'Putting Patients First': what do we really mean?

Executive summary of research into the language of the 'patient agenda'.
Gill Ereaut and Dr Rebecca Whiting, Linguistic Landscapes, January 2013.

Why did we do this work?

The starting point for this project was language. It's often recognised that the 'patient agenda' contains many terms and phrases - *putting patients first; person-centred care; shared decision making; 'no decision about me without me'; patient involvement; patient participation; patient engagement; patient experience* – and more. People may use individual terms to mean something specific, but this meaning is not always clear; others use several terms interchangeably. So, the *NHS Institute* and *National Voices* asked us to help them consider these questions:

- What is going on here? Does woolly language indicate woolly thinking? What are the risks?
- Is there a way we can all be clearer about what we mean? Can we use analysis of this language to help patients, staff and others across the healthcare system bring about real change in the relationship between that system and its users?

In the event though, the findings and their implications went far beyond language, raising additional and important questions:

- How can we fundamentally change relationships between professionals and lay people, while respecting the value of what it means to be a 'professional'?
- How do new ideas such as truly involving patients in health services become accepted as 'normal'? And how can we work with these processes to bring about desired change?
- How can we manage the fact that, at root, such changes will mean a redistribution of power – something which is generally difficult to do?

The brief summary below can only give a flavour of the key ideas to emerge; more detail can be found in the presentation slides.

National Voices
People shaping health and social care

NHS
Institute for Innovation
and Improvement

What did we analyse, and how?

We gathered many hundreds of pages of documents relating to the 'patient agenda', including policy guidance from NHS, DH and patient organisations, and selected parts of relevant websites. We also interviewed 12 people within the NHS and other organisations whose roles concern this issue. These documents and interview transcripts were rigorously analysed using tools and concepts drawn from *discourse analysis*.

Discourse analysis shows the hidden but powerful way language both reflects and shapes cultural norms – ideas we all just take for granted - and how language 'positions' people by setting up a range of possible roles within these norms. It allows us to see more clearly how a familiar situation is maintained, such as the existing relationship between professionals and patients in the health system – how it is made to feel 'normal' and inevitable. Revealing how norms are maintained is potentially transformative, because it lets us examine and question those things that are taken for granted, and thus hard to see. In doing this, potential new roles and relationships can be named, discussed and made thinkable; and a new 'normal' established about how we best create healthcare for today.

What were the key findings?

The discourse of the 'patient agenda'

Analysis of the language around 'involving patients' showed some persistent and significant features:

- The language is **prolific** – many apparently similar or overlapping terms are in use, often combined in strings or 'word salads' – for example *'Patient & Public Involvement & Engagement'* (RCN); *'Patient and Public Voice and Information'* (NCB); *'Patient and Public Experience and Engagement'* (a network).
- The language is apparently **impotent** – it seems to have been unable to help bring about real change.
- The language is **unstable** – it changes frequently with new policies, personalities or regimes; terms are also inconsistent in meaning even amongst those within the field.
- The language contains many language forms **likely to create cynicism*** – abstract nouns (*engagement; involvement*); slogan forms *('no decision about me without me')*; jargon or hard to decipher terms (*co-production*).

    * Linguistic Landscapes research for DH 2010

So, language in this field has a particular and peculiar quality: it is treated as important (for example by policy-makers) but seems impotent; it is extensive but also highly unstable; it is intensely meaningful (touching on issues of clear significance to those involved) but easily becomes meaningless.

This kind of discourse strongly suggests something going on beneath the surface – a collective anxiety or struggle to deal with important things, dearly-held and protected by groups or individuals. It does not take much exploration to reveal that those things are fundamental - issues of **power**, professional **identities**, professional **boundaries** and **politics**.

'The patient' vs. 'patients'

The first clue to understanding this is found in the language used to refer to 'patients' themselves. We noticed two subtly but distinctly different ways in which the 'patients' are talked about in practice – the kind or role or position they are given.

- 'The patient' has been, since the development of modern medicine, **the object of professional medicine** – the essential complement to the role of 'the doctor'. Though we didn't see this directly in this material, we heard (and we know from other work) that when doctors talk about 'patients' they generally mean the ones they actually see – 'my patients'. However, they certainly extrapolate from them to patients/people in general.

