Co-production to inform clinical commissioning in COPD: an evaluation of Working Together for Change

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Abstract

\textbf{Rationale, aims and objectives:} Patient involvement in healthcare decision-making is often limited to consultation. Co-production is an approach that empowers patients to work collaboratively with providers as agents of change. The objective of this study was to explore participants’ experiences and satisfaction with a co-production process, Working Together for Change (WTfC), used to inform the commissioning of services for people living with Chronic Obstructive Pulmonary Disease (COPD).

\textbf{Method:} Mixed methods developmental service evaluation drawing primarily on qualitative data from semi-structured interviews. Setting and participants: Community-based intervention with COPD patients, carers, commissioners and providers of COPD services. Intervention: One-to-one reviews with 45 patients identified what was working, not working and what was important for the future regarding COPD management. In 2 one-day workshops attended by 14 patients and carers and 17 professionals this information was analysed to inform commissioning priorities.

\textbf{Results:} Participant satisfaction was high. Thematic analysis identified 3 themes: (1) an engaging experience, (2) a constructive process enabled by strong patient presence, real patient experiences, collaboration, sense of freedom, a range of contributions and commitment & (3) personal gains from the patient and carer voice being counted, mutual understanding, seeing the value of patient involvement and learning and sharing. Some concerns were raised about the process and suggestions made for improvement.

\textbf{Conclusions:} WTfC was an acceptable process to inform COPD commissioning activity and resulted in an agreed and priorities action plan for COPD service commissioning. It supported collaborative working, egalitarian relationships and mutual learning between patients, carers and professionals. As a standalone activity it was not possible to evaluate the value of the outputs to commissioners or the objective impact but it provided a powerful introduction to co-production methods. WTfC can be an impactful starting point for embedding co-production into the commissioning process.

\textbf{Keywords}

Chronic Obstructive Pulmonary Disease (COPD), commissioning, co-production, developmental service evaluation, patient and public engagement, patient-centred care, patient empowerment, patient involvement, person-centered healthcare, self-management, Working Together for Change (WTfC)

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Introduction

Patient involvement in healthcare is promoted by the World Health Organisation [1] and integral to UK health policy. The NHS Constitution states that services should be co-ordinated around the needs and preferences of patients, their families and carers [2]. This is driven by the need to address increasing demands on health services and the belief that services are better able to address underlying problems that lead to healthcare need and to meet those needs when people are in equal relationships with healthcare professionals [3]. Partnership working recognises people as experts in what it is like to live with or care for someone with an illness or condition [4]. Evidence suggests that the public wish to have their preferences, ideas and knowledge utilised in the development of healthcare services [5] and prefer that a
range of groups should be consulted [6]. However, user participation in service planning is commonly limited to consultation and satisfaction surveys, rather than interactive decision-making [7]. Involvement often means one or two patient representatives on committees which may under-represent the views of vulnerable or disadvantaged groups [8]. Those relying most on healthcare services are often the most disempowered by conventional service development models [3]. There may be inequalities of power and perceptions of worth and patients may have difficulty influencing providers [9]. Co-production seeks to mitigate such inequalities by enabling people to become agents of change. It involves recognising people as assets, building on their capabilities, promoting mutuality and reciprocity, developing peer support networks, breaking down barriers between professionals and recipients and facilitating rather than delivering.

The UK Care Act (2014) [10] identifies co-production as an important principle which should underpin commissioning activity. However, there is little good quality evaluation of how patients can be effectively involved in health decision-making at a population level [11-14]. Many studies do not provide sufficiently detailed descriptions of the methods they employed making them less useful for informing new initiatives and making it difficult to conclude which approaches are most successful [15,16]. Working Together for Change (WTfC) [17] is a structured, clearly defined approach for putting co-production at the heart of strategic commissioning and engaging patients in a dialogue which incorporates their experiences and priorities for change. The process has been widely used in social care and mental health settings [18], but we found no evaluations of it in a physical health setting.

