Moving from tokenism to co-production: implications of learning from patient and community voices in developing patient centred professionalism

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Abstract:

Professional practice in healthcare is under increasing challenge from changes in society and modes of care delivery. It is widely held that deep cultural shifts, both individual and systemic, are required to transform relationships in healthcare towards co-production to improve outcomes in health. The movement to involve the public in health professional learning in education and service development to help make these shifts, is now mandated in the UK but what this means in practice is only beginning to be understood. In both the UK and US, our long term programmes of public involvement have found that both professionals and patients can benefit and practice can change, but how and why it works or not, is not yet fully articulated.

We have argued that the deficit model of the patient and the wider community remains a significant barrier to learning patient-centred professionalism as espoused by professional leaders. The dominant research paradigm in medicine, privileging reductive over experiential evidence and ignoring power relations and context, is not adequate for understanding the value, processes, meaning and impact of the contribution of patient and community voices to the development of professional practice. This paper reports an interdisciplinary and multi-professional approach to developing a practice-based understanding of the impact and outcomes of patient and community involvement – based on shared participatory processes across our programmes – that recognises community capacity and builds this voice in healthcare. The project aims to strengthen the connection between theory and practice towards the development of collaborative research.

All participants engage in a spiral of reflection to explore their own experiences during this mutual enquiry. Examples of patient, community and professional experience in learning together are explored and analysed from diverse social and learning perspectives, with patient and community voices at the heart, to gain understanding of the effects of public participation in the emergence of new ways of thinking about professionalism. Resistance to real and effective participation and a tendency to manipulate participation for professional ends, rather than pursue co-production, will be examined. Modes of involving the public in the design and implementation of their roles in professional education are compared. Implications for future conceptualising within the field and current practice are drawn.

Introduction and background

"I'm the doctor. You're the patient. It's not your job to cure them, it's mine."
"Doctor, patient…a curious, human distinction."

– Prot, visitor from the advanced planet K-PAX, alias Robert Porter, psychiatric inpatient, talks with his psychiatrist in the film K-PAX (USA, 2001). Prot has intervened in his fellow inmates' prescriptions for recovery.

New roles and relationships for professionals and patients are nascent in 21st century healthcare, in the light of changes in public and professional understanding and attitudes, evidence about the need for working in partnership with patients (with long-term conditions in particular), and pressures of cost containment. The contributors to this paper – and to the research project for which this is a background briefing – have been developing models for understanding and working with health in the UK and US, over decades. We have worked in learning for community health and professional development, in separate sites with occasional links, attempting to bridge the gap between those seeking health and practitioners in health and social care. We are part of current international enquiries into the 'Patient Voice[1]' in professional learning and have come together in this context to examine what happens in this work – in terms of learning and change – and how our own long-term programmes of public participation in learning can bring benefit.

Outline

This paper outlines the shared values, approaches and participatory processes in our different programmes and elucidates the research framework we are developing, with patient and community voices, through our varied disciplinary and practice perspectives. We then apply aspects of this framework to examples of patients and community members learning and teaching with practising or student professionals. We identify key research questions and useful theoretical frameworks.

The models in use of the participating researchers: practice and theory

Penny Morris came to Leeds School of Medicine to lead communication skills learning, after conducting a series of experiments in medical education in the UK and the US. With *Ernie Dalton,* she has developed simulated patient training to include the patient voice and expand this influence. *Andrea Armitage* came from a patient advocate background to develop the patient perspective in the curriculum*, Jools Symons* came from carer advocacy to develop and support patient and carer voices*, Rob Lane* brought his experience of communication learning in palliative care to develop clinical teaching and *Fiona O'Neill* brings a background in nursing, practice development and policy research to the team's work in patient and community voices in professional learning.

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[1] By 'Patient Voices' we mean the active contribution into professional learning of patients, carers and the community. The term 'patient' is used here as shorthand also for other terms used in different settings: client, consumer, service user, survivor, lay. This is contested in debates about the meaning of these and more independent and equitable terms such as citizen, community, stakeholder and public.

This work is based in a consistent learning model. Its origins were in community activism through the arts and when this practice was brought into medical student learning (Whitehouse et al, 1984) and analysed, it was most closely linked to learning and psychoanalytical theories applied in community and family development and medicine (Freire,1972; Balint, 1957; Bowlby, 1969). Together, they emphasise a focus on capacity, rather than deficit; self-awareness; and safe structures for learning and creative change.

