Taskforce for Lung Health Working Group Position Paper on NHS England' 5 Year Vision for Pulmonary Rehabilitation

This briefing sets out the Taskforce for Lung Health's position on NHS England's (NHSE) 5 Year pulmonary rehabilitation (PR) vision and has recommendations to support the improvement of PR services for people with a range of different respiratory conditions.

Why a new vision is needed

NHS England are looking to develop a new 5 Year vision for PR that would support transformational and innovative approaches to effective PR delivery. A revised plan would refresh Long Term Plan commitments for PR and help convey NHSE's goals for improving PR, which include among other things:

- Improving the quality of PR in England
- Expanding access to PR
- Reducing health inequalities
- Supporting patients with self-management.

The policy landscape behind the Long-Term Plan has changed. As highlighted in our '*future of pulmonary rehabilitation'* paper, the pandemic has both exacerbated existing issues in accessing PR services, but also enabled the re-imagining of services. We believe that it is right that Long Term Plan PR goals are reviewed, as part of this vision to ensure that they reflect current challenges and opportunities afforded PR services, in light of the pandemic.

This paper welcomes the overall goal of creating a new vision for PR and sets out the ways that we think this can be achieved with reference to our 5 Year Plan. We also make recommendations for where the NHSE vision could go further than commitments outlined in the Long-Term Plan so that many more people would benefit from PR.

Summary of recommendations

- Expanding PR to people with MRC breathlessness scores of 2 and above and people with other respiratory conditions.
- Better data collection to understand both gaps in accessing PR and what makes quality PR.
- Better data collection on online/hybrid PR models.
- Identifying and reducing health inequalities.
- A sustainable PR workforce.
- The development of resources that include patient and carer experiences, as a means of improving referrals and uptake of PR.
- Strong patient involvement in NHSE's 5 Year PR Vision.

Improving access to quality PR

Taskforce for Lung Health Recommendation 4c: *"expand the use of non-pharmacological treatments for breathlessness and cough"*

The respiratory sector is in urgent need of funding – even prior to the pandemic, services were stretched thin. Funding has and will be allocated to NHS regions to support the delivery of PR for the period 2021-2022 and 2022-2023. We believe that in order to ensure sustainable expansion of PR, a multi-year package will be needed. Whilst we welcome current rounds of annual funding to regions, we are concerned that it is not enough to address current and future levels of demand for PR. For Long Term Plan ambitions on PR to be truly effective people must not struggle to access services because they are languishing on long waiting lists or experiencing other barriers to participation.

Our '*future of pulmonary rehabilitation briefing paper*' outlines the PR backdrop in 2020/21 – including the difficulties that people have experienced accessing PR services. Increased demand from people both with pre-existing respiratory conditions, coupled with a new group of people with Long COVID-related breathlessness has put additional pressure on already strained services. Similarly, programmes that were paused over the first lock down have had a knock-on effect on the delivery of PR programmes – resulting in delays and extended waiting lists for people with lung disease.

In Asthma + Lung UK's recent report '*Failing on the Fundamentals'* which charts Chronic Obstructive Pulmonary Disease (COPD) care over the pandemic, it was found that overall (MRC breathlessness score 1-5):

- 46.3% of people with COPD had not received PR and;
- 12.2% of respondents had never heard of PR.[i]

The Taskforce for Lung Health's data tracker shows that even pre-pandemic, access to PR services needed improvement – Quality and Outcomes Framework indicators (currently paused) reveals that only 43% of the eligible COPD population were referred for PR in 2019/20. Whilst this is an improvement on the 15% figure in the National Asthma and COPD Audit Programme's (NACAP) 2015 audit,[ii] it is still less than half of people with COPD who are eligible.

We are pleased that the Long-Term Plan committed to expanding PR for people with COPD over a ten-year period. However, we believe that the 5-year vision should also provide clarity on concrete actions that will be taken to improve access to PR among eligible populations, to ensure that everyone who would benefit is referred to and able to access this vital service.

Recommendation: We would urge NHS England to ensure that additional funding is sufficient to both find and treat people with COPD and other respiratory conditions.

