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## Showcasing patient and public involvement: Using consultation, collaboration and co-design to shape a respiratory programme

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### Abstract

The NHS is committed to working with patient groups and the public to co-design health services to ensure that lived experience is used to optimise service design and delivery. This case study describes and considers methodologies used by commissioners to meaningfully engage and collaborate with patient groups to co-design respiratory services in a region of England. Stakeholders agreed a two-stage approach to the patient and public involvement (PPI) for this specific project; an initial consultation with patient groups on existing services, to inform a collaborative co-design process for the new pathway. The full pathway was not commissioned, but elements of it were implemented which resulted in patients appreciating that their views had been sought and acted on and strengthened relationships between commissioners and patient support groups. Commissioners should be pragmatic in engaging with patients and the public and consider the needs of a specific population in undertaking meaningful engagement and co-design processes.

### Keywords

Patient and public involvement (PPI), patient engagement, health service co-design, experience-based co-design (EBCD)

### Introduction

In 2017, there was an unexplained spike in the number of people admitted to hospital with respiratory conditions in one area of South West England. Service provision in this area varied, particularly in equality of access to community and secondary care services and between General Practitioner (GP) practices. A Respiratory Programme was established to address disparities by improving respiratory care in primary care and community services, helping people self-manage their condition and reducing unnecessary hospital admissions.

The Programme's approach reflected a broader local commitment to involve service users, carers and the public in designing health services, to capture the evident added value of commissioning services informed by local peoples' experiences and aspirations. This is supported by national legislation,<sup>1</sup> which stipulates a statutory duty on Clinical Commissioning Groups (CCGs) and National Health Service (NHS) Trusts to involve patients, carers and the public in developing and commissioning health services. The right of patients to be involved in planning services is also set out in the NHS Constitution.<sup>2</sup> Additionally, the NHS Standard Contract<sup>3</sup> obliges NHS service providers to actively engage with the public in service redesign. The mechanisms by which their views

can feed into NHS services are described in the 'Framework for Patient and Public Participation in Public Health Commissioning'.<sup>4</sup>

To ensure any service changes would address lived experiences in order to meet service users' needs, the Respiratory Programme Board worked with people living with chronic obstructive pulmonary disease (COPD), a group of lung conditions that cause breathing difficulties, to co-design the new respiratory pathway for the CCG area. Experience-based co-design (EBCD) is described as an approach to improving services by understanding, considering, and drawing on the experiences of patients who have accessed them and staff who have delivered them.<sup>5</sup> Application of EBCD varies throughout healthcare systems. The extent to which 'pure' EBCD is attained depends on factors including resources and capacity. It is defined as an aspirational yet pragmatic approach, which can mitigate for the influence of these limiting factors, as commissioners identify and blend different elements of EBCD to meet specific contextual needs.

The Respiratory Programme Board, coordinated by a CCG Programme Manager, comprised representatives of local CCGs, primary, secondary, social and community care providers, patient and carer representatives and the Voluntary and Community Sector (VCS), to ensure the

approach captured contributions from all key stakeholders. The VCS was represented by the British Lung Foundation (BLF), a charity that funds research aimed at preventing, treating and curing lung diseases. They run awareness campaigns on preventing lung disease, provide support for people affected via different channels, and facilitate member led 'Breathe Easy' support groups, where people with lung disease can meet locally. The Board also consulted with local Healthcare Change Makers. This voluntary role was introduced to bring a patient voice into planning and delivery of health, social care and wellbeing services as part of a joint initiative between acute and community providers to create a collaborative relationship between the healthcare system and the communities it serves, in response to the NHS Five Year Forward View.<sup>6</sup> The role was promoted and recruited by the Acute NHS Trusts, and Change Makers were trained in patient leadership by involvement managers from across the healthcare system.

This case study details the Patient and Public Involvement (PPI) methodologies employed by the Programme to carry out meaningful engagement, presents the findings and discusses how these have shaped regional respiratory services. It will consider whether this process achieved the 'gold standard' of PPI, co-design via collaboration as defined by the National Institute for Health research (NIHR),<sup>7</sup> or whether this real-world example illustrates how barriers to 'co-design' in its purest sense can be worked around to facilitate a 'good enough' outcome for service planners and users alike.