One study was a controlled trial with a cohort of medical students and their clinical teachers learning communication skills (Morris, 1992), followed by a development project to embed personal and professional development in medical student learning (Morris et al, 1998). Methods used included group observation, experience and reflection and the notion of 'patients as teachers', through simulated patients bringing an independent patient perspective

The conceptual model behind the interventions came largely from the influential study 'Meetings Between Experts', an analysis of GP consultations in London, which argued that a major aim of medical consultations should be to ensure a sharing of ideas between doctors and patients and that for this to happen more effectively the patient as well as the doctor must be clearly conceived as an expert in his/her own health care (Tuckett et al, 1984). These and similar interventions helped spearhead changes in medical education towards more person and patient-focused elements.

An action learning study with GPs was undertaken by members of a research group of GP Educators, to examine how GPs could improve consultations they found difficult by reviewing each others' consultations on video (Morris et al, 2001). The research group was strongly influenced by autobiographical and reflexive approaches (West, 2001). GP Educators involved in this group contributed to the medical student learning programme.

An increasing focus of the developing pedagogic understanding of these programmes was on how to ensure an effective learning 'crucible', where change and personal shifts in understanding and behaviour could occur. An important emphasis has also been on testing educational development in the context of daily practice, i.e., learning processes for students are undertaken by their clinical teachers for their own learning and as a model of self-reflection. A key finding was that doubting patients' capacity to contribute to their own care and discounting their expertise was behind doctors' lack of listening.

More recently, the model has been extended at Leeds School of Medicine, in the context of society and policy changes around the role of patients and the public in health. A series of projects around the 'patient voice' have widened the team of simulated patients to include a more diverse group, extending their role and arena (Morris et al, 2004; O'Neill et al, 2006). Knowledge Transfer activities have broadened the contribution of patients, carers and communities to local health service improvements, and developed an induction programme for members of patient and carer groups to bring their expertise to health professional learning – the 'Patient Learning Journey'. Capacity building projects with other Universities continue to broaden the focus beyond the silo of medicine.

This later work has made further connections to theories of community development, planning, complexity and narrative that highlight the value of participatory processes with the patient at the centre of learning and practice (Morris and O'Neill, 2006).

Jackie Reed directs the Westside Health Authority, an African-American community organisation in Austen, Chicago, Illinois. A community activist, then social worker, then community development worker, she was inspired to bring together local groups working in health to form a 'community table' to which health providers and policy makers come to discuss and collaborate, rather than the community becoming involved in outsider, institution-led initiatives. The community organisation does its own work in 'finding ways to utilize the gifts and capacities of the discarded, discounted person' to 'encourage each other as we try on the new role of *gift-giver* rather than *client'* and believes 'the community's strength lies in using the capacity of people who are often perceived as victims'.

Community activist researchers (McKnight, 2003), influenced by notions of harm provoked by professional power (Illych,1972), identified capacity versus deficit frameworks for understanding the role of the community in health in the widest sense – counting assets, not gaps. Community-based participatory research at the Authority investigates and builds on people's gifts and relationships (Kretzmann and McKnight, 1993; www.health.authority.org).

Health communication researchers (Arntson, 1999) have helpfully outlined differences between notions of client, consumer and citizen. Participatory action research compared the Westside citizen voice to the consumer notion becoming more widespread in the UK (Morris, 1992a). This led to joint UK/US projects: 'Patient Teachers' were introduced in work with elders and youth, to develop community relationships and talents, and to support local doctors and medical students to understand and collaborate with their perspective (Morris et al, 2005). The 'Every Block a Village' programme of neighbourhood building has since grown 40+ Citizen Leaders who have trained over 400 Cook County Hospital physicians.

Arlene Katz is a teacher and researcher at Harvard Medical School Department of Social Medicine and the Cambridge Health Alliance. She collaborated with community elders and professionals to develop a unique program to address ageism by creating a Council of Elders to help teach residents and nurse practitioners about the lived experience of aging (Katz et al, 2000). This was a continuation of a series of community based, participatory, ethnographic research projects inviting the 'voice' of patients and community in the development of 'resourceful communities' of those involved in clinical practice, training and care, in part to address issues of inequality and access to care, and to increase a sense of answerability to our communities.

Her work has emphasized the importance of hearing the 'voice' of the patient and the community in care, training and research. Reports of these studies include papers on a "social poetics" approach to the understanding and elaboration of diagnostic practices in primary care medicine as well as in the process of mentorship (Katz and Shotter, 1996; Shotter and Katz, 1996; Katz et al, 1996). She has led ethnographic studies of the changing face of healthcare (Katz, 1998) the experience of research ethics in a Children's hospital (Katz and Fox, 2004) and recently, a participatory ethnographic project focused on hearing authentic voices in infant mortality and pregnancy (Katz and Fox, in press). The methods of engagement of the Council have been carried over and tailored to other settings and other populations. At the Cambridge Health Alliance, medical residents who were part of the Council project are now collaborating with patients and community members on the development of a multi-cultural, multi-immigrant council.