NHS structures – Integrated Care Systems (ICSs)

We recognise that ICSs will be placed on a statutory footing through the Health & Social Care Bill. We ask NHSE to set out how these structures will operate in practice, so that it is clear how the money flows through the system and how PR services will be commissioned. We hope there will be a clear commitment from ICSs to improve both – availability and access to high-quality PR, for all people who could benefit.

As such, the Taskforce for Lung Health welcomes the Community Rehab Alliance's calls for better rehabilitation through among other things, clear guidance, and allied health professional representation at Integrated Care Board level. The Alliance, which brings together patient organisations, charities, and professional organisations is also supporting Baroness Finlay of Llandaff's amendments to the Health & Social Care Bill.[iii] The amendment requires Integrated Care Boards to produce an annual rehabilitation plan. It is vital that NHS systems devise a clear strategy

that sets out how they will improve PR delivery within their areas – we look forward to seeing how rehabilitation will be prioritised within these structures.

Milder forms of breathlessness and other respiratory conditions

The new vision should also go further than current Long Term Plan ambitions, which focuses on people with COPD whose MRC breathlessness score is 3 and above. In the Taskforce 5 Year Plan, we set out the following recommendation for improving access to PR:

Taskforce for Lung Health Recommendation 4b: *"improve access to pulmonary rehabilitation so that every person with an MRC breathlessness score of grade 2 and above is identified, referred to and has the opportunity to complete, a programme."*

There are too many people for whom PR could be beneficial who are not currently included in Long Term Plan ambitions. This includes:

- People with milder forms of breathlessness (such as MRC grade 2)
- People with other respiratory conditions, and specifically people with interstitial lung disease (ILDs), including idiopathic pulmonary fibrosis (IPF).

It's essential that NHS England includes these groups in its vison to ensure that everyone who could benefit from PR are able to access the service.

There is good evidence that PR is effective for people with respiratory conditions when offered earlier on – with studies highlighting that it can help improve a person's quality of life, psychological status, and ability to exercise at all stages of their disease [iv] and can also help improve shortness of breath symptoms.[v] PR is also a very important treatment option for people with ILDs such as IPF – with a study showing that it can improve quality of life and exercise capacity.[vi] Taskforce for Lung Health's storytellers tell us:

"I always say to people, "You've got to treat pulmonary rehab as a medication". It's a treatment. When my consultant showed me the figures, you could see the difference. When I started the treatment, I had been able to complete seven sit-to-start exercises in ten seconds. At the end of it, I was able to do 10 in the same amount of time. I was also able to walk much further, which makes a big difference."

(Ron Flewett who has IPF)

"PR taught me that living with a lung condition doesn't mean that life has to stop. Hope is the one thing that PR gave me. Before completing PR, I wasn't sure what I should or shouldn't do. It's been a lifeline."

(Maggie Barlett who has IPF)

Rapid access to high-quality, tailored PR is imperative for improving the quality of life for people with ILD[vii] given the short prognosis for these conditions, on average. Despite this, we continue to hear of difficulties getting referrals into PR for people with ILDs. Action for Pulmonary Fibrosis have uncovered some of the challenges that people living with ILDs experience in accessing PR:

"Locally pulmonary rehab is only available to covid patients currently."

"... Now I've moved to a different area (same county but an hour away) when I asked my new GP about it [pulmonary rehabilitation], he said 'we save that for people that really need it'."

"It's really sad when you see... the benefits PR has, and you know with all the cutbacks, backlogs, covid issues you haven't a hope of starting this when it's actually needed and maybe never."

We're therefore urging NHS England to include a plan for how to deliver improvements in access to PR for these groups of people with lung disease, and ensure they're not left behind.

Recommendation: NHS England and services should adopt a principle of equity of access to PR for people with milder forms of breathlessness (e.g., MRC 2)

Recommendation: NHS England and services should adopt a principle of equity of access to PR for all people with respiratory conditions who would benefit (e.g., ILDs), and those with respiratory complications caused by COVID.

