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# From awareness to involvement? A qualitative study of respiratory patients' awareness of health service change

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## Abstract

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**Background** Despite the policy rhetoric, patient involvement in health service decisions remains limited. Highlighted barriers include a concern that most patients are unable to see beyond personal aspects of their care in order to contribute meaningfully to health service development, and a perception that professionals do not welcome patient involvement.

**Objectives** We aimed to explore respiratory patients' awareness of changes in local health service provision and provide insight into health professionals' attitudes to engaging patients.

**Methods** Nested within an ethnographic study of health service reconfiguration, we recruited 31 patients with a range of respiratory diseases from four case study areas in England and Wales. Data from telephone interviews, illness diaries and focus groups with patients, and interviews with health professionals and managers were transcribed and analysed using the Framework approach.

**Results** Participants were not only aware of trends in health service provision (e.g. emergence of new professional roles, shift from secondary to primary care) but interpreted changes in the light of local and national events. Despite this awareness, none of the patients was formally involved in service development, though some contributed to local voluntary groups. Professionals generally welcomed the need for patients' views to be heard.

**Discussion and conclusions** Our data give grounds for optimism. Patients are aware of and interested in a broad range of health-related issues. Professionals' motivation to involve patients in service

development may be underestimated. Although practical obstacles remain, our findings should encourage the ongoing search for effective models of promoting patient engagement in health-care services.

## Introduction

Echoing global trends, UK policy promotes the involvement of patients not only as partners in their own care but also in influencing the way in which the National Health Service (NHS) works.<sup>1–5</sup> The vision is that increasingly decision making will be devolved to as near the point-of-delivery as possible in a partnership between commissioners, service providers and patients.<sup>6–8</sup> Despite this policy drive, recent reports have concluded that patient involvement in planning remains limited<sup>9,10</sup> and raised concerns about seemingly empty rituals designed to satisfy government rhetoric.<sup>11–13</sup>

Although studies have explored the potential benefits of patient and public involvement in improving service design and shaping priorities,<sup>14–17</sup> there is still limited empirical evidence to support the effectiveness of these initiatives.<sup>18–21</sup> Structural barriers to public participation have been highlighted and include uncertainty over the practicalities of promoting patient involvement,<sup>22–25</sup> the precise role the public should play,<sup>26</sup> poorly resourced integration into systems for service improvement,<sup>27</sup> and professional attitudes to patient involvement.<sup>28–31</sup>

A commonly cited concern is that patients' knowledge and awareness focus predominantly on their personal elements of care, with few patients having the awareness and/or motivation to understand the broader perspectives required for involvement in strategic health service planning.<sup>32,33</sup>

Using respiratory disease as an exemplar long-term condition, our ethnographic study explored the processes of workforce change in four Primary Care Organizations (PCOs) responsible for delivering local health-care services,<sup>34</sup> and revealed pertinent insights into patients' awareness, knowledge and interest in the health services and how professionals feel

about engaging with patients.<sup>35</sup> The core data we present here emerged from the nested patient experience phase of our study in which we aimed to explore how aware patients with chronic respiratory diseases were of current health-care trends within their local services. In order to substantiate and contextualize our findings, we also present relevant data from the ethnographic study in which providers had shared their impressions and opinions on involving patients.

## Methods

This study was undertaken with the approval of South-East Multicentre Research Ethics Committee and research governance approval from the four PCOs.<sup>36</sup> The PCOs are described in Table 1, using pseudonyms to preserve their confidentiality.

### The ethnographic study

Our ethnographic study undertaken during 2006 and 2007 had four distinct phases, with the broad aim of understanding and comparing the process of workforce change in respiratory services and the impact on patient experience.

1. Screening interviews. We developed a broad picture of respiratory service development through interviews with a representative from 30 PCOs.<sup>37,38</sup>
2. Case studies. Four PCOs were selected on the basis of our analysis of the screening interviews, representing a range of models of respiratory care, key players and conditions for service development. We conducted serial semi-structured interviews over the course of a year with 34 health-care professionals, and 17 health service managers as part of detailed case studies of respiratory service development in four selected PCOs.