Meg Gaines, Professor of Law at the University of Wisconsin, established the Center for Patient Partnerships after her experience of surviving cancer. The Center helps individuals and families facing life-threatening and serious chronic illnesses, get the care they need, make informed decisions and address issues related to serious health conditions. Through its advocacy programme, patients become more effective self-advocates. These services are provided through an interdisciplinary graduate course for student doctors, lawyers, nurses, pharmacists, health policy experts, social workers and health systems engineers, supervised by experienced patient advocates. Students learn the skills they need to advocate for individual patients and for health system transformation.

The Centre also promotes 'consumer-centered' research, education and policy initiatives (www.patientpartnerships.org.) It collaborates closely with Masters' programmes for Health Advocates at Sarah Lawrence College in New York (www.sarahlawrence.edu/health_advocacy) where 'Students are challenged to find their own voice as health advocates and to acquire essential knowledge about themselves, by engaging in self-reflection and becoming more comfortable with ambiguity, uncertainty and multiple perspectives.' (Peterson, 2006).

Models in use: commonalities

These models embody emancipatory values. They all require collaboration with patients and community members as subjects with voices, not objects. They all share a focus on personal understanding and development of self. The researchers are also practitioners in the work we are investigating. We have reflected on our roles as professionals and as patients and, to a greater or lesser extent, citizens.

Later, we will explore further understandings that have arisen through seeking to establish this research project.

Patients' views in the development of professionalism

The contested complexities in the phrase 'patient-centred professionalism' have been well explored elsewhere (Askham and Chisholm, 2006, Collins et al, 2007). As the phrase is in daily use in our institutions, or the institutions we relate to, it is the forum in which we discuss our interventions. A recent conference aimed to gather momentum for patient-centred professionalism (Picker Institute, 2007). Patient-centred standards to drive care have been developed by medical opinion leaders, in consultation with patient groups and researchers, for both the UK and US: 'Good Medical Practice'. This offers one framework for the patient voice; however, in the patient-centred model, the patient is still a recipient and the location of health and healing is being re-conceptualised.

'Patients as teachers' are recommended for developing partnership in medical education (Hasman et al, 2006). At Leeds, this means bringing in to clinical skill and professional development the service user, carer and community perspective, voiced through patients, carers and other community members and not mediated by others. Specifically, in the communication theme of the Leeds medical curriculum, this is about ensuring a patient and carer perspective in preparing learners to work in partnership while making decisions.

Reports and analyses are growing of the role of the 'patient voice' in professional learning internationally, covering health and social care education and practice. ('Patient Voice', Conferences, 2005, 2006, 2007).

It is apparent that, in the UK, patient and public involvement has a concerted rhetoric and practice, due to State policy for the NHS and also the influence of service user movements in mental health care and disability. Involvement is mandated for NHS services and in social care education, but what this means in practice is only beginning to be understood. Lack of clarity about the different, and sometimes conflicting, agendas under the broad umbrella of involvement can cause well-meaning initiatives to fail. Contributors to this paper are part of the steering of these meetings and a research agenda is being established. We hope our collaboration, bringing in a wider view from broader stakeholders, practitioners and thinkers – whose starting point for study and action is not professional education nor service delivery, but rather health and healing itself – will help illuminate why patients' perceptions have not managed to change professional practice as much as desired.

The research design and developing framework

'Despite…..mushrooming of sociological, psychological, communication and reflective practice modules in medical training, emotional learning and critical perspectives, including struggles for self-knowledge, remain firmly on the edge.'

– Sinclair, 1997

We have identified the following base for our further research design and framework:

In order for the 'messy world' and reality (Launer, 2002) of patients and present-day practice to count for change in professionalism and health, different epistemological frameworks need to be acknowledged. Knowing through our encounters (experiential knowledge), knowing how to do something (practical knowledge), knowing how we know (propositional knowing), are usefully explored in an analysis of the potential of focus groups in action research (Chiu, 2003). This identifies how a new consciousness can be shaped by the interplay of how we know with what we have learned. This reinforces the value of participation by patient and community understandings in research (as independent patient voices and as part of the identified contribution of professionals, i.e., the use of self) – the missing expertise.