- 'Patients' also appear in language as an amorphous category, more like 'the public' or 'voters' – and this category operates differently from the above within the broad healthcare discourse. We found that real people – all of us, who are or who will be 'patients' at some time – largely appear within the language of the NHS as **different kinds of proxies** - versions of patients who are not messy and real, but measurable and understandable in familiar terms. These proxies might be, for example, conditions or patterns of attendance, Patient Participation Group (PPG) members, measures such as Patient Reported Outcomes Measures (PROMS) or the Friends and Family test, 'lay members' and so on.

Both the figure of 'the patient' and the proxies for 'patients' represent attempts to bring the essentially messy and ill-defined world outside the system into the ordered, systematic and measurable forms required by the dominant discourses within the health system - a) medicine itself and b) bureaucratic and managerial discourses. (By 'discourses' here we mean organised ways to think and talk about something. A discourse contains characteristic types of language but also enshrines certain ways to evaluate people, things and courses of

action – medicine, for example, requires evidence and scientific forms of proof; another discourse such as that of religious faith would not necessarily value these things.)
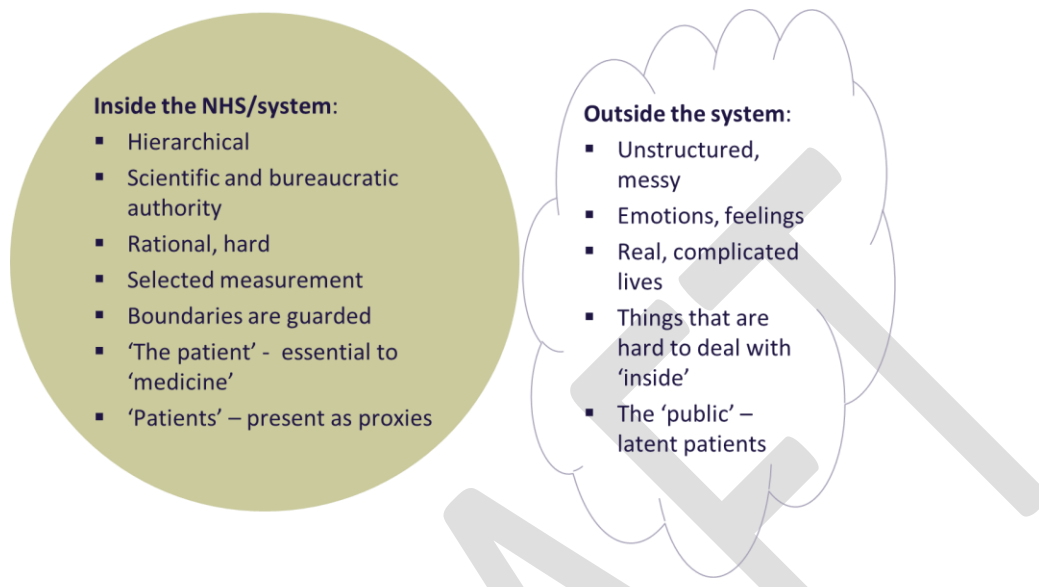
Inside the NHS/system:
- Hierarchical
- Scientific and bureaucratic authority
- Rational, hard
- Selected measurement
- Boundaries are guarded
- 'The patient' - essential to 'medicine'
- 'Patients' – present as proxies

Outside the system:
- Unstructured, messy
- Emotions, feelings
- Real, complicated lives
- Things that are hard to deal with 'inside'
- The 'public' – latent patients

Fig 1: The health system as set of discourses - shared ideas, language and ways of making sense

Developing patient proxies by using the managerial discourse already established within the health system is quite understandable. However, we heard that in practice there are problems establishing both the usefulness of these proxies (does anything actually change if boxes are ticked?) and the legitimacy of those people or measures purporting to represent the interests of 'patients' in this context (it may be measurable but is it meaningful?).

The emerging 'patient profession' - language as vehicle for legitimacy

An important way by which any group or concept becomes treated as a normal, natural and unremarkable – in a word, legitimate – is through discourse. Over time and through shifts in public discourse people come to accept something as real and true that was once unnamed and not 'real' –like 'road rage', for example. One way to understand the confusion and proliferation of language in the 'patient' field is to see it as symptomatic of a struggle for legitimacy by a relatively new 'profession', with language being used to establish its real-ness and value.