We applied WTfC to determine and agree commissioning priorities amongst people living with COPD, their carers and health and other professionals with an interest in COPD services. In order for commissioners to judge the value of the process in a COPD context we conducted a developmental service evaluation. Evaluation objectives were to explore participants’ (i.e., patients, carers and professionals) experiences and satisfaction with the process of WTfC.

**Method**

**Objectives and design**

We employed mixed methods with a primarily qualitative focus to support a developmental approach. Semi-structured interviews provided analytical depth and were complemented with survey feedback collected at the end of the process.

**Intervention**

WTfC has an established 6-stage framework [18] in which information from person-centred reviews [18] is analysed in two one-day workshops using co-production principles and quality improvement techniques. As person-centred reviews are not a feature of COPD services we instead conducted dedicated one-to-one person-centred discussions in participants’ homes prior to the workshops (see Table 1). One-to-one person-centred discussions were conducted by members of the project team (TW, KH). Workshops were held in community venues and facilitated by members of the project team (TW, PF, KH, JR, AG).

**Participants**

**One-to-one discussions**

We adopted a purposive sampling approach to identify people with a diagnosis of COPD who had not previously taken part in involvement activities and who reflected a range of disease severity and social circumstances, including travellers. Names were identified from the COPD list of a GP practice, the pulmonary rehabilitation register of a local service, secondary care lists in the local acute hospital, a patient support group (Breathe Easy) and a local self-management programme. Patients were invited to take part by a clinician, provider representative or member of the project team who was known to them.

**Workshops**

Patients taking part in one-to-one discussions were invited to the workshops along with their carers. Purposive sampling was used to identify a range of professionals through local networks who had an interest in providing and commissioning COPD services. An invitation email was followed by a telephone call from a member of the project team (KH, TW). Targeted roles included commissioners, healthcare professionals, managers and third sector organisations.

There is no recommended sample size for WTfC and numbers are based on what is achievable within the time and resources available; the optimum number for workshops is 25-30 to allow effective facilitation [18]. We aimed to recruit 40 patients to one-to-one discussions and to achieve a balanced representation of patients, carers and professionals at the workshops.

**Data collection and analysis**

Survey feedback, rating aspects of the workshops on a 5-point scale, was collected at the end of the second workshop. Responses were collated for frequency. Following the workshops semi-structured interviews were conducted by FE, PF, AG, KH, TW with patients, carers and professionals to explore their experiences and satisfaction with the workshop process. Interviewees represented a range of circumstances and roles. Interviews with patients and carers were conducted in their homes and
**Table 1 Working Together for Change applied in COPD context**

<table>
<thead>
<tr>
<th>Stage</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stage 1</td>
<td>Gather person-centred information from patients: One-to-one discussions in the home</td>
</tr>
<tr>
<td></td>
<td>Explore with regard to the person’s COPD: (a) what is working in their life, (b) what is not working and (c) what is important for the future. The patient indicates the two most important statements in each category. Patient and carer are invited to attend the workshops.</td>
</tr>
<tr>
<td>Stage 2</td>
<td>Workshop preparation by the Project Team</td>
</tr>
<tr>
<td></td>
<td>Each patient’s most important statements are transferred to cards for use in the workshops.</td>
</tr>
<tr>
<td>Stage 3</td>
<td>Workshop activity: Cluster the priorities into agreed themes</td>
</tr>
<tr>
<td></td>
<td>Workshop participants (patients, carers and professionals) work together with a facilitator to cluster the important statements into themes. This is done for each category: what’s working, what’s not working and what’s important for the future. Each theme is labelled with a first-person statement that best describes the theme, for example “I never have enough time with my GP” and “I feel like I am pre-judged because I am breathless” might be labelled “I am not listened to.” Participants are given 3 sticky dots and vote for what they think are the highest priority themes in the ‘not working’ category. The 6 highest priority themes are taken forward to the next stage.</td>
</tr>
<tr>
<td>Stage 4</td>
<td>Workshop activity: Analyse the information</td>
</tr>
<tr>
<td></td>
<td>Groups of 5 to 6 patients, professionals and carers analyse the root causes of the 6 priority ‘not working’ themes. The group asks the question ‘why’ several times to generate as many root causes as possible. Each group identifies their 5 most important root causes, pins them on a board and everyone dot votes for what they think are the most important root causes. Success statements are formulated to represent what success would look like if each root cause were addressed. Success statements are considered from the point of view of patients, commissioners, clinicians and practitioners and the third sector and generated under the headings ‘radical’, ‘traditional’ and ‘different’ to encourage creativity while recognising the best of what already exists.</td>
</tr>
<tr>
<td>Stage 5</td>
<td>Workshop activity: Action plan</td>
</tr>
<tr>
<td></td>
<td>Participants discuss what could be done differently to generate the successful outcomes. Solutions are ranked according to the risk/benefit involved and ease of implementation, resulting in 4 categories of actions: major projects, quick wins, fill-ins and thankless tasks. For each action the group discuss and agree: where do you want to be in 6-months’ time, what needs to happen first, how will you ensure co-production principles persist in working towards this action?</td>
</tr>
<tr>
<td>Stage 6</td>
<td>Post-workshop activity by the project team: Share the information</td>
</tr>
<tr>
<td></td>
<td>Outputs from the process are summarised in a report by the project team and circulated to commissioners for their consideration.</td>
</tr>
</tbody>
</table>

