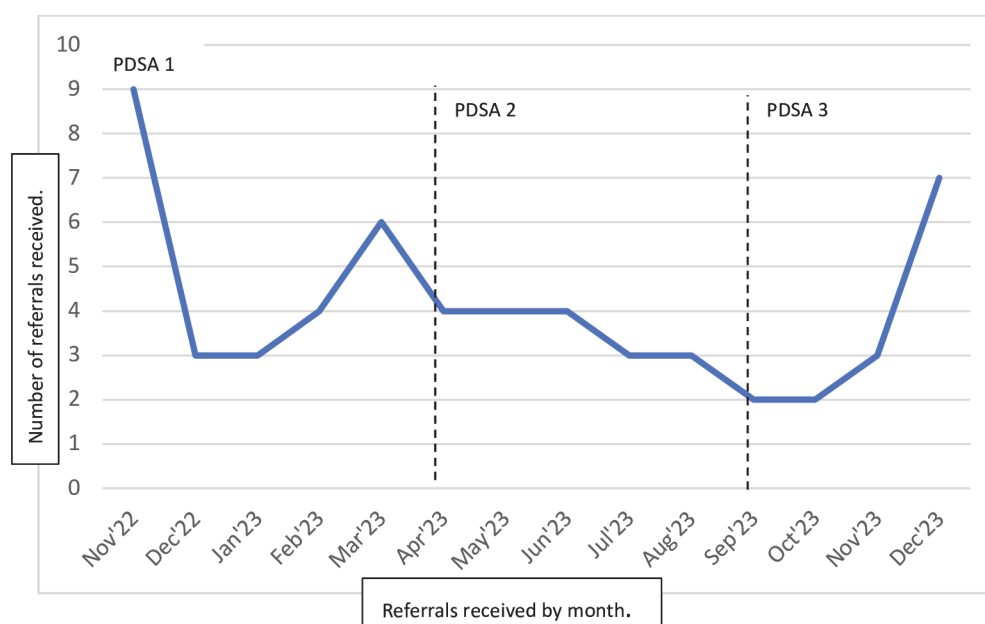


Figure 3 Referrals received from BL by month. BL, better lives; PDSA, plan-do-study-act.

Table 1 Characteristics of patients referred to PR and those who were assessed

Referral	Value
Total referrals	57
Previously referred to PR prior to this project n (%)	6 (10)
Mean age (range) years	55 (31–73)
Male: female	41:16
Eligible patients offered initial assessment n (%)	45 (79)
Assessment	Value
Total assessed	38
Mean days referral to assessment	43 days
Male: female attended assessment	29:9
Average MRC dyspnoea scale score (range)	3 (2–4)
Existing mental illness n (%)	36 (95)
Tobacco dependent n (%)	32 (84)
History of smoking heroin n (%)	22 (58)
History of smoking crack n (%)	19 (50)
History of smoking cannabis n (%)	12 (32)
History of using cocaine n (%)	10 (26)
Offered PR following assessment n (%)	31 (82)
Declined PR following assessment n (%)	1 (3)
Commenced PR following offer n (%)	21 (68)
Mean days assessment to commencing PR	9 days
Attended 80% of the allocated sessions n (%)	7 (33)
Attended discharge assessment n (%)	4 (19)

MRC, Medical Research Council; PR, pulmonary rehabilitation.

when I am breathless, I know I can control it'). They also felt valued and reported that the sessions reduced isolation, distracted them from smoking and gave a structure to the day.

Lessons and limitations

At the start of the project, we anticipated that many more patients would be referred to the PR programme, given the previous evidence of high prevalence of respiratory disease in this cohort. BL held approximately 2000 patients in their caseload during the project period; only an estimated 3% (n=57) patients were referred to PR. Although disappointing, through the PDSA cycles, we gained valuable insights into the reasons for low referrals and how access to PR could be improved.

The findings indicate that improving access to PR for substance misusers requires establishing a broader, holistic respiratory care pathway. We have demonstrated the efforts required to develop a joined-up approach to service development and provision, but acknowledge

that work is required to maintain the level of integration required to maximise the potential benefits for patients. For example, raising awareness of PR needs to be ongoing, with reminders provided in team meetings and including PR awareness in the general induction for new staff. Linkage to diagnostic services was also important. Even though the spirometry pilot did not bring in many PR referrals, more patients were newly diagnosed and added to the primary care COPD register and should, therefore, be on appropriate treatment pathways. Subsequent to this project, a WH nurse-led respiratory clinic has commenced at BL, which can provide access to respiratory consultant input if needed.

As expected, patient engagement was difficult. Early involvement of patients in developing the PR programme was limited. There was an emphasis on gaining feedback from participants once they had worked with the PR team and established trust. We confirmed the initial conclusions from the mapping exercise that creating trust is paramount, by taking services to patients and connecting through their familiar contacts, such as voluntary organisations and key workers. Nonetheless, maintaining patient engagement remained a considerable challenge. We recommend that services exhibit tolerance have a lenient DNA/discharge policy and make reasonable adjustments to maximise patient engagement. We defined PR completers as having participated in at least 80% of the allocated sessions and as having a discharge assessment. In retrospect, this was unrealistic, even with the level of support provided by patients' key workers.

Further research is clearly needed to understand how patient adherence to PR can be improved among this cohort. This is a key limitation of our QI project. With larger numbers, we would have hoped to have examined trends in progress through the referral system by patient characteristics, such as age, sex, deprivation, mental illness and specific substance misuse problems.

CONCLUSION

We have established a sustainable diagnostic and referral pathway and provided a treatment opportunity for eligible patients who had not been offered PR before. Yet, attrition from referral to completion was substantial; only a third of those referred started the PR programme. While specific to substance misusers, the results are consistent with wider themes identified in the literature as barriers to access and delivery of PR services.⁹ They are also relevant to other patient groups who find accessing PR difficult, such as those with a serious mental illness and people experiencing homelessness.

Based on our findings, we suggest that BTS recommendations that PR programmes comprise a minimum of 12 sessions, two times a week over 6–12 weeks,¹ may not be best suited to substance misuse patients. The evidence underpinning the existing PR guidelines has some important weaknesses, not least that there is next to no research on our population of interest. In addition,

recommendations for session frequency are based on weak research evidence, and there are relatively few studies of shorter versus longer PR programmes.¹

A review of the BTS guidelines recognises more recent innovations in PR service delivery and related areas of research priority.¹⁹ In particular, new interventions to improve referrals, uptake and completion of PR are recommended, as well as the evaluation of approaches to meeting diverse population needs.¹⁹ We propose, therefore, that a redesign of the PR service for substance misusers may be required, providing an abbreviated programme option for those unable to commit to the full 12 sessions. This looks like a more realistic proposition, given high levels of drop-out, but will require a future substantive study to assess the feasibility and acceptability of this approach, from both patient's and provider's perspectives.

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Contributors DN and JS conceptualised the project, collated and analysed the data, and led implementation of the project. DN, JS and DS were all involved in drafting and reviewing the manuscript. DN is the guarantor of this submission.

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Patient consent for publication Not applicable.

Ethics approval Whittington Health NHS Trust approved this QI project and submission of this report.

Provenance and peer review Not commissioned; externally peer reviewed.

Data availability statement Data are available on reasonable request.

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