**Table 1** Key features and interviewees of the 30 screening interviews and four case study areas

Screening interviews	
Semi-structured telephone interviews with the person responsible for developing respiratory services in 30 PCOs in England and Wales purposively sampled to represent a wide spectrum of attitudes to the reconfiguration of respiratory services	<p><i>Number of professional interviewees</i></p> 19 PCO Managers 7 Nursing service managers 3 GPWSts
Case studies	
The case studies studied four Primary Care Organizations (PCOs) with diverse organizational contexts who were developing different models of providing respiratory care to respond to the needs of their local population. PCOs are freestanding statutory NHS bodies with the responsibility for delivering health-care and health improvements to their local areas. They commission or directly provide a range of community health services, such as district nursing, as part of their functions. <sup>34</sup> Under Practice-Based Commissioning (PBC) arrangements, GP practices are given indicative budgets to commission care for their practice populations. <sup>34</sup> A key focus for our ethnographic study was the role of GPs with a Special Interest (GPWSts)	
Team PCO	<p><i>Number of professional interviewees</i></p> 3 PCO Managers 1 GPWSt 1 Respiratory consultant 1 Community specialist respiratory nurse
Situated in a market town, development was driven by a multidisciplinary team with a 'diagnosis to death' vision of respiratory services. Clinical services were led by a GPWSt, working closely with the local respiratory consultant. The appointment of a specialist respiratory nurse was an early focus of the development plan	
Merged PCO	<p><i>Number of professional interviewees</i></p> 6 PCO Managers 3 GPWSts 2 Respiratory consultants 2 Community specialist respiratory nurses 2 Practice respiratory nurses 3 Hospital specialist respiratory nurses 1 GP PBC lead 1 Community matron
The existing service was led by a GPWSt working with a respiratory nurse to provide a referral service for local GPs. Following the merger with four neighbouring PCOs, the Merged PCO, who had inherited a major financial deficit, actively rolled out the GPWSt model in order to reduce secondary care costs	
Commissioning PCO	<p><i>Number of professional interviewees</i></p> 3 PCO Managers 2 Respiratory consultants 1 Senior community specialist respiratory nurse 1 Paediatric specialist respiratory nurse 2 GP PBC leads 1 Hospital Manager
The PCO commissioned a nurse-led community respiratory service, with the primary aim of reducing hospital admissions. The service worked closely with the University teaching hospital and provided proactive care for patients with chronic obstructive pulmonary disease	
Rural PCO	<p><i>Number of professional interviewees</i></p> 4 PCO Managers 7 GPs 2 Respiratory consultants 1 Community specialist respiratory nurse 1 Practice respiratory nurse 1 Practice nurse
The rural location and absence of nearby hospitals resulted in a service based on developing existing primary care resources. The GPs and community nurses were supported by a specialist respiratory nurse who provided education to primary care professionals	

3. Patient experience. We explored patients' perspective of current health-care trends in each of the case study areas.
4. Multidisciplinary workshop to aid interpretation of our findings.

A detailed description of the study methodology is available in the study report.<sup>35</sup>

### Nested patient experience phase

#### *Participant recruitment*

Patients with chronic respiratory diseases were recruited by advertising in the local press and distributing posters and information leaflets via general practitioner (GP) surgeries (both using mail-shots and opportunistically), outpatient

clinics, pharmacies and Breathe-Easy patient support groups. Respondents provided information on their age, gender, experience of the health-care services and type of respiratory illness, so we could ensure a range of profiles. Potential participants were contacted by phone, asked for consent and invited to take part in either keeping an illness diary with telephone interviews and/or a focus group discussion. All topic guides are available in our study report.<sup>35</sup> We recruited until we reached data saturation with respect to our aim of exploring respiratory patients' awareness of health-care trends within their local services.

#### *Illness diaries and telephone interviews*

For 1 month, participants recorded symptoms in the context of their overall life situation, the range of formal/informal support, information sources and health-care services accessed. The benefits of using this method in health research include the possibility of exploring internal dialogues that may be easier to express in the written form than through oral accounts.<sup>39</sup> Two 30-min semi-structured telephone interviews were conducted: the first, prior to commencing the diary, explored how participants dealt with their condition in the context of available services; the second used the completed diary entries to trigger discussion on key issues highlighted by the patient, including their awareness of changes in the health-care system.

#### *Focus groups*

In each of the PCOs (excluding the very rural area where a single focus group was impractical), a 1-h focus group was arranged and facilitated by two researchers. Groups included some patients who had kept illness diaries as well as additional participants. The scheduling of the focus groups towards the end of the study enabled us to use these discussions to confirm emerging themes and further explore issues related to awareness of local service development, and involvement in health care. Discussions were audio-taped with consent.<sup>40</sup>

#### Health professional and managers' interviews

Patient involvement and representation emerged as a theme from the analysis of the screening and serial case study interviews (see Table 1).<sup>35</sup> We have drawn upon data from these interviews to explore professional and managerial attitudes to patient involvement, and provide a context within which we can interpret our findings from the patient experience phase.

#### Data analysis

All data were transcribed, coded and entered into NVivo 7 (QSR International, Doncaster, Vic., Australia). We used the 'Framework approach', developed specifically for applied qualitative research,<sup>41</sup> as this method allows for the combination of inductive and deductive coding. The coding frameworks are available in our study report.<sup>35</sup> Triangulation of data occurred through constant comparison of the findings obtained from the different data collection methods. We specifically looked for deviant cases.

Themes and sub-themes were developed in regular discussion with the multidisciplinary research team members and further explored in workshops with a wider team of collaborators and advisors. This iterative process enabled integration of data from the patient phases with emerging themes from the screening and case study phases. We drew on policy documents and social science literature regarding patient and public involvement, and health staff attitudes to participation to inform our analysis and thinking.

## Results

### Participants

Of the 49 patients who expressed interest, 31 patients with a range of respiratory conditions of differing severity agreed to participate. Tables 2 and 3 provide details of the numbers of patient participants per site, gender, age and disease. Table 1 lists the 30 screening interviewees and 61 case study participants.