**Table 2 Workshop participation**

<table>
<thead>
<tr>
<th>Source of contact</th>
<th>Approached</th>
<th>Participated in one-to-ones</th>
<th>Attended workshops</th>
</tr>
</thead>
<tbody>
<tr>
<td>Breathe Easy support group</td>
<td>10</td>
<td>9</td>
<td>7</td>
</tr>
<tr>
<td>GP list</td>
<td>37</td>
<td>25</td>
<td>4</td>
</tr>
<tr>
<td>Acute respiratory ward</td>
<td>3</td>
<td>2</td>
<td>0</td>
</tr>
<tr>
<td>Pulmonary rehabilitation register</td>
<td>7</td>
<td>2</td>
<td>0</td>
</tr>
<tr>
<td>Self-management programme</td>
<td>4</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Occupational Therapist</td>
<td>1</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Invited directly to workshop</td>
<td>-</td>
<td>-</td>
<td>3</td>
</tr>
<tr>
<td>Carers</td>
<td>-</td>
<td>-</td>
<td>8</td>
</tr>
<tr>
<td>Total</td>
<td>62</td>
<td>45</td>
<td>22</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Sector/Organisation</th>
<th>Approached</th>
<th>Attended Day 1</th>
<th>Attended Day 2</th>
</tr>
</thead>
<tbody>
<tr>
<td>Acute Trust</td>
<td>5</td>
<td>3</td>
<td>2</td>
</tr>
<tr>
<td>Acute Trust / HCP*</td>
<td>4</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>Ambulance Service</td>
<td>1</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>CCG*</td>
<td>6</td>
<td>2</td>
<td>0</td>
</tr>
<tr>
<td>CCG / HCP</td>
<td>1</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Community Trust</td>
<td>2</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Community Trust / HCP</td>
<td>2</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>NHS England / HCP</td>
<td>1</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Healthwatch</td>
<td>1</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Housing</td>
<td>2</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Public Health</td>
<td>2</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Public Health / HCP</td>
<td>1</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Multi-agency</td>
<td>1</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Voluntary Sector</td>
<td>1</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Total</td>
<td>42</td>
<td>15</td>
<td>16</td>
</tr>
</tbody>
</table>

*Healthcare Professional  *Clinical Commissioning Group
with professionals at their place of work. They were audio-recorded and transcribed. Average duration was 36.5 minutes (range 14 to 77 minutes). Transcribed interviews were imported into NVivo software and analysed thematically [19]. A deductive coding frame was defined from the interview topic areas by FE. Transcripts were read by FE and SW and emergent codes were incorporated into the coding frame. All transcripts were coded for all codes by SW. Codes were entered into the matrix function from the interview topic areas by FE. Transcripts were organised into themes and sub-themes by SW and FE. Codes were entered into the coding frame. All transcripts were coded for all codes by SW. Codes were entered into the matrix function from the interview topic areas by FE. Transcripts were organised into themes and sub-themes by SW and FE.

