'Patient Zero':
A critical investigation of the concept of public and patient involvement in the National Health Service

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Abstract. *Over the last three years, there has been a major shift in healthcare policy within England. This has radically altered the relationship between General Practitioners (GPs) and patients. This article examines the role of patient and public involvement within the National Health Service (NHS) from the perspective of volunteers and health practitioners. The aim of the study is to explore how different models of patient and public involvement (PPI) are characterised through ideological perspectives which construct the goals and motivations of service users and health practitioners. This article draws on data from a small qualitative study of 16 participants analysing different narratives and experiences of patient and public involvement within the North East of England. The study analyses data from health professionals, including General Practitioners and health managers, and patient volunteers who make up part of a range of different health advisory groups in the NHS. Whilst all respondents agree about the importance of public involvement to assist localised NHS healthcare, it should be noted that what is meant by patient and public involvement in this study is somewhat unclear for people involved in the process. The research concludes by illustrating how practitioners' and volunteers' interpretations of patient and public involvement diverge in terms of their expressed motivations, aims, goals and expectations.*

Keywords: *models of patient involvement; healthcare policy; Patient & Public Involvement (PPI); NHS volunteers; service users & practitioners motivations*

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Introduction

In social care, the inclusion of service user voices in practice has become routine within adult and children's services (Rickard & Purtell, 2011; Boxall & Beresford, 2012). Similarities can be drawn between the inclusion of service user involvement in social care, and in healthcare services, which in the NHS is referred to as Patient Public Involvement (PPI). Under the last Labour Government (1997-2010), the NHS attempted to actively develop partnerships with patient and local health care services. As Platt and Staniszewska (2011) suggest, within the current health care system contemporary health outcomes cannot be achieved simply by treatment, but by the cooperation and help of the people concerned. Patient Public Involvement (PPI) is now seen as a requirement, particularly for localised healthcare, for many NHS services throughout England (Baggott, 2005; Greener, 2009). It has been proposed that the importance of patient involvement within healthcare services not only impacts on reducing discovery/recovery practices, but can be seen as a necessity owing to the growing number of people with long term conditions which require health management rather than cure within the NHS (Daykin *et al.,* 2007; Hunter *et al.,* 2010).

This article will examine different narratives concerning PPI in the NHS in relation to its effectiveness and the commitment of professionals and volunteers involved. It suggests that, although PPI is frequently referred to by the NHS, what it actually means or what its aim should be are often not clear for service users and practitioners. With this in mind, the article will examine the different ideological meanings of service user/patient involvement by comparing the narratives of GPs/ clinicians, Primary Care Trust managers and service users that have been involved in the PPI process. The article will discuss four models of service user involvement found in healthcare practice and apply them to qualitative data collected from patients in the North East who have been involved in the NHS PPI. It concludes by suggesting that the NHS needs to adopt a less tokenistic service user approach to participation in order to improve the current practice of PPI (Forbat *et al.,* 2009).

A brief history of public and patient involvement in the NHS

When the NHS was established in 1948 it incorporated a variety of institutions, all with their own forms of governance and connections with the public (Timmins, 1995; Webster, 2002; Greener, 2007). Its formation eliminated a whole range of local healthcare connections with the public, through local boards, elected councils or even voluntary groups involved in fundraising (Glasby *et al.*, 2007; Taylor-Gooby, 2012). Yet, what we now understand as the primary care aspects of the NHS (that is, maternity and child welfare, district nursing, health centres and community

health) continued to be organised by elected local councillors until the Conservative Government reforms of 1974. These services have been returned to elected local councillors following the 2010 *Equity and Excellence* White Paper. These significant reforms placed all health services under the control of Health Authorities, although welfare and social services remained with local authorities (Timmins, 1995; Greener, 2007; Taylor-Gooby, 2012).

A major change in 1974 was the establishment of Community Health Councils (CHCs), which could be seen as a move towards re-establishing public involvement. These were intended to represent the public interest and included councillors (Timmins ,1995). The CHCs were able to investigate complaints and refer them to the hospitals' complaints procedures. They were also able to investigate issues and challenge the hospital authorities, although they very rarely did so (Levitt, 1980; Baggott, 2005; Taylor-Gooby, 2012). The performance of the CHCs varied, but they continued until the 2001 Health and Social Care Act. The CHCs were replaced by Patient and Public Involvement forums and the establishment of the Commission for Patient and Public Involvement in Health (CPPIH) in January 2003.