The emerging 'patient profession' is trying to bring the interests of the wider public into healthcare systems – see Fig 2. Note - by 'patient profession' we do not mean 'professional

patients'*, but an emerging domain of expertise, with its own language, forms of knowledge, ideology, and so on. [* We have learned since this analysis that the term 'professional patient' is one used to constrain or delegitimise parts of this emerging and necessarily unstable domain – especially those which are not 'inside' the system.]

There have long been voices outside or on the fringes of the system calling for change. But now in the UK the loose category of 'patients' (the second meaning above) is being established as **a specialist subject** within the system too - we can see this in its everyday language. Increasing numbers involved in this work are paid professionals – and there are many such in the new NHS structure e.g. in the NHS Commissioning Board.   New activities abound - 'patient engagement', 'patient involvement' and so on – but these are largely spoken about as if **separate from the core business of medicine** – as things that have to be done or 'undertaken' by professional specialists. As an emerging domain, the 'patient profession' must engage with the two more established professional domains - the domain of medicine and the domain of professional management (these two are themselves in some degree of tension). These dominant discourses are allowing a 'patient profession' some limited legitimacy by allowing it to create and measure proxies (as above) e.g. measuring 'engagement'. This may leave core ideas unchallenged, however – the phrase '*putting patients first* , for example, nevertheless retains the idea of the patient as the passive object of a medical gaze and system.

We also saw the idea of a different 'space' being constructed in the language, in which the profession shapes and owns (a metaphorical, sometimes literal space) where 'real' patients can be heard – this space is neither 'inside' health system, nor 'outside' it in messy real life, but forms a new arena and site of expertise altogether.

The idea that the patient domain is important and to be taken seriously is vulnerable - the embryonic legitimacy of taking patients seriously can still be routinely dismissed and dismantled in discourse. People involved in such work - especially those outside the NHS itself - may for example be written off as 'the usual suspects' and/or their objectivity and value dismissed by doubt being cast on their ability to represent anyone other than themselves. Some of those in 'the patient profession' are of course volunteers – but if they are not seen and treated as having professional (and not just personal) expertise to bring to the table, their experience is that they are easily dismissed and denied legitimacy.

Interestingly, while adopting *managerial* language and concerns (for example a focus on measurement) is a common strategy for achieving acceptance within the system, there was little evidence that the 'patient profession' has yet adopted the discourse of *medicine* to support the patient agenda – a gap that would be worth exploring further. That is, expressing the value of sharing power with patients in terms of what is valued within medicine – largely clinical outcomes and effective clinical practice – could help bring about a positive evolution of definitions of contemporary 'good doctoring', rather than the patient agenda being constructed, even if this is unspoken, as a threat to professional power and autonomy.
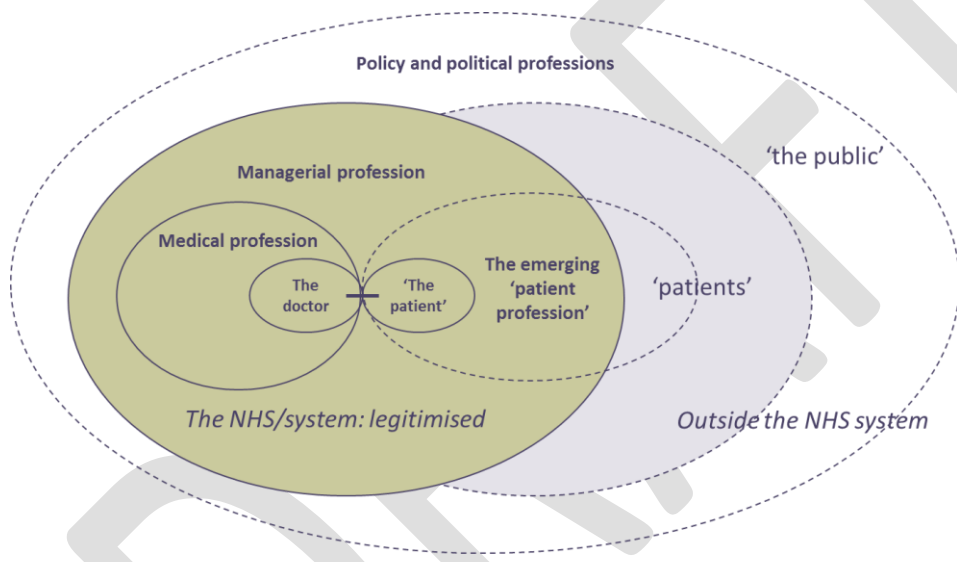