The project was designated as a service evaluation at Cambridge University Hospitals NHS Foundation Trust (Project Registration No. 2789). Patients and carers were invited to take part in the evaluation by KH and TW (Project Registration No. 2789). Patients and carers were invited an and 17 (40%) attended, 15 on Day 1 and 16 on Day 2. Representatives from public health and the ambulance service were invited but unable to attend. Those unable to attend had previous commitments. See Table 2 for a breakdown of participants.

### Table 3 Participant feedback after second workshop

<table>
<thead>
<tr>
<th>Survey feedback</th>
<th>Public N=19</th>
<th>Professionals N=13</th>
</tr>
</thead>
<tbody>
<tr>
<td>I feel satisfied with the work we have done in the workshops</td>
<td>SD 0 D 0 NS 2 A 8 SA 9</td>
<td>Blank SD 0 D 0 NS 0 A 2 SA 7</td>
</tr>
<tr>
<td>I think that the work done here will provide useful information for service providers</td>
<td>0 0 0 6 13</td>
<td>0 0 0 4 9</td>
</tr>
<tr>
<td>I feel confident that the output from the workshops will be considered seriously</td>
<td>0 2 7 10</td>
<td>0 3 7 3</td>
</tr>
<tr>
<td>The ideas generated were a fair reflection of the discussion in the room</td>
<td>0 0 0 10 9</td>
<td>0 0 0 4 9</td>
</tr>
<tr>
<td>The workshop discussions reflected my personal needs/aspirations</td>
<td>0 0 6 8 4 1</td>
<td>0 0 4 7 2</td>
</tr>
<tr>
<td>I understand other people’s needs and viewpoints more than I did before</td>
<td>0 0 1 12 6</td>
<td>0 0 1 3 9</td>
</tr>
<tr>
<td>I was able to have my say in the small group discussions</td>
<td>0 0 1 9 9</td>
<td>0 0 0 3 10</td>
</tr>
<tr>
<td>I was able to have my say in the whole room discussions</td>
<td>0 0 1 8 9</td>
<td>0 0 1 8 4</td>
</tr>
<tr>
<td>The small group work at tables ran smoothly</td>
<td>0 0 0 7 12</td>
<td>0 0 0 4 9</td>
</tr>
<tr>
<td>The workshops were interesting and engaging</td>
<td>0 0 0 8 11</td>
<td>0 0 2 6 5</td>
</tr>
<tr>
<td>I enjoyed attending the workshops</td>
<td>0 0 1 11</td>
<td>0 0 2 5 6</td>
</tr>
<tr>
<td>Total</td>
<td>0 0 14 90 103 2</td>
<td>0 0 13 58 70</td>
</tr>
<tr>
<td>Percentage</td>
<td>0 0 6.7 43.1 49.3 1</td>
<td>0 0 10.5 40.6 49</td>
</tr>
</tbody>
</table>

SD (strongly disagree), D (disagree), NS (not sure), A (agree), SA (strongly agree)

### Results

#### Participation

#### One-to-one discussions

We invited 62 patients to take part in one-to-one discussions. Forty-five (72%) participated (23 male, 22 female) (see Table 2). One was a traveller and 6 were dependent on oxygen. Several declined without giving a reason and some refused due to ill health, sick relatives or other priorities, for example, moving house.

#### Workshops

Eleven of the patients (24%) who took part in one-to-ones attended the workshops (8 male, 3 female) along with 8 carers (1 male, 7 female). One patient was on oxygen. Two attended only the second workshop. Reasons for not attending included lack of confidence, ill health and lack of mobility and stamina. Two members of the Breathe Easy support group and a lay tutor on a self-management support training programme also attended. Forty-two professionals were invited and 17 (40%) attended, 15 on Day 1 and 16 on Day 2. Representatives from public health and the ambulance service were invited but unable to attend. Those unable to attend had previous commitments. See Table 2 for a breakdown of participants.