This illustrates the second wave of major reforms that occurred in the 1990s following the NHS and Community Care Act 1990, which introduced an internal market into the NHS (Henderson & Petersen, 2001; Martin *et al.,* 2010). This, in 2002 under New Labour, led to the formation of Primary Care Trusts, which would take control of up to 80 per cent of the NHS's annual budget. The Health and Social Care Act (2001) established distinct strands for public involvement and accountability. These were the local authority Overview and Scrutiny Committees, which had considerable power and gradually developed their confidence and authority (Taylor-Gooby, 2012). This was followed by Advocacy for Patients, which was an independent Complaints and Advocacy Service (ICAS), established to give independent support to patients. In 2003, the Commission for Patient and Public Involvement (CPPIH) established Patient Forums where members of the public could scrutinise the health service and require it to report back on issues they had raised. The CPPIH was replaced in 2008 by LINks (Local Involvement Networks), which are now, under the 2010 reforms (NHS, 2010), to be strengthened to become Healthwatch.

The structure was complex, and a further strand was added in 2006 when Practice Based Commissioning was initiated. Thus there was an incentive: if Practice Based Commissioning (PBC) were to work GPs had to have evidence that they had consulted the public, particularly 'hard to reach groups', which to a certain extent was achieved through Monitoring and Advisory Boards (DoH, 2006). In 2006, *Our Health, Our Care, Our Say* set out a new direction for health and social care within England (DoH, 2006, p.7). There was a substantial section on local involvement, at the same time people were given greater choice and control over the services they used (Taylor-Gooby, 2012). In the NHS, commissioning was initially controlled by Primary Care Trusts, although the recent reforms, *Equity and Excellence 2010 and the Health and*

Social Care Act 2012, have moved the commissioning of services to GPs and other clinicians, and in effect the practice of public/patient involvement. GPs had already become involved in commissioning under the original *Our Health, Our Care, Our Say* proposals in 2006, but under the supervision of the Primary Care Trusts. As Primary Care Trusts have now been abolished, the full responsibilities of commissioning have been shifted to GPs working with other clinicians. Furthermore, the recent Health and Social Care Act (2012) has established NHS Clinical Commissioning Groups to facilitate this process. The Clinical Commissioning Groups are led by GPs and other health professionals and their aims are to organise the commissioning decisions for patients in local geographical areas. Hence, public/patient involvement is now the responsibility of GPs at a local level.

Models of patient involvement

The idea that the health service has been successful when incorporating the voices of the public has been dismissed by many patient/service user groups (Barnes and Mercer, 2003). These groups suggest that, historically, any attempt by the NHS to include patient/service user voices in healthcare improvement/commissioning has been somewhat tokenistic (Morris *et al.,* 2007). Carmichael (2004) and Barnes and Mercer (2003) illustrate this critical approach concerning the NHS's claim of successfully including patient/service user voices in healthcare services. They suggest that current attempts at patient involvement have continuously resulted in sustaining medical practice rather than representing service user desires. This is due to the unequal distribution of power in the NHS between healthcare professionals and service user/patients.

From this perspective, the idea of involvement has multiple meanings which are structured through power. Hence, service user/patients aim to improve their individual services, whereas health professionals look to reinforce their profession. It is argued that participation is underpinned by different ideological meanings, which are determined by professional and public perceptions (Greener, 2007; Forbat *et al.* ,2009). In order to achieve a successful, rather than a tokenistic, partnership between health professionals and patients all parties need to have a clear understanding of what is meant by service user involvement. Owing to the complexity and ideological nature of service user involvement a number of theoretical models have been defined to measure different understandings of involvement in healthcare.

When discussing models of participation in both healthcare and social care, the traditional measurement of participation has been defined by the classic and widely employed work of Sherry Arnstein. Arnstein (1969) constructed a system that measured degrees of power which included or excluded service users from being involved in services; this is referred to as Arnstein's 'Ladder of Citizen Participation'

(Arnstein, 1969). It has degrees of participation; the ladder shows a progression from 'non-participation' to 'tokenism' to actual 'citizen power', and has been a useful tool for identifying bureaucratic healthcare structures (Forbat *et al.,* 2009). Expanding Arnstein's measurement of participation, Forbat *et al.* (2009) have identified four contemporary models of PPI within healthcare in order to categorise contemporary ideologies which underpin participation.