The emancipatory tradition of the models in use by those contributing to this paper demands 'a reflexive learning space…..in which emotional insight develops alongside critical and social awareness' (West, 2006). This will mean moving between personal reflection and the wider context in the analysis of data.

Story telling (Lambert, 2006) in a careful process can apply in this critical space, as part of Patient Learning Journey work. Creating their own digital stories – defining and expressing the essence of their own story (Hardy, 2007) – can also consolidate experiential knowing for patients, thus deepening their contribution. It also brings feelings to action, as opposed to sentimentalism or voyeurism.

The involvement of patients and practitioners in multiple layers of reflection enables them to critically reflect on their own narratives. Processes such as simulated patient encounters (Morris, 2006) and collaborative Council meetings enable reflection on practice in both contexts.

The contribution of patient expertise by experience: examples

This section illustrates some endeavours to involve people in professional education. Here, there are implications that go beyond professional learning, as benefits have accrued for patients and carers themselves, raising questions about the role of faculties of health in 21st century universities.

Patient Learning Journey groups

'*We've kept it hidden, not realising its value'*.
– Patient Learning Journey group member, West Yorkshire, UK

Recognising that the patient voice in teaching can provide a model of patient expertise, research and development began into further understanding and bringing forth that expertise. The Expert Patient programme had adapted a US programme of self help groups (Holman and Lorig, 2000) for those with long-term conditions for the UK. A group of local Expert Patients, mainly with arthritis, helped the Leeds team to develop an approach for enabling and supporting people to become involved with medical education. Through reflection and sharing experiences, the group discovered that many patient training approaches did not recognise the importance of listening to and building on the experiences of patients. By starting with the personal experiences of patients and only then moving on to consider how this insight and knowledge could become part of professional learning, barriers to an authentic expression of patient expertise could be overcome. Patients applied their growing self-awareness to develop understanding of the needs of learners, and ways that providers and patients could work together differently.

The approach has been further developed with other service users and carers and extended to include a focus on service development and wider health professional education. Throughout is a sense of mutual learning, rather than training. A 'holding' structure is given for the exploration of difficult experiences and their meaning, and participants can co-lead future groups, in a cascade of capacity building: '*….we make a safe space and encourage people to see their own strengths and use these to address problems and find solutions*' (Morris and O'Neill, 2006)

Interim evaluations through focus groups and wider, reflective meetings point to the transformative potential of involving patients and carers in journeys of mutual learning and discovery. As with other programmes of involvement and 'giving back', participants who have gone on to teach report greater self-efficacy, improved relationships with professionals and increased well-being. They attribute this to being valued and having a chance to make a difference in the world. They describe a journey of personal development, including increased employability.

What happens in the groups, and why, is being analysed by participants and facilitators (who also share their own experiences). For many, it was a first opportunity for telling aspects of their story, and daunting, though, in the end, welcome:

'In the end it was a secure, confidential environment for people to share their stories and experiences. Not one was the same, but there are threads…Where else can I talk like this? I don't want to bore my family and professionals haven't the time…'

– Carer and lead group facilitator

A particular theme is the sense of moving on, through shared understanding:

'*It was a revelation. I discovered all these things in common with other people. I'd felt anxious, depressed, but had put on a brave face. I could say – yes, I'm suffering,…(it was) a privilege to have a chance to get all that emotion out, share with other people, learn something about myself... People get to see themselves differently and others see them differently'.*

– Expert Patient, member of original group

Then, an empowered position from which to contribute is created:

'I've been wheeled out as a token user…. (Then) I'm pushed back out the door and the meeting goes on - the message there is how tragic, sad, poor old thing – there's no learning from it. ……In this work, you feel you have a priority and a place, rather than being wheeled out as a token. You can share what you understand, translate it for them, fill a gap.'

– Patient and wheelchair-user, member of Trust service development learning group

There is a sense of the group work being a learning resource for these participants, who in turn, by mining their own experience, become a more effective learning resource for others. There is growing evidence that bringing forth this expertise as a model for learners is helpful (Dalton and Morris, 2004).

Another model places the expertise of patients and community members together in the same round with senior clinical teachers:

The Council of Elders

> "*Have the young doctors come to one of our meetings… they could look us over, and they would see that we have something to say.*"
>
> – Council of Elders member, Cambridge, Ma., USA

In an era of medical delivery systems, it is unusual for health care professionals and trainees to be able to have a closely engaged dialogue with a group of elders for whom they care. It is even more unusual for each to express their own worries and concerns to the other, and for community elders to offer teachings from their own lived experience and wisdom.