#### WtFC outputs

One-to-one discussions generated 240 statements of what’s working, what’s not working and what’s important for the future. These were themed during the first workshop. High priority themes in the ‘not working’ category were: I can’t do what I want to do; I’m anxious and depressed; I can’t eat well; I can’t get appointments when I want them; I don’t think the left hand knows what the right hand is doing [regarding healthcare services]; I’m not treated as a person. Root causes were identified and prioritised, success criteria defined, actions prioritised and an action plan agreed.

#### Survey feedback

Thirty-two workshop participants (82%) (13 professionals, 19 patients/carers) completed surveys rating their experience of the process (Table 3). Ninety-one per cent of responses were positive, the remaining being unsure or blank. For the majority of participants the process enabled effective participation, enhanced mutual understanding, was enjoyable and they were satisfied with the outputs. The greatest degree of uncertainty was in relation to “The
workshop discussions reflected my personal needs/aspirations” where 31% of patients and carers and 30% of professionals were unsure of their agreement with the statement.

**Semi-structured interviews**

Three patients (male), 3 carers (1 male, 2 female) and 7 professionals (3 commissioners, 2 clinicians, 2 third sector) were interviewed. Three themes were identified: an engaging experience, a constructive process and personal gains. Concerns were raised about the process and suggestions made for improvement.

**An engaging experience**

The experience was enjoyable and engaging for patients, carers and professionals. A pleasant, friendly, relaxed and honest atmosphere contributed to overall group engagement. Participants felt able to share their opinions without feeling judged:

“… there was a good atmosphere, it was very open and honest and jovial almost the atmosphere at times, I think that was very, that was key to getting the engagement we got.” (Professional ID 11)

“… you didn’t feel you was on show if you stood up and made a, or if you called out and made a comment, you know with some places you could do like at a big general meeting and, you know, you would feel a bit on show but there you didn’t necessarily.” (Patient ID 4)

**A constructive process**

Participants felt that WTfC was a constructive way of bringing patients, carers and professionals together to achieve valid outcomes. Several factors contributed to this.

**Strong patient presence**

Professionals recognised the significance of having so many patients and carers present which elevated their input from token representation to equal and active participants:

“… pleased to see the amount of patients who came along, it was more than, I think it’s, sometimes you get one or two and that is almost sometimes you think it’s a little bit top-heavy with sort of health people … and actually talking to some of the patients there, they said … they said they found it a lot better because there were more patients, they felt more of a group as opposed to a representative or a token person who’d been asked to come along and therefore they felt it easier to have their voice heard.” (Professional ID 10)

**Real patient experiences**

Hearing real patient opinions and experiences of COPD was highly beneficial. The use of “I statements” gave issues a stronger sense of reality as it related them to people rather than being abstract. Opinions and issues were more powerful because they were personal to patients:

“I think the best bit for me was when we started to put it into “I” words and that was really powerful for me because it made you think about it as the person rather than as something, and that was really, really good … I really liked the fact that the cards had real live comments from patients, so this wasn’t people had come up with a list of things that they thought we should have, this was real comments …” (Professional ID 14)

**Collaborative partner**

There was a strong sense of collaboration and equality among participants regardless of their role or situation outside the workshop. This was important for success. People living with COPD and carers in particular found the process gave them confidence to speak out and felt their contribution had equal weight. Many highlighted a sense of inclusivity:

“… you were given the opportunity to contribute, you know, which to me is great … I don’t usually contribute a lot to discussions because I feel that there was people that were more qualified than I was to express their opinion but then as the day went on you felt that you could put your little piece in and everybody listened which was great …” (Patient ID 4)

**Sense of freedom**

A sense of freedom allowed ideas to emerge. This came from having no pre-determined end-point, anonymity in dot voting and participants involved in leading the process:

“I liked it because you know, everybody got involved and it wasn’t too dictatorial, you know, you were allowed to make your own comment basically.” (Carer ID 3)

**Range of contributions**

The broad range of contributors and perspectives was important for effectiveness. Patients, carers and professionals helped each other. One professional stressed the importance of having all the individuals who could be part of a solution to the issues present at the workshop. A good balance of patients, carers and professionals and the mix of backgrounds at each table made for good discussion:

“… your experiences are very different to anybody else’s, you can say what you, you know, what your thoughts are but it’s only really when you get a lot of people perhaps who’ve put different perspectives on it” (Professional ID 10)

**Commitment**

Professionals, patients and carers felt that everyone was committed to the process. This was essential to success - it
would have been pointless to attend the workshop and not be committed because the process could not have worked:

“… they [professionals] all gave a certain input and I thought they did very well the way they all joined in to it and put, you know, they could have just said “Oh I’ve got a day off and free lunch” and sat there and sort of, but they all gave quite a lot of input into the thing.” (Patient ID 4)

“It was interesting to come along to something with a real mixture of people in the room, patients and carers, voluntary sector, people providing services, and actually truly feel equal because everyone came to participate and that came across very clearly.” (Professional ID 14)

**Personal gains**

Participants gained personally from taking part in several ways.

**My voice count**

Patients and carers had a strong sense that their opinion counted and that they were making a real contribution to an influential process. In other situations they had not felt heard but here they felt all information would be kept and taken seriously, even if some issues were not included in the final action plan: they shared the belief in a need to participate and that came across very clearly.” (Patient ID 4)

“… they could sort of vote them off and vote them on, what they liked and what they didn’t which gave them, which makes you think in a way that you have got a voice in something, you know, even if it’s putting that sticker on what you like or dislike you are actually getting a chance to pass an opinion on it … normally you haven’t, you’ve just got, a doctor will say “Well that’s it, that’s it, get on with it”, kind of thing [laughs].” (Patient ID 4)

“I got the feeling they wouldn’t be lost … I felt that all of the stuff was precious and was going to be kept and it was simply saying, you know, which are the priorities that we realistically can implement in some way.” (Patient ID 6)

**Mutual understanding**

Patients, carers and professionals gained mutual understanding of each other’s circumstances through spending time together. Patients and carers learned about commissioning and the challenges facing professionals and professionals learned about the reality of patients’ and carers’ lives, their experience of services and the changes they wanted made:

“… we found out a lot of things too which we weren’t aware of, or didn’t know very much about, particularly this changing of the doctors to being commissioners and all that sort of thing.” (Carer ID 2)

“I think because it does open your eyes to what patients want, it’s a very positive experience, I think it, you know, it changed the way I … I think it changed the way I view patients and I think it changed the way that patients view doctors and other professionals.” (Professional ID 11)

**Seeing the value of patient involvement**

The experience increased professionals’ awareness of the value of public involvement in decision-making and the importance of obtaining public opinion in order to understand what their real issues are. One planned to use a similar process in their own work to obtain feedback on what patients really need and think:

“It tends to be clinicians, us in commissioning and clinicians know what they want, they want, you know, they want to see their service and they see it all singing, all dancing but there’s never really much patient input at all into any sort of service developments … we don’t always have the time to think about organising or have the time to organise sort of patient focus type groups but I would like to, that’s what I would like to be able to do.” (Professional ID 16)

**Learning and sharing**

Patients and carers gained from sharing and learning about support and resources of which they had been previously unaware. This came from material discussed during the workshops and from talking with professionals which had more salience for some than information in leaflets or literature. For some the workshops were enlightening and helped them to understand their condition better. It helped them to realise that although there were activities they could not do anymore, they could adapt and do things differently; this is easier with greater knowledge of what help is available:

“It was through going there that I met the guy and he gave me the leaflet which could in the end make a big difference to me, I don’t know because I haven’t asked the doctors or anything yet, only the GP.” (Patient ID 4)

**Concerns**

Three concerns were raised. (1) Some patients and carers were confused in the early stages of the first workshop, but it began to make sense as it went on. (2) Most participants were positive about dot voting, but a minority of professionals were concerned that it might encourage a ‘herd mentality’ and that people would be influenced by where other people had placed their dots. However, patients and carers found the method empowering. (3) Some professionals were concerned about the achievability in the local context of some actions in the action plan.
Suggestions for improvement

Some professionals felt that the process would have benefited from the participation of other professional groups, particularly community care, for example, the ambulance trust, pharmacists, paramedics, practice managers, county council, social services, psychologists and mental health services which would have brought a wider range of perspectives to the discussions.