Data

The following questions were raised during initial conversation that NHSE had with a range of academics, charities, professional bodies, and the Taskforce, to help inform its data modelling work in the 5 Year Vision. The Taskforce for Lung Health agrees that these questions will need to be considered and addressed by NHSE to ensure that people can access high-quality PR services:

- **Who needs to access PR**: better data is needed to identify who is and isn't eligible for PR, broken-down by condition (e.g., COPD, ILD, Asthma), severity of breathlessness (e.g., MRC Grade), protected characteristics e.g., age, gender and ethnicity, and geography.
    - Questions that NHSE will ultimately need to consider to achieve the above include:
        - What are the eligibility requirements for accessing PR? There is no agreed upon criteria for who should be referred for PR. The Taskforce position is that the eligibility criteria should include, at the very least those with an MRC grade 2 and above. NHSE must confirm what the eligibility criteria will be for this modelling and explain the rationale behind it.
    - The above insight will allow us to understand:
        - What capacity is needed within the NHS to address demand?
        - How does this compare with current capacity?
        - What would relaxing the eligibility requirements mean? PR has been shown to be beneficial at all stages of disease and thus the earlier that people with lung disease can access PR the better.
        - Are there currently any groups of people under-represented in PR?
    - What is the ambition for accessing PR? It is important to establish clear objectives based on what we currently know. By this we mean objective that are specific, measurable, attainable, realistic, time-bound (SMART).

Recommendation: NHSE should gather data to better understand gaps in accessing quality PR services; including identifying under-represented groups.

- **What is the economic case for improving PR:** The Chartered Society of Physiotherapy's (CSP) COPD PRIME Tool looks at the costs and savings associated with PR and provides estimates based on if PR was delivered to all people currently eligible using the criteria of MRC grade 3 and above. The tool was published in 2017 although leverages data that pre-dates this.
- Based on analysis using this tool, improving access to PR could reduce exacerbations in the eligible population by 13%. This would free up 150,924 GP appointments, 106,532 hospital bed days and 26,634 hospital admissions, all of which currently costs the NHS £69m per

year. The additional cost of delivering PR to all eligible patients (MRC 3 and above) is £61m per year according to the CSP's COPD PRIME Tool. This equates to a net saving of £8m per year plus the non-financial benefit of improving patient outcomes.
- These figures are a very crude attempt at considering cost savings and do not consider the compound effect of improving the health of the patient population over time nor other impacts such as reduced social care costs, reduced inhaler usage, etc. These figures also only consider the COPD population and only those with an MRC Grade of 3 and above.

Recommendation: NHSE should gather data to better understand the economic impact of improving access to PR for all major respiratory conditions based on the current eligibility criteria.

The above recommendation is a first step. The expectation is that NHSE will first conduct work to understand **what** gaps are present in access to PR. Followed by investigating **why** these gaps have occurred (e.g., barriers to access). Followed by a strategy of **how** to resolve these barriers.

Once these have been identified and understood, NHSE should work with local NHS organisations to implement a strategy, setting how barriers to access will be addressed.

- **Quality of services:** We must also establish what good looks like. Improving access to substandard PR is not sufficient. The goal must be to improve access to quality PR - therefore quality is a key component of meeting the above recommendation.
- It was suggested that the gold standard for PR seems to be accreditation.[viii] What we still need to understand is:
    - How does accreditation compare with different PR delivery models such as digital or hybrid PR.
    - Is accreditation alone enough to ensure high quality services that improve patient outcomes.
    - What proportion of services are currently high-quality/accredited? It would be helpful to frequently be updated on this.
        - Our understanding is that current accreditation rates are very low. What is the current plan for distributing this at scale if it is deemed the best approach?
    - What is NHSE's ambition for improving the quality of PR services? It is important to establish clear objectives based on what we currently know. By this we mean objective that are specific, measurable, attainable, realistic, time-bound (SMART).

Recommendation: NHSE should utilise existing data on quality PR and work with NACAP and partners to identify what makes good PR.

Combination: Through better data on both access and quality we can produce the following insights:

X% of the eligible respiratory population are currently accessing ***quality*** PR, meaning there is a gap of X% to fill to meet our 20XX target. To deliver ***quality*** PR to the full eligible population we need to expand services and improve accreditation by X% and X% respectively. The would result a net cost saving to the NHS of X per year. Currently, X groups are underrepresented, suggesting specific measures for improving access for these communities are key to success. There is a case to expand the eligibility criteria to include X. Expanding the eligibility criteria would benefit X number of people but require an increase in service capacity of X.