Social democratic model

Forbat *et al.* (2009) define the traditional model of patient/service user participation as the 'social democratic model' (Forbat *et al.,* 2009; Greener, 2009; Vincent-Jones, 2011). This model refers to health services as a social expectation of the welfare state arising from a collective position. Service user and patient involvement is devolved through political representation. Hence, individuals use their democratic power in order to elect local and national governments which will make decisions over health and social care services. If these decisions go against local and national opinion then this will lead to a shift in public support from one party to another. This system is further enriched by political patient and service user groups which lobby local and national governments and influence the development of social policy (Needham, 2003; Forbat *et al.,* 2009). In this model, service user/patient involvement is conceptualised through the UK's democratic tradition of healthcare as a political establishment.

Free-market economy model

The next model that Forbat *et al.* (2009) identify is referred to as the 'free-market economy model'. This approach draws on the recent marketisation of the UK's health and social care institutions (Greener ,2009). This managerial structure in healthcare was cultivated under the Thatcher and Blair governments, which developed a quasi-market system within healthcare. Health services are no longer protected by the NHS and have to compete against other private and third sector services following a 'free market doctrine' (Needham, 2003; Forbat *et al.,* 2009). As service users and patients are offered multiple services the most efficient and effective services thrive, whereas the less effective services disappear. This approach incorporates the voices of patients and service users through the notion of 'customer feedback'. (Greener, 2009; Forbat *et al.,* 2009). This form of involvement is based on a market ideology where services compete for funding through a system of league tables/targets (Exworthy & Halford, 1999; Daykin, 2007).

Experiential-knowledge Model

The third approach can be defined as the 'experiential-knowledge model'. In this model, service user and patients work in partnership with GPs/clinicians to create an individualistic system of care which is tailor-made for patients (Forbat *et al.,* 2009; Platt & Staniszewska, 2011). The central ideology which underpins this model is a move away from the traditional structure of healthcare, where health professionals know best and patients are viewed as the docile recipients of services. This model draws on the experiences of individual patients in partnership with a health professional to create an individualised care plan for the patient (Guadagnoli & Ward, 1998). This approach suggests that patients and carers have a unique understanding of their social position and medical condition, which is subjective in nature and determines the type of health care/treatment to which they need access. This model allows for multiple care options, and the patient can choose the service most appropriate for them at a particular time in their lives. This model is determined through an interactionist approach to healthcare services (Forbat *et al.,* 2009).

Experiential-knowledge Model

The final model of participation has arisen out of the service user group movements of the late 20th century and is underpinned by feminist and disability rights philosophies (Forbat *et al.* ,2009). This is referred to as the 'emancipation-empowerment model' and is firmly entrenched within service user/patient discourse, where service user involvement and experiences are paramount to all health and social care services. (In social work literature this would be referred to as the social model of disability: see Oliver *et al.,* 2012). This model rejects the general opinion that the history of health services has on the whole improved the lives of service users. It implies that healthcare services often create social barriers which disempower service users through intrusive research, stigmatisation, isolation and exploitation (Barnes and Mercer 2010). The importance of service user and patient involvement is conceptualised as a human right, as only service users have the ability to determine their individual needs and identify the structural barriers which they face within their general lives (Forbat *et al.,* 2009; Oliver *et al.,* 2012).

The aim of this article is to apply these four models of participation in order to identify different ideologies, meanings, goals and motivations that underpin patient public involvement in the NHS from a service user, health professional and health manager perspective.

Methodology

A qualitative approach was used in this study to collect data on the perceptions of public/patient involvement in the North East of England healthcare services. Sixteen extended interviews were undertaken in the spring of 2010. This particular District had traditionally suffered from poor health. A range of statistics in the 1980s and 1990s indicated problems in all areas (Townsend *et al.,* 1987, 1994). This research project was completed before the proposals to abolish Primary Care Trusts and to give a major role in commissioning to GPs. These were announced in the NHS White Paper *Equity and Excellence: Liberating the NHS* in July 2010. However, these data are still significant as although GPs are acquiring the commissioning process, in this area these GPs are receiving training in patient public involvement from previous employees from the abolished Primary Care Trusts.