Discussion

Public engagement in planning and delivery of healthcare services has often been limited for want of effective methods to support it, with the public consequently limited in their ability to function as user representatives in a meaningful way [14]. Well-defined and proven methods that go beyond consultation are needed. This study evaluated a clearly described co-production process called Working Together for Change (WTfC) to explore its value in agreeing commissioning priorities for COPD services. The experience was engaging, constructive and beneficial for participants and empowering for patients and carers. An action plan was agreed and the majority of participants were satisfied with the process and its relevance for COPD. The process could have been improved by including a greater variety of professional roles to bring wider perspectives and by ensuring greater clarity about the process at the start of the workshops. Some professionals were concerned about the potential achievability of some actions in the local context.

The structured, collaborative format of WTfC facilitated egalitarian working. Ideas could emerge freely rather than be imposed by healthcare professionals and the strong public presence presented a voice that counted. This joint development of ideas from the outset is a key distinguishing feature of co-production and WTfC compared to other involvement methods [3]. For example, the deliberative method, involving discussions of reasons for and against proposed actions, aims to engage the public in complex issues [11] but does not necessarily involve joint agenda setting.

During WTfC professionals experienced the value of public involvement first-hand and saw its value for other service development areas. Patients and carers learned about the challenges of developing and delivering services. Other engagement methods have demonstrated mutual influence and concordance between clinicians and patients. For example, Boivin et al. [20] tested patient involvement in selecting indicators for healthcare improvement using a 2-day deliberation meeting and nominal group technique. Patients and clinicians changed their opinions relative to baseline priorities and a fostering of mutual influence led to more concordance compared to control sites. However, in that process the starting point was a set of validated quality indicators whereas WTfC starts with the patient voice. Interestingly, in the Boivin et al. study professionals were more influenced by public contributions when views were presented as representative of the population rather than as personal stories, whereas in our study patients’ and carers’ personal experiences were a powerful influence on the professionals. Perhaps WTfC encouraged a more intimate connection between public and professionals; it provided an opportunity for patients, carers and professionals to experience a different kind of role in relation to each other, particularly for healthcare professionals whose typical patient encounters may be different from those of, for example, voluntary sector professionals. In WTfC participants moved beyond traditional healthcare roles of patient as a passive recipient of care and professional as expert and problem-solver [21].

During WTfC professionals learned first-hand about the reality of patients’ and carers’ lives and their experiences of services. This is important to counteract a potential tension at the heart of co-production between professional (biomedical, disease-oriented, third person) and patient conceptions of health (illness-orientated, first-person conception of the effect of health on one’s life) [22]. Owens and Cribb [22] argue that this tension must be addressed in order to realise co-production ideals because the two conceptions may reflect a different sense of what matters, creating conflict if not recognised. In raising awareness of and giving equal weight to, the first-person perspective, WTfC can contribute to a pluralistic account of health as determined by biomedical, psychological and socially constructed causal structures; this is essential to accommodate the complexity of ill-health and for co-production to succeed without engendering conflict [22]. Starting with individual patient issues, WTfC allows patients and professionals to communicate about underlying problems and what really matters to patients. Their needs, preferences and expertise of living with COPD can then be at the heart of service design and professionals will be better equipped to develop person-centred services with potential to prevent longer-term problems.

Further benefit may have been gained by including other health professional roles, for example, public health and the ambulance service. Although a vital element of co-production is the involvement of experts by experience and of people with authority to make decisions and our workshops included both of these, other roles could have broadened the discussion about potential actions.

Some professionals raised concerns about dot voting leading to bias in agreeing priorities. However, it is one part of a wider process which includes whole group and small group discussions and patients found it empowering. The potential for bias is less than for user engagement methods which begin with a pre-determined agenda.

Some participants were uncertain whether their personal needs were reflected in the outputs from WTfC. It is inevitable that not all individual needs will be reflected in a process designed to agree population-level priorities, but it is good practice to clarify this at the outset.