**Table 2** Number of patient participants by Primary Care Organization (PCO) and contribution

	Phone interview only	Illness diary + phone interviews	Focus group discussion
Team PCO	2	4	1*
Merged PCO	–	7	4†
Commissioning PCO	1	4	10‡
Rural PCO	–	2	–

Overall 31 participants took part in the patient study. A few contributed to several of our data collection methods and are thus double-counted as noted below.

\*Three participants had been expected, only one turned up. This participant was also involved in the illness diary.

†Three of these participants took part in the illness diary.

‡None of these participants took part in the illness diary.

### Overview of results

Participants demonstrated considerable awareness of trends in health service provision (specifically the shift to community care, changing professional roles, coordination of services, competencies and hierarchies, and promotion of self-care). None of the patients was formally involved in service development, though some were involved with local voluntary groups. Professionals and health-care managers generally welcomed the concept of patient involvement, though raised practical concerns about implementation.

### Awareness of trends in the health service

#### *The shift to community care*

In general, participants were aware and generally supportive of the shift towards providing care in the community. Being cared for at home

was welcomed in part because it avoided the risks accompanying hospital care, such as acquiring methicillin-resistant *Staphylococcus aureus* (MRSA), the impersonal and busy atmospheres usually prevailing in hospitals, and (for some) the neglect experienced during previous admissions.

...when you hear, you know, ministers of the government saying that they've got the cleanliness of hospitals under control, they've got the diseases, the MRSA and the C diff under control it's a lie, a total lie. And I tell you something, I am petrified of going back into hospital. (60- to 69-year-old man with lung cancer, Merged PCO)

Others cited practical reasons for preferring care at home describing difficulties travelling to hospitals, long waiting times and accessibility issues, especially in the rural areas.

It's a bit of a job [getting to hospital] but our community matron she checks me out every week. She checks me to make sure everything's alright. [...] And it saves me [the trip]. I'm being selfish, it saves me and it saves my wife. [70- to 79-year-old man with COPD, Merged PCO]

#### *Changing professional roles*

The majority of respondents were aware of the changes in professional roles that had accompanied recent workforce changes. The traditional GP role had changed and some lamented the loss of the family doctor, a person they equated with 'whole person' and 'whole family' care and whose coordinator role eased navigation between services.

**Table 3** Patient participant details by age category, gender and type of condition

Age range	Women	Men	Type of condition	Total number
40–49	2	–	Asthma (2)	2
50–59	4	2	Asthma (2), asthma and COPD (3), sleep apnoea (1)	6
60–69	1	10	COPD (5), asthma and COPD (2), bronchiectasis (2), sarcoidosis (1), lung cancer (1)	11
70–79	4	7	Asthma and COPD (1), COPD (9) sleep apnoea (1)	11
80–89	–	1	Asthma (1)	1
Total	11	20	Asthma (5), asthma and COPD (6), COPD (14) sleep apnoea (2), bronchiectasis (2), sarcoidosis (1), lung cancer (1)	31

In the olden days, when ... you saw your GP and I think that was the role that tied things together. But now, there are so many specialist clinics ... you go to the asthma clinic at the surgery, you go to the diabetic clinic at the surgery, you see? You know, they're all compartmentalised I think. [40- to 49-year-old woman with asthma, Team PCO)

With the perceived decline in 'family doctors', many interviewees welcomed the emergence of new professionals and teams, some of whom they saw taking over aspects of the GP role. Although not universally available, those benefiting from their services appreciated the community matron and specialist respiratory nurse for their ability to build relationships with patients and carers, their involvement, accessibility and availability in the community and in peoples' homes.

The one in the community [respiratory nurse] seems to be more... willing and able to think flexibly and... a bit more laterally and think 'What can we really do to help?' (40- to 49-year-old woman with asthma, Team PCO)

So I have a list of all these different numbers to ring and out of hours and if I'm taken bad like that quickly I pick up the phone and they're with me. (60- to 69-year-old man with COPD, Commissioning PCO Focus Group)

Others, however, expressed frustration with the multiplicity of new professional roles which they perceived as additional layers that they had to navigate in the quest for medical 'expertise'.

I mean what's happened now (...) we're getting into an overkill situation we've now got the district nurse, the district respiratory nurse, the senior district respiratory nurse, the respiratory manager nurse.(...) How many more people are going to be a buffer zone with you and the doctors? [60- to 69-year-old man with COPD, Team PCO)

#### *Coordination of care*

Participants drew attention to the need for coordination between the increasing numbers of professionals now involved in their care. Examples were cited of cumbersome and delayed referrals, inconsistent access to medical records and difficulty building a relationship due to the constant turnaround of staff, resulting in a perception of fragmented care.

And they do change (...). One goes and there's a new one and there is that feeling of incompetence. You go in and they have never seen you before and you have never seen him and he doesn't know what is wrong with you. (60- to 69-year-old man with asthma and COPD, Commissioning PCO)

#### *Competencies and hierarchies*

Participants not only demonstrated an understanding of both tension and conflict but also mutual respect between health-care professionals. Thus community matrons were described as potentially clashing roles with respiratory nurses, or negotiating decisions about care with consultants. GPs were depicted as needing to be careful not to 'step on the toes' of consultants.