Fig 2: Categories implicit or explicit in the discourse around the 'patient agenda'

Supporting a changed relationship between the health system and those using it

Over the years, those seeking to move away from a picture of the patient as passive and grateful recipient of the doctor's skills (and the NHS's benevolence) have developed a number of ways of talking about patients differently – alternative 'positions' they might be seen to occupy. One can see several common 'positions' buried within the language and at the outset of this project Jeremy Taylor, National Voices, had already identified several; *whole person (not condition or body part); customer; citizen; community; partner; and leader* (Taylor 2012**). We were able to recognise all of these in the material we analysed

and identified two others – those of *specialist subject* (as above) and *helpful outsider*.   The problem with all of these 'positions' – and indeed the fact that there are so many – is that they become confused and confusing. They are also not without problems – the value of thinking of patients as 'customers', for example, is hotly and widely contested. (This in fact deserves unpacking, since 'customerness' contains many meanings, some of which are arguably less problematic than others and may be genuinely useful – see full report).
** Jeremy Taylor: speech to Dr Foster Ethics Committee 17/1/12

In the analysis, we outlined several ways in which seeking to change traditional relationships with patients is commonly legitimised – by pointing out the monetary benefit of such action, for example; or telling compelling stories about its effectiveness (there are many other such strategies in use).   Across the material analysed we could see different groups putting together different kinds of arguments, also mixing and matching across the possible new 'positions' for patients. Again, this is not of itself problematic and there is no 'right way' to act or talk to bring about change. What is clear, though, is that the 'top level' terms and phrases – abstract terms like 'patient engagement' and similar – are only loosely and uncertainly connected to such legitimising arguments. This explains why two people can use the same term and yet mean *completely* different things. The shorthand language is not helping the process of legitimising – arguably it needs underpinning with more concrete, specific and deliberate language strategies.

Why pay attention to language? And what can you do?

Why are we suggesting you pay attention to language? First because there are risks in not doing so; second because working consciously with language potentially helps bring about change. Language and action are sometimes seen as two separate activities. But our discursive perspective shows how language *is* action. This approach challenges the notion that language simply reflects reality and introduces the idea that language fundamentally shapes social practice and social reality.

Risks within the current discourse

The primary risks involved in the current language are twofold.

- Important things, like shifts in power and redefinition of professional boundaries, which underpin real change, are barely talked about at all – they are not there in the common discourse. Currently, language appears to act as **a decoy, deflecting attention from**

fundamental issues of power and politics – especially power regarding professional identities, and politics concerning the definition of priorities and allocation of resources.

- For those involved in the field, the language can create a frustrating kind of paralysis – language designed to support real change in the relationship between people and the health system actually ends up **maintaining the status quo**, even if unintentionally and subtly.

Practical outcomes of the work – using language for positive change

What can individuals do differently having read this paper? There will of course be many different views and priorities within the audience for this work; there are many possible applications of the analysis for many groups, and many ways to think about and delve into these findings. Although we found that language is both a decoy and a symptom of struggle, it is nevertheless powerful force both for and against change. Language does not merely reflect a situation, but shapes and constitutes that situation.

How people talk and write about the intention to change relationships between health services and the people who use them is part of the 'conditions of possibility'. That is, language always contributes to building up commonly-accepted ideas about things – and these ideas then allow people to inhabit certain roles and act in certain ways. When making a choice at a particular moment about how to speak to or about a patient, for example, the individual has 'free will' – but is also both prompted and constrained by familiar ideas and conventional ways of speaking. Those ideas and the language available to that person forms a social context. It is this context which enables or constrains how individuals think differently about patients, or behave differently in their work. This research unpacks some of those familiar ideas and conventional ways of speaking – and begins to offer ways to question them.

Concrete suggestions for developing the work so far include a workshop involving people from across the system, and outside it, to work through all the possible 'legitimising' arguments, as resource for sharing. Another is to produce a simple graphic illustrating the different patient 'positions' that are available, to help people remember the multiple options that are available. We would welcome your thoughts and contributions.

We would like to thank all those who gave their time to be interviewed, and those attending the webinars for their helpful and stimulating contributions.