Some professionals were concerned that some of the agreed actions may not be achievable in the local context. WTfC would have reduced value if the outputs had no impact on commissioning. We cannot comment on how the actions were progressed as this was outside the evaluation scope. A follow-up study of a community participation
exercise to design rural service delivery models in Scotland lacked evidence of longer-term impacts - the study found only one direct sustained service change and identified a number of barriers [23]. Notably, as in our study, the purpose had been to develop a community participation method rather than directly support service change. The change that was sustained involved citizens coalescing to provide an additional local service rather than a change to state-authority delivery. WTfC is one link in a longer chain of events and the need for subsequent action needs to be directly addressed, planned and supported.

In our local clinical practice person-centered reviews are not a routine part of COPD care and so we conducted dedicated one-to-one discussions, which required funded staff time and travel. However, in settings such as mental health where person-centered reviews may be part of normal care this extra expense would not be necessary. While one-to-one discussions are time-consuming they ensure that the voices of people who do not otherwise participate in involvement activities are included. The desire to integrate one-to-one reviews by emulating care planning processes in mental health and social care settings in patient encounters for people with chronic disease is much discussed nationally. If such approaches became the norm then the addition of local WTfC processes would be less resource intensive and be more powerfully representative of a population than the dedicated home visits we carried out. Other potential costs include venue hire, facilitator training, professionals’ time and travel expenses for patients and carers. We did not conduct a cost-benefit analysis but commissioners commented that the process was highly valued and professionals who attended reported that the time spent was beneficial. Successful implementation depends on representatives of the patient population attending the workshops and accommodations may be required for people with limited mobility or disabilities.

WTfC provided an introduction to co-production, generating motivation and goodwill. The ongoing challenge is to embed co-production into the commissioning process. WTfC allowed freedom for ideas to emerge which could be a barrier for conventional approaches to commissioning; co-production is ‘messier’, activities evolve and success is found in outcomes that are less easy to measure. Collaborative commissioning models are needed that encourage recovery over treatment, a focus on wellbeing and which include patient-set goals and patient-reported outcomes and ensure that the commissioning process reflects the lived experiences of users [24]. An evidence base of innovative commissioning models that include these principles is being established [25].

WTfC is a generic process and we found no reason to suppose it would not be successful for other long-term conditions. Another aspect of transferability is whether the results of one WTfC intervention could transfer to the same condition in another health economy. The process is designed to promote engagement and understanding with a local population, rather than generalisation. Differences in services and demographics may mean that what works in one area may not work the same way in another. However, work is underway to look at local, regional and national actions and decisions which could be potentially scaled across a number of Clinical Commissioning Groups in different areas.

In terms of the limitations of this study, a disproportionate number of Breathe Easy members, who may represent a group more engaged with healthcare matters, attended the workshops compared to patients from other sources. However, the WTfC process ensured that the issues of non-attenders were fairly represented through the information from their one-to-one encounters. Also, the evaluation focused on the workshop process and the results reflect the patient views only of those who participated in both one-to-one discussions and workshops. This project was designed as a co-production activity with embedded service evaluation rather than as a structured research study which may have yielded further learning.

Evidence suggests that ‘people powered’ health interventions are linked to more efficient utilisation, improved health outcomes, quality of life, patient experience and satisfaction and reduced cost [26]. Future research should evaluate the impact of WTfC on service delivery and health outcomes in a physical health setting. Outcomes are affected by context and research frameworks conceptualising community participation as a process rather than an intervention may be useful to address this [27].

Conclusion

There is a need more clearly to describe and evaluate methods to support patients as active partners in decision-making about healthcare services. WTfC is a co-production process that is acceptable to and beneficial for, patients and healthcare professionals in a COPD commissioning context. It supported collaborative working, enhanced relationships and was person-centred, resulting in an agreed and prioritised action plan for service commissioning. As a standalone activity, it was not possible to evaluate the objective impact or value of the outputs on services or downstream health outcomes. To test this and to build on this promising process it would be necessary to embed co-production throughout the commissioning process. Our evaluation suggests that WTfC is a useful and impactful starting point for such an endeavour.

Acknowledgements and Conflicts of Interest

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