Knowledge was depicted as a powerful determinant of status within the hierarchy, which could be used to delineate professional territory. The specialist status of new professional roles could be validated on the basis of training and experience in respiratory care:

You know, and she's brilliant because when I was talking to her last time there'd been that programme on the TV with the London hospital (...) So I think that's why she's very knowledgeable because she worked there before she came up [here]. (50- to 59-year-old woman with sleep apnoea, Team PCO)

Others, however, expressed unease with 'specialist' being 'tagged' on to roles; they were not entirely confident of the expertise that these titles denoted and were concerned that their care was being compromised.

Is she, although they say, alright, she's a specialist respiratory nurse, she's not a specialist...they haven't made her a specialist doctor. So if, for example, we need to change my medication, should I be quite happy that she changes it for me without seeing the doctor? I don't know...? (70- to 79-year-old man with COPD, Merged PCO)

So he's the interested GP who specialises in respiratory troubles. But he's just a GP...not a consultant or anything. (70- to 79-year-old woman with COPD, Merged PCO)

*Promotion of self-care*

Many patients were aware of the policy shift towards self-care, and described how health professionals increasingly seemed to acknowledge patients' understandings of their own body and health and were happy to transfer some responsibilities over to their patients' control.<sup>42</sup>

My consultant leaves me with a supply and they really leave the managing of the disease to my knowledge of how I am and if I know that I'm growing something horrible and it's a weekend or at night, I can self-medicate. (60- to 69-year-old woman with bronchiectasis, Rural PCO)

*Making sense of the changes*

Most respondents explained changes in the context of financial cutbacks that dominate the current popular rhetoric on the NHS, though some also referred to other underlying drivers of shifts within the system and roles.

*Financial cutbacks*

Many references were made to NHS budget limitations, and some patients were suspicious that politicians were attempting to gloss over the reality of cutbacks. Despite general satisfaction with the services they received, some felt let down and expressed discontent at having paid into the health services for years only to feel their own care was compromised when they needed it. Participants often explained the limited availability of services and the emergence of new nurse roles in the community with reference to financial constraints.

I think so much is happening these days and so much is financially based you think to yourself, 'Hang on a minute, are they really qualified to take some of this work or is it just a financial get out?' We can't find enough doctors, so we'll say that some of these nurses are qualified enough to be able to do some of those things and it's purely a financial get out. And that's always at the back of your mind. (70- to 79-year-old man with COPD, Merged PCO)

Went to relaxation class... at my local hospital. This activity is excellent and so rewarding. Like everything else in the NHS, this service is limited

due to lack of funding and lots of patients queuing up for weeks for treatment. (Illness diary: 60- to 69-year-old man with lung cancer, Merged PCO)

*Nature of the condition*

Despite recent media coverage which had raised the profile of respiratory illnesses, some participants believed that respiratory conditions were still not being taken seriously. Several patients suggested that respiratory conditions might be less 'fashionable' or 'exciting' for health professionals.

[Asthma] is not very interesting is it? You rush in there from a huge car accident or a massive coronary, and then there is the psychological 'I can save somebody here'. (60- to 69-year-old man with asthma and COPD, Commissioning PCO)

I mean when I was first diagnosed with the COPD [...] it was basically 'take your medication, we'll see you occasionally' and that's about it, you know. But then last year when [...] I was diagnosed with cancer the whole scenario and situation changed. They couldn't do enough for me, there was help and advice from different quarters, the respiratory nurse was available at anytime, you know, I could phone up and also the oncology department. So yes, there was a complete different outlook on the care. (60- to 69-year-old man with lung cancer, Merged PCO)

*New policies and arrangements affecting health services*

Some patients explained changes in their health-care in the context of new frameworks within which professionals were operating. Thus a number of interviewees rationalised their discharge from hospital clinics as 'cutting the waiting lists by getting people out' (50- to 59-year-old man with asthma and COPD, Rural PCO) in order to satisfy waiting list targets. Others held the recently established 'pay-for-performance' arrangements of the GP contract responsible for repeated checks or pressure to comply with influenza vaccination.<sup>43</sup>

In the [newspaper] a GP article says: 'Courtesy of the GP contract, there is more clogging up of medical notes, with measurements done for no



good reason, except that the contract demands it....' (Illness diary: 60- to 69-year-old man with asthma and COPD, Commissioning PCO)

....they are paid on the percentage [influenza vaccinations] they achieve so they'll jab any, take the cat, they'll jab the cat [60- to 69-year-old man with sarcoidosis, Merged PCO focus group)

#### *Local and regional differences in care*

The patients displayed considerable awareness of local differences in care provision. Focus group participants expressed mixed feelings about the differing experiences of care within a particular location and used the term 'postcode lottery' to underline the perceived serendipity in accessing 'good' practices within their area. Several interviewees highlighted regional differences in care provision and painted a somewhat disjointed picture of care at a national level.