Evidenced-based innovation

Quality

The evidence behind new models of PR is not as developed as the evidence behind traditional forms of PR. NACAP and partners measure PR services against well-established standards of care – the purpose of which, is to ensure high quality services are being delivered. Whilst there are no dedicated standards of care for alternative PR models, current standards do not necessarily exclude hybrid PR models which offer some PR components online and some face-to-face. This highlights the potential that hybrid models may have in offering high -quality PR in a range of settings.

The Taskforce for Lung Health has previously stated that at the very least, initial assessments for PR ought to be delivered face-to-face, welcoming more evidence behind at-home assessments. We continue to advocate this as an approach and believe NHSE should support a review of digital and hybrid PR models to support quality control.

Our recommendations therefore remain as follows:

Recommendation: NHSE should collect data and evidence for online/hybrid models of PR to inform the effective design of current and future PR services that improve patient outcomes; and share evidence base and best practice with services.

Preferences

We are already aware that the pandemic has given rise to innovative PR delivery models, such as those highlighted by the University Hospitals of Derby and Burton NHS Foundation Trust.[ix] We have heard of some services offering PR programmes solely online; others continuing in a face-to-face format and others offering hybrid models – yet we also anecdotally know that patient preference is mixed.[x]

Digital literacy will play a key role in how well people access alternative PR models. A recent study discovered varied levels of access to and confidence in using digital tools to participate in PR – either wholly or in part.[xi] It found that:

- Only 31% reported using mobile phone for emailing
- 26% reported using mobile phone for internet browsing
- 51% used the internet daily
- 31% had never accessed the internet.
- Only 16% had experience of video calling
- Less than half feeling “extremely” or “quite” confident using the Internet

The study also showed that:

- 45% of people were interested in digitally accessing self-management aspects of PR.
- 29% had no interest in accessing any PR components remotely.
- The vast majority (79%) preferred face-to-face PR.

Our patient representatives also highlight the merits of being able to digitally access self-management aspects of PR in particular – noting the importance of accessing tools that can promote movement in a safe way and can help people manage their condition. It is vital that people are given the support they need. This includes the digital skills that can empower people to test-out tailored digital/hybrid PR or self-management tools and services in a new and effective way.

We recognise that current digital PR offerings need to be given space to improve and adapt so they can better match the needs of people with lung conditions both now and in the future. **We would urge NHSE to consider how they can help shape a supportive environment for innovation in digital PR within its vision.**

Self-management

The Long-Term Plan commits to providing the following, regarding self-management of COPD:

"New models of… rehabilitation to those with mild COPD, including digital tools… to provide support to a wider group of patients with rehabilitation and self-management support."

Self-management is important in helping people manage their conditions without experiencing further exacerbations. The Taskforce for Lung Health supports the use of self-management tools:

- Where face-to-face PR programmes are not available, or there are long waiting lists.[xii]
- To help many people with lung conditions keep active and avoid deconditioning.

The British Thoracic Society's (BTS) resource pack, provides a useful overview of online resources that people can utilise to self-manage.

BTS Quality Standard 7 for pulmonary rehabilitation in adults recommends that people completing PR are given *"individualised structured, written plans for ongoing maintenance."*

Whilst we are pleased that 81% of people assessed and enrolled for PR in 2019 received an individualised discharge plan – almost one fifth of patients did not.[xiii] NHS England's new vision should find ways of encouraging plans that support people who have finished a PR course, to self-manage.

Recommendation: Healthcare professionals should continue to offer self-management plans that help people maintain physical activity.

Reducing health inequalities

Data on Index of Multiple Deprivation scores for people using PR services, as highlighted by the Taskforce for Lung Health's data tracker shows that 1 in 4 people (20%) using PR services are from the most deprived parts of society. Similarly, NACAP data for 2019 reveals that those in the most deprived parts of England, Scotland and Wales are less likely to attend discharge assessments, when compared with people from less deprived areas.[xiv] It is vital that people with respiratory conditions complete PR programmes in their entirety because PR, when fully taken advantage of, can help with people's breathlessness; improve people's quality of life, exercise function and reduce feelings of depression and anxiety.