The data collection aimed to examine whether respondents who had been involved in PPI felt that the public voices were being represented at a senior level within the NHS. The interviews used a semi-structured approach in order to obtain specific information on participation, but also allowed respondents to expand on any points that they felt relevant to the study (Bryman, 2008; Gilbert, 2008). Data were collected from the Practice Based Commissioning Board (PBC Board), the Monitoring and Advisory Board (MAB), and a North East of England Primary Care Trust (PCT). The PBC Board was located in a district of the North East and consists of representatives from 17 GP practices in the area. The PBC Board meets monthly. The MAB consists of representatives of GP Practice Forums where these exist, and representatives from community stakeholders (voluntary bodies and local government). The concept is that ideas feed into the MAB from the GP patients and the wider community so as effectively to advise the PBC Board. The MAB also meets monthly and advises the PBC Board. Once a year a conference on commissioning guidelines is held, attended by GPs, hospital consultants and volunteers drawn from the MAB and the PBC Board.

To gain an overall idea of the views of the different groups of participants, the interviewees were selected as follows. Five were professional members of the PBC Board (two GPs, two practice managers and one practice nurse); one was from the Primary Care Trust (a senior manager); ten were volunteers of the MAB (including five volunteers of GP Practice Forums). The latter two categories tended to be older people and people involved in a range of community activities. The interviews considered the perceptions of those involved with the MAB and PBC Boards as to how far PPI influenced commissioning in the NHS. The study aimed to ascertain the perceptions of those involved regarding what people feel they are achieving through involvement and how effective it is. Ethical approval was obtained from the North East NHS Ethical Committee before interviewing began.

Involvement and service improvement

The Government report *Real Involvement* (NHS 2008) states that the aim of 'involvement' should be 'focused on improvement'. Within the narratives of the MAB volunteers, there was a feeling that many of the patient public involvement schemes progressed quickly at first then lost pace. It was suggested that, owing to a lack of resources, the MAB had gone over the same ground more than once, and needed to move forward to have any impact on healthcare services. The issue of the PBC Board and the MAB having more resources was mentioned by two respondents. The MAB Chair of the local Health Forum implies:

> *Abolishing the local Health Forums, which could actually do something in the community, was a retrograde step. The NHS invites comments from people, but is better at telling people what it is going to do than listening to them.* (MAB volunteer)

MAB volunteers also commented on how far they felt their involvement influenced and improved the wider NHS services outside their own practice and area. The general feeling was that people were much happier influencing their own surgery and practice, where they could see concrete results. One MAB volunteer expressed views which others also held:

> *The wider NHS organisation is told about what is going on at the grass roots, but does not seem to take much notice. It is much easier to involve people with their GP. Like, putting up screens to tell people when their appointments are so that hearing impaired people do not miss them.* (MAB volunteer

The PBC Board practitioners noted that the formal mechanism for involvement was the Primary Care Trust, but this did not always seem to work very well. Two PBC Board members seemed to indicate that the NHS's practice was grounded in traditional bureaucracy, rather than the more devolved structures identified by recent governments under the heading of managerialism. Hence, the NHS wants participation and involvement, but seeks to impose it from the centre rather than let it evolve locally. One MAB volunteer suggested:

> *One has to get the Primary Care Trust to agree to a proposal. It is very bureaucratic – too many layers. There is also a lack of clear answers. In a perfect world information would go up to the Primary Care Trust to influence their decisions. The Primary Care Trust often appears to think it knows best.* (MAB volunteer)

Two MAB volunteers stressed the importance of better feedback from the NHS in order to inform them that their hard work was paying off, whereas a number of MAB volunteers felt that it was necessary to have a 'success story' to show that

involvement in commissioning worked, thereby convincing the wider NHS of its worth. In line with these comments from MAB volunteers, PBC Board Practitioners suggested that there needed to be increased evidence of service improvement in order to improve future resources:

> *The Primary Care Trust needs evidence [including that there has been* public/patient involvement] *together with proof of outcomes. If the PBC can do this, the Primary Care Trust will take notice.* (PBC Board Practitioner)

Overall, there was a feeling that the system could work, but needed improving. What was needed was better liaison between the PBC Board and the MAB, and properly informed work so that a proposal was more likely to be accepted by the Primary Care Trust. Then there would be clear evidence that the PPI process worked.