I mean you take social services and health services as a whole, I mean, are fragmented all over the place aren't they? And not only country to country but also region to region with all these, you know, health services, all these health authorities [...]. It's not a National Health Service is it? It's a collection of regional health services. (70- to 79-year-old man with COPD, Merged PCO)

#### *Resources used to make sense of the changes*

Participants gained their knowledge on developments in the health service through newspapers and magazines, and also by discussing issues with friends, relatives or colleagues and through the Internet and Breathe-Easy group meetings. Interviewees reported negative media coverage on elder abuse in homes, patient experiences of neglect in hospitals, risk of contracting MRSA, financial cutbacks and their impact on care provision and benefits. Such reports enabled people to relate their personal concerns to national events.

Wasn't it in our national papers? A 93 year old man who, committed suicide because he'd got to go in hospital and he was afraid. I can understand that, I can really understand that. (60- to 69-year-old man with lung cancer, Merged PCO)

#### Getting involved

Although none of our participants was involved with the health services at a strategic level [e.g. as lay advisors in PCOs, citizen's juries or local involvement networks (LINKs)], many demonstrated a good understanding of the system and some were involved in local voluntary initiatives.

#### *Patient levels of involvement*

Some participants mentioned how their clinicians had encouraged them to talk at Breathe-Easy groups or to speak with other patients about their experiences of dealing with the condition. One patient had taken the initiative and started a diabetes support group after several patients had approached him for ideas. Despite the fact that they could not find health professionals to speak at their meetings, the group continues to meet in a local restaurant from time to time, for emotional support and 'to have a laugh'. Others described their involvement in schools, talking to teachers about children with respiratory conditions.

It was a course about what you can do with asthmatics and what you can't do and how to administer the inhalers and what inhalers should be in schools [...] and then we'll get a certificate to say we're asthma friendly and we can deal with this and deal with that. (50- to 59-year-old woman with asthma, Merged PCO)

Some participants described their attempts at disseminating information that they had discovered through their own researches. Apart from sharing their insights with support groups and their health-care professional(s), several had also tried to contact people at higher levels in the NHS or political structures.

I told the doctors at the hospital and also my GP and they were all very, very interested and I've supplied them with literature and DVDs and copies of the book and I even wrote to the Secretary State for Health, the Prime Minister, to local MPs [...]. (60- to 69-year-old man with lung cancer, Merged PCO)

There were also examples of how patients who felt let down by an unexplained change in their

care had taken the initiative and contacted their local political representative, who they hoped could influence the health-care system.

Made appointment to see my assembly member to complain about being discharged from the chest clinic. (Illness diary: 50- to 59-year-old man with asthma and COPD, Rural PCO)

Interestingly, none of the patients in our study mentioned the campaigning and lobbying role of patient groups such as the British Lung Foundation or Asthma UK.

### Professionals' perspectives on involving patients

Many of the clinicians and managers we interviewed in the screening interviews and case-study phases of the study spontaneously mentioned the value of patient participation. Generally professionals seemed positive about involving patients, emphasizing the importance of ensuring that finite resources were used 'to the best advantage of the patients' (Rural PCO: GP) and that services were grounded in the 'reality' of patient experiences.

I think I have to remind clinicians that we have to think of what the public's needs are really and a lot of it is assuming that patients are happy with the service ... well are they happy? Have we asked them are they happy? (...). (Merged PCO: Clinical Lead for Long Term Conditions)

One of the things which we want to do is to actually get patients who've had experience of going through the system and speaking with them and getting their story basically to see what their experience is like. Because I think that's very important because you can always set up lovely, nice flowcharts that look very nice on paper but for the individual it doesn't always match reality. [Team PCO: Respiratory GP with a Specialist Interest (GPwSI)]

In addition, the support of patients was seen as an important asset in negotiations for funding; indeed, sometimes a prerequisite when compiling formal bids for service development, though some respondents expressed concern about the risk of involving patients merely in order to fulfil criteria, but without enabling meaningful input.

We also want to get a patient representative on it as well because I think that's important, again it's an ally. You need your allies because at the end of the day it may not be [possible] but if a patient stands up and says 'I think this is wonderful, I think this is great, it's got to make a difference'. (Team PCO: Respiratory GPwSI)

I don't think it's high enough on anyone's agenda, the patient experience. They give it lip service but I've yet to be convinced that what patients say and complain about has much influence. (Team PCO: PCO Manager)

Several practical barriers to patient participation surfaced. These included inaccessible meeting venues, medical or health service jargon in documentation, professional time involved to ensure patient involvement and the potential load on user groups. The premise that the one patient who was able and willing to attend a meeting could represent 'the general public' was questioned by several professionals.

My worry is we [...] tick a box that Joe Smith is there but [...] will he speak on behalf of the community or will he speak on behalf of himself? (Merged PCO: Manager)

## Discussion and conclusions

### Summary of findings

Patients were critically aware of both the strengths and weaknesses of reorganized services. They described trends within the NHS not only from an 'individual' perspective but also at a 'citizens' level.<sup>12,33</sup> From their personal perspective, they described how changes affected professional response to and coordination of their care needs and the impact on their relationships with clinicians. As citizens, they showed awareness of, and interest in the new professional roles, the fragmentation of care and what was happening at regional and national levels usually through the local and national media.