However, completion rates can be impacted for several reasons, many of which are bedded in health inequalities. We know that those who are living in the least deprived communities are 1.65x more likely to complete a PR course than those in the most deprived.[xv] We therefore believe that any new commitments in the 5-year vision must include an effort to understand how health inequalities are impacting completion rates along with ways to reduce these for people living in the most deprived areas, otherwise health inequalities will continue to be inadvertently exacerbated.

One area we have data on currently is whether or not services provide funded transportation for PR participants. A lack of funded transportation likely results in a lower attendance of low-income individuals.

Recommendation: NHS England should work with local NHS organisations to understand why completion rates are lower for people living in deprived communities and develop plans to address barriers to participation.

Recommendation: to improve equity of access to PR programmes and completion rates among people living in the most deprived areas, NHS England and providers should review the merits of offering to meet the cost of transportation for people attending PR programmes, where feasible.

Workforce

Respiratory services across the board, including PR services are in urgent need of more staff. Even prior to the pandemic, the Taskforce's 5 Year Plan noted that an additional 1,000 additional staff were needed to support services – this included an extra 600 physiotherapists and other registered staff and 400 support staff. Similarly, throughout the pandemic PR staff have been redeployed. A 2020 British Thoracic Society survey of respiratory leads found that:

- 71% said that they don't have enough medical staff to manage workload.
- 80% said they don't have enough non-medical staff to manage workloads.
- Only 50% said they had enough staff and equipment to treat patients remotely.

The Getting It Right First Time (GIRFT) report also reveals shortfalls in registrars, consultant nurses, physiotherapists, and admin staff to name a few. As well as fewer applicants to physiology training and fewer respiratory medicine training posts.

The GIRFT report also acknowledged insufficient numbers of data entry staff that can help with NACAP audits.[xvi] This has led, in some instances to clinical staff filling out patient details for NACAP themselves – taking time that could be spent supporting patients.[xvii]

In light of these pressures, it may also be appropriate for NHSE to consider the use of exercise professionals and other potentially underutilised workforces in the delivery of PR. As well as recognising the role that patients and carers can have in supporting participants and overcoming fears.

Recommendation: in its 5-year vison, NHS England should allocate additional funding for respiratory and administrative staff where workforce modelling identifies shortfalls, to enable effective and equitable delivery of PR services

Optimal uptake and retention

The Taskforce for Lung Health agrees with ambitions to improve uptake and retention of PR. We support resources that help encourage people to find out more about whether PR might be right for them. We have therefore developed a video highlighting the benefits of PR to potential participants, encouraging the uptake and completion of PR.

Information is essential in improving uptake and helping to dispel myths – healthcare professionals in both primary care and in secondary care must have the information they need to understand why an individual could benefit from PR and effectively refer people to a programme. This includes understanding the merits of referring people at earlier stages in their diagnosis; understanding the need to refer people with a variety of respiratory conditions; and to refer people to a programme following discharge from secondary care.

People with respiratory conditions must also understand what PR is and why it is important for them to attend and complete a programme – to achieve this in a way that resonates, it is essential that

people who have previously attended PR programmes are featured in resources highlighting the benefits of participating in and completing PR.

Similarly, carers of loved ones who have previously attended a PR class, would also provide valuable insight into its benefits. Given the crucial role that carers play in encouraging PR uptake by their loved ones, targeted information must also be produced specifically for carers, setting out its benefits.

Recommendation: we recommend that NHS England creates a suite of resources for healthcare professionals, that explains the benefits of pulmonary rehabilitation and ensures referral into PR programmes.

Recommendation: we recommend that NHS England creates a suite of resources for local NHS systems to share, that explains pulmonary rehabilitation to patients and carers and encourages participation and completion of PR.

Patient involvement

We believe that for the new 5-year vision to be effective, it must be co-produced with people with lung disease. Patients and carers must be involved in conversations around PR service design, delivery, and improvement. There must also be a clear understanding of what the issues/opportunities currently are for patients in accessing and completing high-quality PR.

Recommendation: to ensure PR services reflect the needs of patients and carers, NHS England must consult people with respiratory conditions and their families in the development and implementation of its 5-year vision for PR.

Recommendation: patient and carers must be represented on working groups developed as part of the new 5-year vision for PR.