The "Council of Elders" is a collaboration between professionals and community elders at the Cambridge Health Alliance, during which community elders were invited to function as a "Senior Faculty" to whom medical residents were encouraged to present the most challenging clinical and moral dilemmas they were encountering while caring for their elderly patients. In the ensuing conversations, the community elders – two of whom were over a hundred years old – come to function not merely as teachers, but as collaborators in a process by which the doctors, researchers, and elders together created a community of resources, making visible ways to overcome difficulties that had not been apparent to either group separately. These meetings had a special nature, involving the careful preparation that is necessary in order to build a dialogic relationship between participants from different worlds, different generations, and different cultures – in this case, the professional culture and the world of lived experience.

These Council meetings created the opportunity for a special kind of "open dialog" in which moral dilemmas could be presented, discussed, and reflected upon. This project also helped the trainees to reflect on their own words in such a way that the elders could engage and respond to them. Not only did the elders give good advice – frequently – but they also provided an orientation for young medical residents to gain a better sense of the elders' lived experience, of what mattered most to them in their local moral world.

All ill people are to some extent "experts" on how to live with their illnesses, because they can draw upon resources from within their own lived experiences that are unavailable to others. The Council of Elders project has been particularly effective in addressing the problem of ageism – it provides a way to render visible the many stereotypes and adverse values that are prevalent in the world of conventional medicine – allowing decisions to be made *with* the patient, not *for* the patient. This model is not restricted to elders and their providers: many aspects of health care would benefit from the creation of a forum in which disparate groups could be encouraged to meet together to sharing those resources that are unique to their own particular worlds. For instance, at Cambridge Health Alliance, several medical residents who were part of the Council of Elders project are now collaborating with patients and community members to develop a multi-cultural, multi-immigrant council.

Conclusions: issues arising, key questions, research plans

Capacity and deficit: how power works for and with vulnerability

'Blessed are the cracked
For they let in the light'

Gathered Images: Cracked (F)

What is shared in our approaches is an emphasis on working first with, and building on, what people can and do. When applied to patient care, this is in line with exhortations for self-care and political, economic imperatives to contain costs. Pain can be denied and patients abandoned. Discussions during the research project have helped us maintain awareness of how vulnerability interacts with notions of responsibility and power. One of the tasks for the research group will be to discuss examples from our practice in order to ask key questions, and find answers, for this growing area of debate (Collins et al, 2007).

Relationships

'Relationship-centred care' (Roter, 2000) is becoming a favoured model in US and UK practice. It describes the ideal physician- patient relationship as medically functional, informative, facilitative, responsive and participatory. It is becoming more apparent that wider relationships are highly significant, not only beyond medicine to the wider team, but also beyond professionals, and need to be taken into account in the development of a new professionalism. We shall be looking at this context while exploring with patients as teachers what is needed in the patient/professional relationship.

Language

We try to write in a common language, both in the sense of being careful to unpick and re-define what we mean, so that we can attempt shared understanding across our different perspectives and contexts, and also in the 'plain English' sense. This is because we purposefully involve a range of patient, community and practitioner voices and hope to speak to a wide audience. But words mean different things to different people.

In debates about the acceptability of notions of 'using' patients, the key determinant of causing offence is who is doing the using. Westside Health Authority publicity talks of 'utilizing' people's gifts. Accountability of the Authority to its community will help ensure this is not a plundering, as some public involvement has been experienced – as one Patient Learning Journey group member said: *'I wondered: are they going to use us and dump us?'*

Origins and Structures

Where the different programmes originate and sit in relation to community and universities is very important. The Westside Health Authority and Council of Elders relate to professional learners on their own ground. The Center for Patient Partnerships serves its local community directly. The Leeds work serves the University mission to engage with the local community, but structures for involvement so far support the notion of the community as a laboratory for University endeavours, rather than of a learning partnership.

Research plans

Examining resistance to validating and privileging different forms of knowledge and expertise in these different contexts is beyond the scope of this paper but is a necessary part of the study. We also plan to:

- unpick how notions of expertise and knowledge, coupled with deficit and capacity models, apply when professionals and patients learn and work together
- report how examining our experiences and their wider context from different perspectives – professional (practitioner, educator or academic), patient and community – illuminates our understanding of health, ill-health and healing and related professional practice
- look at how power relations, institutional and learning structures, role understanding and lived experience affect the way people voice their ideas in this work, the communication between them and their learning
- compare modes of participation and their effects on learning, knowledge and practice for both professionals and patients.

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