Generally, professional interviewees acknowledged the need for patients' views to be heard and adequately addressed, and indeed seemed to welcome this possibility. Several however highlighted the difficulties in ensuring that patients'

experiences, needs and thoughts on their care were included in planning services, pointing towards structural barriers within the system.

#### Strengths and limitations

Our advertising strategies may have attracted particularly motivated and interested patients; however, if this was the case, the lack of formal involvement in our respondent group was all the more striking. We may not have covered the full range of perspectives on health service developments, especially views from younger people and ethnic minorities; however, our participants presented a range of age, gender and respiratory conditions typical of a primary care population with significant long-term respiratory conditions. We reached data saturation, suggesting that we had an adequate sample size. In order to enable transferability we have provided information about the patients and the PCOs who provide their care.<sup>44</sup>

Patient awareness of local change was the primary focus of our enquiry, and we may not have fully explored participants' thoughts on formal involvement and how it may be enabled, though discussion of this issue was encouraged whenever it arose. Analysis was iterative and as we became aware of the significance of this theme patient involvement was highlighted in topic guides. Finally, our findings are in keeping with and build on the broader, but limited body of knowledge on the (lack of) formal patient involvement.

We were aware that researcher attitudes can influence data collection and analysis,<sup>45</sup> though the illness diaries allowed patients to voice their uninfluenced reflections. Scheduling the focus groups towards the end of the study provided opportunities to validate our emerging findings. Regular multi-disciplinary discussions also contributed to a balanced interpretation.

#### Awareness as an under-discussed prerequisite of involvement

None of the patients we interviewed was currently formally involved or expressed the intention of getting involved at the planning

levels of the health system, though some were actively contributing to (for example) voluntary support groups. However, our findings suggest that respiratory patients are very aware of health service trends which affect their care and actively sought to understand them. Many interpreted their personal experiences in the light of national developments which they followed through various sources of information, including the media, their social networks and support groups. It has been suggested that severely ill patients are less interested in anything apart from their own health,<sup>32,33</sup> but we found no evidence of this as those whose illness diaries and interviews suggested more severe disability seemed equally aware of changing national and local health trends.

Harnessing this awareness offers scope for increasing patient involvement at various levels of the health system. In the UK, public interest in standards of hospital care echoed by our participants has recently led to calls for the public to assume greater responsibility for quality surveillance especially for in-patient facilities.<sup>46,47</sup>

#### Power struggles

Patients in our study questioned the formation of new professional roles and many were aware of the shifting 'knowledge boundaries' that arise from the creation of these new specialist roles. Recent policies suggest devolving some power for planning new services to patients, invoking strategies such as citizens' juries, Patient and Public Involvement Forums and local involvement networks.<sup>1,4,6,7</sup> Increasingly, both patients' and professionals' perceptions of who holds true 'authority' and 'power' within the health decision-making arena may thus change. Previous studies have concluded that this challenge to professionals' dominance over health-care decisions may stifle active promotion of patient involvement despite positive rhetoric.<sup>48</sup> By contrast, our professional interviewees seemed genuinely to welcome 'indirect' involvement (using patient feedback to inform decisions) whilst

recognizing practical barriers to 'direct' involvement (patients taking part in actual decision making).<sup>49</sup>

However, there were also hints of more strategic motives. With the emerging market economy in the English NHS and the growing emphasis on commissioning, patient voices may be important levers for service change. There is thus a potential danger of patients being used as pawns in power struggles over service priorities, including contests between clinicians and managers. Previous research has raised concern regarding the agenda behind patient involvement and suggested that health professionals may insist on determining the nature of public involvement activities rather than encouraging 'direct' participation which risks overthrowing the traditional distribution of power.<sup>14,50–55</sup>

Barriers to public involvement in health services development may be generated by the very policy which is intended to promote it. Tritter<sup>49</sup> points to a tension between patients as consumers linked to the development of market-based change, and patients as citizens linked to a policy of community capacity and collective action. Whilst rhetoric and some initiatives, such as LINKs appeal to the latter, changes in English health services position patients as consumers, with few possibilities to influence the system other than through individual choice between existing services. The lack of direct involvement in decision making which we observed may reflect this issue.

### Conclusions and implications

While patient involvement is as yet limited, our data give some grounds for optimism on two fronts. Firstly, concerns that patients can only see issues in relation to their own personal situation may be tempered by their evident awareness and interest in broader issues concerning the health systems, offering a strong basis from which true public participation could become a reality. Secondly, professionals' motivation to engage with patients in order to

develop appropriate services seems to be underestimated, though there are some concerns about 'strategic' use of the patients' voice.

Many practical obstacles to patient involvement remain. Widespread changes to the structures of the health system, e.g. funding decisions, electoral procedures and commissioning processes, will be needed before patients' awareness of health-care changes can be harnessed into meaningful involvement, and before professionals' interest in patients' perspectives translates into active partnership. Our findings, however, suggest a fertile environment which should encourage the ongoing search for effective models of promoting patient engagement in health-care services.