Motivations for involvement

In this study, all members of the MAB expressed a strong belief in involvement. Their motivations were all similar as they wanted to improve health services in their area and they felt health initiatives had generally come from medical practice. MAB respondents generally held a strong belief that the patient had a unique insight into his/her particular situation. These respondents suggested that, although clinicians might know something about the symptoms and nature of the disease or condition they were experiencing, only they knew what it was really like to experience it and what their needs were:

> *I do not like leaving everything to the professionals – they can make mistakes. You know more about your own disease and particular situation. Although the doctor may know about clinical symptoms – the patient is a person not an object.* (MAB volunteer)

From a service user/patient perspective, the narratives reveal that the reason participants became involved with the MAB was to influence the type of care they received by the NHS. In this study the analysis seems to indicate that service users conceptualised patient public involvement either through the notion of developing an equal partnership between patients and healthcare professionals (an experiential-knowledge approach) or through a general focus on removing barriers to NHS services (an emancipation-empowerment approach). Service users felt they had a role to play within healthcare provision and wanted to take control over local healthcare services within the North East of England. One MAB volunteer's narrative stated 'I do not like leaving everything to the professionals', hence implying that including

service users' voices in healthcare provision would provide a more efficient and beneficial service for patients.

The reasons given by the professional members of the PBC Board were slightly different, but related to the same point. They certainly felt it made their job easier, and enabled them to be more effective. Furthermore, the PBC Board members wanted more power locally. There was also a desire to find out if treatment was working properly, and to obtain feedback from patients and the public:

> *If you do not do it [involvement], it makes things harder, more expensive and less efficient. … I feel that GPs should be involved in the commissioning cycle, and the first part of that is engaging with patients.* (PBC Board Practitioner)

There was certainly an ambition and enthusiasm to take on the organisation of things locally. This was in line with the ideas coming from the Department of Health 2010 GP commissioning approach, although patient involvement was discussed in terms of 'customer feedback'. It became clear from the practitioners' narratives that Patient Public Involvement was more about making efficient, cost-effective services which could compete rather than an equal partnership between professionals and service users. From a practitioner's perspective, PPI seems to be underpinned by the free-market economy model. A significant problem for all interviewees was that at present GP surgeries do not have the resources for innovation.

However, one GP did refer to patient public involvement through the experiential-knowledge model. This GP was keen to point out improvements that had happened when resources had been available to the surgery:

> *I helped identify patients to become members of the [GP] Practice Forum, and set up support groups for Diabetes and COPD. I also promoted the Expert Patient Programme and set up a CHD Group – which a patient now chairs. Patients with long-term conditions need to work in partnership with the health professionals in the NHS.* (PBC Board Practitioner)

Although this narrative is not representative of the other health professionals', it shows that some GPs are willing to adopt an Experiential-knowledge Model to create a relatively 'equal' partnership between health professionals and patients. Furthermore, this GP's narrative suggests that the partnership approach is extremely effective in the treatment/management of long-term health conditions.

The Role of involvement in NHS services

In this study, examples of practical involvement were discussed: both what had actually happened and what respondents thought was possible. In particular, the

study aimed to discover whether involvement was a necessary part of the effective devolution of power creating partnerships between locally based organisations and service users. All the respondents thought that the experience of patients was important, and that an important function of involvement was to relay this information to the professionals. Patients could also support each other:

The expert patient programme is very important. You learn to manage your own illness. You have to take a positive view, think about what you can do rather than what you cannot. I encouraged someone else who was complaining about his situation by pointing out that I was worse than him, but I managed to do things. (MAB volunteer)

In this narrative, the partnership between the volunteer and her healthcare professionals developed beyond her own individual care and led to her reframing her own impairment through positive management strategies: 'You have to take a positive view.' As she illustrates in applying an experiential-knowledge approach, she became confident in sharing management strategies with other people in her local surgery. Within this narrative, she conceptualised the role of involvement through the notion of partnership work.