### Understanding What Needed to Change: Consultation

The Respiratory Programme used a staged consultative and collaborative PPI approach in designing the new respiratory pathway.<sup>8</sup> The Board ratified a Public and Service User Engagement Approach, in collaboration with the BLF's local Service Development manager, based on an approach to co-design used by a neighbouring CCG. This stipulated a first stage, during which a broad range of patients and the public would be consulted on:

- what they think worked well
- what they felt needed improvement in local respiratory services

... and a second stage during which smaller groups collaborated with the Programme Board to co-design the new pathway:

- designing new ways of providing services
- thinking about how to increase uptake of annual GP reviews

- ensuring respiratory services are accessible for all, focussing on groups with protected characteristics who have experienced barriers to services

The CCG Respiratory Programme Manager used mixed methods to lead the PPI approach. In April and May 2017, they invited three BLF Breathe Easy groups to take part in the co-design process. Group members requested that their input be captured at their routine meetings, instead of being represented at CCG service design workshops. The Project Manager held focussed discussion groups to create a baseline for the pathway redesign process in a supportive group setting where participants would feel comfortable in sharing their experiences of accessing respiratory services, and ideas about what needed to change.<sup>9</sup> Detailed notes were taken during these discussion groups to inform the next stage of the process. The Programme Manager also consulted with the Healthcare Change Makers, to capture views of trained 'patient leaders' within the respiratory context. The Programme Manager used a questionnaire to gather a broader range of service users' views on existing provision of respiratory services. This was reviewed by the Questionnaire, Interview and Survey Group (QIS) from a local NHS Trust, comprising public contributors, researchers and collaborators, who reviewed data collection and engagement tools. Respiratory outpatient patients, community respiratory service users and a smaller cohort of patients managed in primary care were invited to complete the questionnaire. The sampling method was opportunistic,<sup>10</sup> so the results were not limited to the experiences of people living with Chronic Obstructive Pulmonary Disease (COPD) – some respondents had more complex respiratory conditions. The Programme Manager collated secondary data from the Patient Advice and Liaison Service<sup>11</sup> (PALS) on complaints, compliments and casework relating to respiratory services. This was interrogated but preliminary analysis did not generate any new or contribute to pre-defined themes, regarding service users' perspectives on current and future service provision.

### Co-designing a New Pathway: Collaboration

The consultation findings were collated and interrogated for themes<sup>12</sup> which were presented at the first four multi-disciplinary service design workshops held at the CCG to inform the design work. The workshops (Table 1) were attended by representatives from CCGs, the three local acute provider Trusts, the three local community health service providers, four primary care providers, a GP-led organisation that represents practices, the Local Authority, the local Commissioning Support Unit (CSU), a hospice care provider, and the BLF.

A high-level care model, based on discussions at Workshops 1 – 4, with specific queries requiring input from service users, were taken to the three local Breathe

**Table 1. Service Design Workshops (held in May and June 2017)**

Workshop	Title
1	Service user and carer education and information
2	Primary care and prevention
3	Acute care and avoiding admissions to hospital
4	Early supported discharge and hospital at home
5	Key Performance Indicators (KPIs)
6	Addressing learning from workshop 1

Easy Group meetings in July and August 2017 for members’ feedback, according to their request that the Programme Manager attend their forum instead of them attending the CCG-hosted design workshops. Group members were very positive about the proposed service design and satisfied that their input had been incorporated within the care model.

**Identifying Priority Outcomes for Service Users**

The next stage of the process was to identify priority outcomes for patients on the respiratory pathway. The Respiratory Programme Board engaged Outcomes Based Healthcare<sup>13</sup> to translate the focus group and questionnaire data into a draft set of outcomes. At this point, the fifth workshop was held, which asked: ‘What matters to patients?’ The same group of stakeholders took part as in previous workshops, again the patient representatives preferred to contribute separately.

Delegates selected a ‘long list’ from the draft outcomes and scored them according to priority. During November 2017, the Programme Manager attended the three Breathe Easy meeting and led sessions following the same format as the CCG outcomes workshop. Members scored the proposed outcomes to achieve a consensus weighting for each item on the long list to identify 12 key service outcomes of the new respiratory pathway. Outcomes Based Healthcare identified relevant, validated Patient-Reported Outcome Measures (PROMs) from the literature, and from these, the Programme Delivery Board selected two PROMs to measure the 12 selected outcomes, the Clinical COPD Questionnaire (CCQ), and the Patient Activation Measure (PAM).