### Competing interests

The authors declare that they have no competing interests.

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The views and opinions expressed herein are those of the authors and do not necessarily reflect those of the Department of Health.

### Contributors

H.P. initiated the idea for the study and led the development of the protocol and securing of funding with G.H. and A.S. H.P., G.H., T.K. and A.P. contributed to study administration and data analysis. All authors contributed to the interpretation of results, writing of the paper and have reviewed the final manuscript. H.P. and G.H. are study guarantors.

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## References

- House of Commons Health Committee. *Patient and Public Involvement in the NHS*. London: The Stationery Office Limited, 2007.
- World Health Organisation. *Ninth Futures Forum on Health Systems Governance and Public Participation*. Geneva: WHO, 2006.
- Department of Health. *Creating a Patient-Led NHS: Delivering the NHS*. London: Department of Health, 2005.
- Transition Advisory Board. *Patient and Public Involvement in Health. Key Messages for the Commission for Patient and Public Involvement in Health and the Department of Health*. London: Department of Health, 2002.
- Department of Health. *The NHS Plan: A Plan for investment, A Plan for Reform*. London: The Stationery Office, 2000.
- Department of Health. *Our NHS Our Future: NHS Next Stage Review – Interim Report*. London: The Stationery Office, 2007.
- Department of Health. *Our Health, Our Care, Our Say: A New Direction for Community Services*. London: The Stationery Office, 2006.
- Department of Health. *The NHS Improvement Plan: Putting People at the Heart of Public Services*. London: The Stationery Office, 2004.
- Audit Commission. *Quicker Treatment Closer to Home: Primary Care Trusts' Success in Redesigning Care Pathways*. London: Audit Commission, 2004.
- Department of Health. *Our Health, Our Care, Our Say – One Year On*. London: The Stationery Office, 2007.
- Craig GM. Involving users in developing health services. *BMJ*, 2008; **336**: 286–287.
- Hogg C. Patient and public involvement: what next for the NHS? *Health Expectations*, 2007; **10**: 129–138.
- Hui A, Stickley T. Mental health policy and mental health service user perspectives on involvement: a discourse analysis. *Journal of Advanced Nursing*, 2007; **59**: 416–426.
- Haigh C. Exploring the evidence base of patient involvement in the management of health care services. *Journal of Nursing Management*, 2008; **16**: 452–462.
- Coulter A, Ellins J. Effectiveness of strategies for informing, educating, and involving patients. *BMJ*, 2007; **335**: 24–27.
- Donaldson A, Lank E, Maher J. Sharing experiences of user involvement in shaping new services: the story of a national patient group. *Familial Cancer*, 2007; **6**: 249–256.
- Coulter A. Patient engagement: why is it important? In: Andersson E, Tritter J, Wilson R (eds) *Healthy Democracy: The Future of Involvement in Health and Social Care*. London: Involve and NHS National Centre for Involvement, 2006: 27–35.
- Fudge N, Wolfe CDA, McKeivitt C. Assessing the promise of user involvement in health service development: ethnographic study. *BMJ*, 2008; **336**: 313–317.
- Challans E. How can users be involved in service improvement in health and social care, and why is this important? *Journal of Integrated Care Pathways*, 2006; **10**: 49–58.
- Nilsen ES, Myrhaug HT, Johansen M, Oliver S, Oxman AD. Methods of consumer involvement in developing healthcare policy and research, clinical practice guidelines and patient information material. *Cochrane Database of Systematic Reviews* 2006, Issue 3. Art. No.: CD004563, doi: 10.1002/14651858.CD004563.pub2.
- Crawford MJ, Rutter D, Manley C *et al.* Systematic review of involving patients in the planning and development of health care. *BMJ*, 2002; **325**: 1263–1267.
- Anderson E, Shepherd M, Salisbury C. Taking off the suit: engaging the community in primary health care decision-making. *Health Expectations*, 2006; **9**: 70–80.
- Gold SK, Abelson J, Charles CA. From rhetoric to reality: including patient voices in supportive cancer care planning. *Health Expectations*, 2005; **8**: 195–209.
- Florin F, Dixon J. Public involvement in health care. *BMJ*, 2004; **328**: 159–161.
- Evans S, Tritter J, Barley V *et al.* User involvement in UK cancer services: bridging the policy gap. *European Journal of Cancer Care*, 2003; **12**: 331–338.
- McKenna H, Keeney S. Community nursing: health professional and public perceptions. *Journal of Advanced Nursing*, 2004; **48**: 17–25.
- Baggott RA. A funny thing happened on the way to the forum? Reforming patient and public involvement