Again, examining the narratives of health professionals reveals that they conceptualised the role of involvement through the notion of support for their professional medical role. Hence, members of the PBC Board perceived patient public involvement as enabling them to do their job better. Furthermore, we can see the discourse of 'consumer feedback' emerging throughout the narratives of the healthcare professionals:

It [involvement] should look at proposed plans, to consider whether they will work from the patient point of view. … People rarely say 'Take this away', but they do say that things can be improved. Information about services which could be 'pushed out' into the wider community. Involvement is an information resource for the NHS. It tells us where people are and what their situation is. (PBC Board Practitioner)

Several people (from both groups) used the phrase 'what works and what doesn't', or words to that effect. There was a strong view from some members of the MAB that a function of involvement was to scrutinise and probe the NHS. Taking forward the idea that the MAB should scrutinise and probe, nearly all the members interviewed had the idea that it should also be a pressure group or lobby, pressing for improvements or new facilities. For example, the MAB had helped lobby for the '*North East* Hospital Link', a bus service to local hospitals. In other words, the process of encouraging volunteer involvement establishes a network, which hopefully feeds into the MAB, indicating what health facilities people both want and need. This information can be fed back into the PBC Board, which will carry it forward:

The process gives patients a stronger voice to speak to consultants and other professionals. … The process of mobilising the public into getting involved is critical. Schemes such as befriending and using volunteers to install fire alarms do this. The volunteers should do additional things to professionals – not replace them. … Volunteers listen to public opinion. (MAB volunteer)

This narrative reveals a greater political voice in relation to the improvement of services within local communities. It is clear within this narrative that the role of patient public involvement is to improve services and add extra value to the existing healthcare structure. This narrative indicates a more emancipation-empowerment-oriented approach to partnership within healthcare. Yet no service user thought that it was the role of the MAB to make decisions for health professionals. One MAB member summed this up as follows: 'It [the MAB] should not be telling GPs and other professionals what to do. They have the expertise.' However, this was in relation to their clinical roles: what participants wanted to influence was overcoming barriers in relation to access to transport and an increase in services for particular long-term conditions.

Involvement had a further dimension when volunteers were in a position to control or influence resources. Thus the MAB volunteer who chaired the Health Forum, which had a small budget devolved from the Primary Care Trust, described the various projects they had undertaken, which ranged from an initiative to install low-level lighting to reduce the risk of falls, to outdoor education for young people, friendship clubs for the lonely, and a campaign to encourage older people to have their flu jab. This enthusiasm for being able to control resources, which meant that they could actually see some of the results of their efforts, was shared by members of the PBC Board:

These small projects can save the NHS money. Lights will prevent falls, and hip replacements. Community organisations can prevent loneliness and depression. Many organisations promote physical fitness. Funding is also spent within the local community. There is less community involvement now with a larger council and Primary Care Trust. (PBC Board Practitioner)

Overall, the view was that involvement improves services by adding the unique viewpoint of the patient. It is also a form of constructive scrutiny, which also leads to improvement. Many respondents, however, felt that their involvement would be more effective if they had some handle on resources to ensure ideas were carried through. Some members of the PBC Board gave examples of health promotion schemes which had worked because the public had been involved, either helping deliver them or promoting them in the community. One GP gave this example

The 'Get Active' scheme has been promoted through public involvement. A weight management scheme was very successful, but funding was limited. When the Primary Care Trust was more locally based it was far easier for the public to be involved. (PBC Board Practitioner)

The MAB volunteer who was Chair of the Health Forum, which had (until recently) access to funding, was proud to list the projects his group had promoted. Projects needed financial help (although most also raised resources themselves), but none could have functioned without volunteers – for example, to carry out the survey of older people's properties. Another success for involvement related to consultations for new local health schemes, such as health centres or GP surgery improvements. The respondents thought this led to improvement in service design. They noted, however, that this successful involvement did not always extend to the wider NHS organisation:

The requests of the GP Practice Forum have improved the telephone system for patients. There are now out of hours and Saturday morning appointments. Overall the system works well, but does not seem to influence the wider NHS. (MAB volunteer)