**What Happened Next**

A key result of this approach to co-design is the service users’ appreciation that their views had been sought and addressed. The patient groups expressed gratitude that the Programme Manager visited them for a ‘you said, we did’ session: *‘they told me, quite often people ask their views, but they never know what comes of their feedback’* (Programme Manager). De-briefing with PPI participants to inform them about how their contributions will be used has been identified as

a valuable exercise in building and maintaining good relationships between stakeholders in a PPI process.<sup>14</sup>

The co-designed respiratory pathway was not fully commissioned, as the proposed integration of community and secondary care was not funded. However, another result of this project was that elements of the pathway worked up by the Respiratory Programme Board following the process described were commissioned and rolled out:

- Timely blood gas tests had been available in two of the three area localities, but patients in the third locality were waiting at least 8 weeks for a test, resulting in substantial delays in accessing home oxygen. These tests are now provided during an initial appointment across the area
- Information provision was highlighted as a key priority for service users. A Standard Operating Procedure (SOP) was developed to govern the patient information provided at different stages of the pathway. For example, prior to diagnosis a BLF leaflet on breathlessness should be given out. At diagnosis six further leaflets should be offered, and at the annual primary care check, another two leaflets were recommended. A leaflet describing the local self-management support available was recommended for all stages in the pathway.
- Variation in patients’ experiences of primary care was a key theme in feedback on existing services. The Programme Manager worked with a CCG Clinical Lead on the respiratory section of the primary care electronic patient record system (EMIS) as a mechanism for standardising primary care for COPD patients
- Consultation with the patient groups on using funding from a pharmaceutical company for two specialist respiratory nurse posts resulted in these posts being included in the pathway

A further outcome of this project is a sustained relationship between the CCG and the BLF. The Respiratory Programme Board has worked with the BLF to develop integrated Breathe Easy Groups, which will be attended by a healthcare professional. This collaboration will also work with GP practices to organise events to raise

awareness of Breathe Easy Groups. Additionally, the needs assessment that informed the respiratory pathway redesign has been used by the BLF to select priority areas and specific practices to partner with to establish additional Breathe Easy Groups.

## Lessons Learned

This programme of consultation and co-design has created a valuable legacy of learning for the lead CCG and commissioning organisations more widely.

### *Being Pragmatic*

The project's consultation phase was not methodologically flawless. Unplanned sampling meant that questionnaire responses were not representational of the CCG area's population, and due to capacity restraints, data was not collected in one of the three localities within the CCG's footprint. Despite these limitations, it was decided to include the questionnaire results in the data analysis, as the results formed part of the initial phase of engagement work, scoping user experience of existing respiratory services, and it was felt that responses would be sufficiently generic to add value to the pathway design work. An improvement to this project would have been to amend the timeframe to allow for planned sampling and proactive engagement with all three localities.

### *Engaging with a specific population*

The main caveat attached to these results is that specific conditions people involved are living with *must* be considered. Many of the participants in this programme experience extreme breathlessness and so use oxygen therapy, which can limit their mobility. Therefore, while the outputs of this project have been substantially improved by the involvement of service users, it was necessary to plan and time-consuming to effect this engagement. The Programme Manager regularly attended patient support groups to inform members of project developments and request their feedback on these. However, the value of capturing service users' input outweighs the resource involved in doing so – so a key message is to: *'Go to groups – don't expect them to feel able to come to you'* (Programme Manager). This perhaps negates the truest meaning of 'co-design,' as to be fully inclusive, all 'designers' should have the opportunity to be in the same room at the same time, with their views heard equally. A two-step approach<sup>15</sup> as employed in this programme means that an intervention or approach has already been planned or part-designed before the 'co-' comes in, from a PPI perspective. This is often the case in the NHS, as service commissioning agendas are based in policy, which is developed prior to NHS-specific PPI mechanisms being implemented.<sup>16</sup> However, the most important element of 'co-design' must be to foster an accessible environment and processes within which all stakeholders feel heard and trust that their input will be

valued equitably. This specific process benefitted from the Project Manager's *'expert facilitator'* skills (CCG Director of Transformation, personal communication, 31<sup>st</sup> August 2018). Therefore, if a 'two-step approach,' as requested by stakeholders in this project, is the agreed method, then outputs achieved by adapting the conventional approach to co-design must be considered as having equal value as those produced following a 'purer' approach. The Respiratory Programme worked well as the VCS representation included professionals who were also service users themselves and so elevated the patient voice at Board level, despite other patient and service user representatives declining to attend this 'first step' of the two-step approach.

## Conclusion

Despite the primary aim of this project; a co-designed respiratory pathway being commissioned for this area of the South West, not having been met, the consultative and collaborative engagement approach adopted worked well and has led to changes to existing pathways, in line with feedback from service users. This should result in locally driven optimisation of these services, specific to the local context. Therefore, it could be argued that the value of the outputs produced using this approach, by planning and fostering a responsive, equitable and productive co-design environment as described above, would be worth investment to ensure that facilitators have the necessary skills and capacity to do so.

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