- in the NHS in England. *Public Administration*, 2005; **83**: 533–551.
- 28 Brooks F. Nursing and public participation in health: an ethnographic study of a patient council. *International Journal of Nursing Studies*, 2008; **45**: 3–13.
- 29 Gagliardi AR, Lemieux-Charles L, Brown A, Sullivan T, Goel V. Barriers to patient involvement in health service planning and evaluation: an exploratory study. *Patient Education and Counseling*, 2008; **70**: 234–241.
- 30 Thompson AGH. The meaning of patient involvement and participation in health care consultations: a taxonomy. *Social Science and Medicine*, 2007; **64**: 1297–1310.
- 31 Murie J, Douglas-Scott G. Developing an evidence base for patient and public involvement. *Clinical Governance: An International Journal*, 2004; **9**: 147–154.
- 32 Harrison S, Dowswell G, Milewa T. Guest editorial: public and user ‘involvement’ in the UK National Health Service. *Health and Social Care in the Community*, 2002; **10**: 63–66.
- 33 Thompson AGH. Moving beyond the rhetoric of citizen involvement: strategies for enablement. *Eurohealth*, 2003/2004; **9**: 6–9.
- 34 Williams S for IMPRESS. *NHS Jargon Buster: Version 2*. London: British Thoracic Society, 2008. Available at: <http://www.impressresp.com>, accessed 20 August 2010.
- 35 Pinnock H, Huby G, Powell A *et al.* *The Process of Planning, Development and Implementation of a General Practitioner with a Special Interest Service in Primary Care Organisations in England and Wales: A Comparative Prospective Case Study*. Report for the NHS Service Delivery and Organisation R&D Programme. London, 2008. Available at: <http://www.sdo.nihr.ac.uk/projdetails.php?ref=08-1519-099#>, accessed 20 August 2010.
- 36 Kielmann T, Tierney A, Porteous R, Huby G, Sheikh A, Pinnock H. The Department of Health’s Research Governance Framework remains an impediment to multi-centre studies: findings from a national descriptive study. *Journal of the Royal Society of Medicine*, 2007; **100**: 234–238.
- 37 Hamilton S, Huby G, Tierney A *et al.* Mind the gap between policy imperatives and service provision: a qualitative study of the process of respiratory service development in England and Wales. *BMC Health Services Research*, 2008; **8**: 248.
- 38 Pinnock H, Huby G, Tierney A *et al.* Is multi-disciplinary teamwork the key? A qualitative study of the development of respiratory services in the UK. *Journal of the Royal Society of Medicine*, 2009; **102**: 378–390.
- 39 Stensland P, Malterud K. Approaching the locked dialogues of the body: communicating symptoms through illness diaries. *Scandinavian Journal of Primary Health Care*, 1999; **17**: 75–80.
- 40 Bernard RH. *Research Methods in Anthropology*. Lanham: AltaMira Press, 2005.
- 41 Pope C, Ziebland S, Mays N. Qualitative research in health care: analysing qualitative data. *BMJ*, 2000; **320**: 114–116.
- 42 Kielmann T, Huby G, Powell A *et al.* From support to boundary: a qualitative study of the border between self care and professional care. *Patient Education and Counseling*, 2010; **79**: 55–61.
- 43 NHS Confederation, British Medical Association. *New GMS Contract 2003: Investing in General Practice*. London: NHS Confederation, British Medical Association, 2003.
- 44 Murphy E, Dingwall R, Greatbatch D, Parker S, Watson P. Qualitative research methods in health technology assessment: a review of the literature. *Health Technology Assessment*, 1998; **2**: 16.
- 45 Cutcliffe JR. Reconsidering reflexivity: introducing the case for intellectual entrepreneurship. *Qualitative Health Research*, 2003; **13**: 136–148.
- 46 BBC News. Failing hospital ‘caused deaths’, 17 March 2009. Available at: [http://news.bbc.co.uk/2/hi/uk\\_news/england/staffordshire/7948293.stm.r](http://news.bbc.co.uk/2/hi/uk_news/england/staffordshire/7948293.stm.r).
- 47 Edemariam A. A hospital is able to tick all the boxes, yet still utterly fail patients. *The Guardian*, 19 March 2009. Available at: <http://www.guardian.co.uk/society/2009/mar/19/nhs-targets-stafford-hospital>.
- 48 Milewa T, Dowswell G, Harrison S. Partnerships, power and the ‘new’ politics of community participation in British health care. *Social Policy and Administration*, 2002; **36**: 796–809.
- 49 Tritter JQ. Revolution or evolution: the challenges of conceptualizing patient and public involvement in a consumerist world. *Health Expectations*, 2009; **12**: 275–287.
- 50 Young R. Introducing role and service changes in health and social care: the impact and influence of user involvement in England and Wales. *Social Policy and Society*, 2006; **5**: 249–268.
- 51 Salter B. Patients and doctors: reformulating the UK health policy community? *Social Science and Medicine*, 2003; **57**: 927–936.
- 52 Small N. The changing NHS: user involvement and palliative care. In: Monroe B, Olivier D (eds) *Patient Participation in Palliative Care*. Oxford: Oxford University Press, 2003: 9–22.
- 53 Brown I. Organizational values in general practice and public involvement: case studies in an urban district. *Health and Social Care in the Community*, 2001; **9**: 159–167.
- 54 Rhodes P, Nocon A. User involvement and the NHS reforms. *Health Expectations*, 1998; **1**: 73–81.
- 55 Sang B. Choice, participation and accountability: assessing the potential impact of legislation promoting patient and public involvement in health in the UK. *Health Expectations*, 2004; **7**: 187–190.