For more information, please contact: taskforce@blf.org.uk

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[i] Asthma + Lung UK, Failing on the Fundamentals, pg. 17
Failing on the fundamentals: our COPD report | British Lung Foundation (blf.org.uk)

[ii] The National Asthma and COPD Audit Programme (NACAP) run by the Royal College of Physicians is an audit programme that seeks to drive improvements in quality of care and patient outcomes for people with asthma and COPD.
National Asthma and COPD Audit Programme (nacap.org.uk)

[iii] CSP calls for greater clarity over community rehabilitation requirements for Integrated Care Systems, Chartered Society of Physiotherapy, 24 February 2022
CSP calls for greater clarity over community rehabilitation requirements for Integrated Care Systems | The Chartered Society of Physiotherapy

[iv] Pinar Ergün, Dicle Kaymaz, Ersin Günay, Yurdanur Erdoğan, Ülku Yilmaz Turay, Neşe Demir, Ebru Çanak, Fatma Sengül, Nurcan Egesel and Serdal Kenan Köse, Annals of Thoracic Medicine, April-Jun 2011; 6 (2):70-76
Comprehensive out-patient pulmonary rehabilitation: Treatment outcomes in early and late stages of chronic obstructive pulmonary disease (nih.gov)

[v] W D-C Man, A Grant, L Hogg, J Moore, R D Barker, J Moxham Department of Respiratory Medicine, King's College Hospital and Lambeth & Southwark Pulmonary Rehabilitation Team, Harefield, UK, Pulmonary Rehabilitation in patients with MRC 2 Dyspnoea Scale 2, Thorax, 29 September 2010

Pulmonary rehabilitation in patients with MRC Dyspnoea Scale 2 | Thorax (bmj.com)

[vi] Dowman L, Hill CJ, May A, Holland AE, Pulmonary Rehabilitation for Interstitial Lung Disease, Cochrane Review, 1 February 2021

Pulmonary rehabilitation for interstitial lung disease | Cochrane

[vii] National Institute for Health & Care Excellence, Idiopathic pulmonary fibrosis in adults: diagnosis and management, 12 June 2013

Overview | Idiopathic pulmonary fibrosis in adults: diagnosis and management | Guidance | NICE

[viii] The Pulmonary Rehabilitation Services Accreditation Scheme, which is run by the Royal College of Physicians and is part of the National Asthma and COPD Audit Programme (NACAP) currently provides an accreditation service of participating PR services.

[ix] Service innovations in the era of COVID-19: IMPACT+ goes virtual, Respiratory Futures, 9 September 2020

Service innovations in the era of covid19 impact goes virtual | Respiratory Futures - working together for better lung health

[x] An example of this is preliminary results from Asthma + Lung UK's COPD survey (February 2022) which found that out of 2105 people who answered the question on what their preference for PR sessions is:

- 54.3% preferred entirely face-to-face
- 26.1% did not know
- 11.8% preferred a mix of virtual and face-to-face
- 7.8% preferred entirely virtual

[xi] Oliver Polgar, Maha Aljishi, Ruth E. Barker, Suhani Patel, Jessica A Walsh, Samantha SC Kon, William DC Man and Claire M Nolan, Chronic Respiratory Disease Volume 17: 1-4, 2020

Digital habits of PR service-users: Implications for home-based interventions during the COVID-19 pandemic (sagepub.com)

[xii] Interesting results have been found in the following paper, which examined whether a 12-week online intervention could improve self-care and be offered as an alternative to PR:

Moving to Better Health – Implementation of the KiActiv® Health service for people with COPD on Pulmonary Rehabilitation (PR) waiting lists, Clare Cook, Hayley McBain, Jen Tomkinson, and Sam Turvey.

Abstract-311.pdf (pcrs-uk.org)

[xiii] National Asthma and COPD Audit Programme (NACAP), Pulmonary Rehabilitation Clinical Audit 2019, p.24

NACAP_PR_Clinical_Audit_Data_and_Methodology_2019_Dec20.pdf

[xiv] Ibid

[xv] Op Cit, p.32

[xvi] Getting It Right the First Time, Respiratory Medicine, GIFT Programme National Specialty Report, Dr Martin Allen MBE, March 2021, pg. 11. In this report, 65% of trusts reported difficulties.

[xvii] Ibid, pg. 136