These narratives seem to be clustered around ideas about what constitutes successful involvement. Yet there seemed to be frustrations, and difficulties, with funding and with liaison with the Primary Care Trust, which seemed to reveal a hint of uncertainty about participation. These frustrations that volunteers expressed about the Trusts being a hierarchical system are illustrated in the narratives of the Primary Care Trust managers. In the narrative below, the Primary Care Trust manager's interpretation of PPI is very different from that of the PCB and MAB respondents in this study:

There are various different forms of involvement in the NHS, both at the local GP level and also on a County-wide basis through the Primary Care Trust and LINks. I think we have to be clear about what PPI should be doing. We (the Primary Care Trust) want to get clear and accurate information about how well services are performing and how they could be improved. This involves survey work, and volunteers can be involved here provided they are properly trained. (Primary Care Trust Manager)

The data analysis reveals that three conflicting goals appeared in the narratives of the PBC practitioners, Primary Care Trust managers and MAB volunteers. The Primary Care Trust managers apply a more traditional Social Democratic Model to PPI, as power over decision-making regarding services would not be given over to service user groups. From the PBC practitioners' viewpoint, patient and public involvement is a mechanism for ensuring quality control, and the whole process of 'patient support' is managed by health professionals (the Free-market Economy Model). This is rather different from MAB volunteers, underpinned either by the Experiential-Knowledge Model or by the Emancipation-empowerment Model, since from this perspective volunteers felt strongly that they should have an influence over local NHS decision-making and services.

Conclusion

Comparable to social care services, there are a large number of mechanisms in the NHS whose aim is to involve people. The discourse of Patient Public Involvement in this study is constructed by three different groups: NHS Primary Care Trust managers, GPs and their clinicians, and service users. Yet it becomes clear from the data analysis that each group attaches different meanings to the discourse of Patient Public Involvement. When applying Forbat *et al.*'s (2009) model-based approach to interpreting different forms of participation, it is clear that all four models are in operation simultaneously.

When service users refer to Patient Public Involvement, they clearly conceptualise involvement through the ideologies of the experiential-knowledge or the emancipation-empowerment model, whereas GPs and clinicians who worked within the local areas were clearly influenced by the free-market economy model (Forbat *et al.,* 2009). Service users conceptualised participation as a partnership to improve individual and community health services. GPs viewed this relationship as improving their 'customer care' and the efficiency and competitiveness of their services. Surprisingly, we also see aspects of the traditional social democratic model appearing with reference to the Primary Care Trust managers. From this perspective, participation is purely a research-based requirement which allows them to collect evidence for effective treatments in the NHS.

At the point when this research was conducted it was the Primary Care Trusts that had total control of local funding for healthcare services within the North East of England. Since this research was completed, the Government has handed over commissioning to 'clusters' of GPs and abolished Primary Care Trusts (White Paper, 2010). Although we saw evidence of the social democratic model within this research, we can make an assumption that as Primary Care Trusts are being replaced with GP commissioning, the dominant ideology controlling funding might be replaced by the free-market economy ideology preferred by the GPs. Applying this model means that involvement becomes a system aimed at gathering customer feedback on services. From a professional point of view, if what is required is evidence of the effectiveness of treatment then survey methods can be established, and these could involve volunteers. Local authorities can provide scrutiny, particularly when services are reconfigured. For a further discussion of how local authorities can be involved see Taylor-Gooby (2012).

Yet from a service user perspective, the role of the MAB and practice based commissioning seems to be more than this. The service user narratives in this study suggest that if PPI worked effectively it would mobilise local people, patients and voluntary organisations to work in partnership with GPs and other health professionals locally. Hence, in delivering an improved localised NHS the emphasis would be on promoting better health and preventing illness through partnership work. Health professionals provide the expertise necessary, but local people and

organisations can publicise the schemes and involve the people who need to be reached.

It is clear from the fieldwork that the GPs and service users wish to organise more services locally. This research shows that people are keen to exert an influence over how NHS resources are spent locally, and to be involved in campaigns to improve health. Having such an influence encourages and mobilises volunteers. It is too early to draw any conclusions as to whether the new NHS reforms will encourage this process. However, it is clear that health professionals, through a 'free market ideology', are still trying to hold on to their power through a hierarchical system of healthcare. As this study illustrates, although the discourse of PPI is widely used within healthcare and political circles, the ideologies which underpin it have multiple meanings for the different groups who have been involved in the practice of it.

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