Patient and public involvement in the new NHS: choice, voice, and the pursuit of legitimacy

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Overview

1. Reforms to the PPI system in theoretical perspective
2. Healthwatch: the new ‘consumer champion’ and the challenges it faces
3. The study, methods and data
4. Findings
5. Discussion
6. Real discussion!
The repeated redisorganisation of PPI

- 1974: Community Health Councils
  - “representing the interests of the local community” (Hogg 1999)

- 1992: NHS & Community Care Act
  - “local communities as advisers to health authorities” (Milewa et al. 1999)

- 2002: PPI Forums
  - bridging consumerist and citizenship-oriented approaches? (Baggott 2005)

- 2007: Local Involvement Networks
  - finding “the collective voice” of the local public? (Martin 2009)

- 2012: Healthwatch
  - ...
Making sense of the turbulence

• Disagreement about the means and ends of involvement (e.g. Martin 2008; Learmonth et al. 2009; Hudson 2015)
  – Democratic versus technocratic rationales
  – Choice versus voice
  – Disinterested, unhyphenated citizens, or groups with (potentially conflicting) interests?

• “Muddled initiatives” due to conflation of “distinct terms and the confusion about the purpose of involvement” (House of Commons Health Committee 2007)

• Local actors empowered to mediate such tensions
  (or left holding the hot potato when things go wrong)
Healthwatch in theory

- A consumer champion, but with multiple functions
  - Signposting and information provision
  - Advocacy and complaints services (not all Healthwatch)
  - Putting forward the views of local publics, especially ‘seldom heard’
  - Facilitating involvement in commissioning and provision
  - Public monitoring of provision (e.g. enter and view)
  - Making recommendations locally and nationally (via Healthwatch England)

- Expected to connect with existing expertise and interest in the local voluntary sector

- Influence “hardwired” through Health and Wellbeing Boards, mandated contribution to local health and social care strategy (Department of Health 2012)
Healthwatch: potential challenges

- Breadth and heterogeneity of responsibilities
- Small budgets, not ringfenced
- Representativeness
- Potentially conflicted relationship with local authorities
- Insiders or outsiders?
- Democratic accountability
- One ‘seller’ in a PPI ‘marketplace’

In sum: many potential challenges to legitimacy (see also Carter and Martin 2016)
How are Healthwatch seeking to enact their roles in light of the multiple rationales for PPI, and given these potential challenges to their legitimacy?
Our study

• Looking at the enactment of PPI in the new system, particularly (though not exclusively) by Healthwatch

• Two stages:
  – Interviews with stakeholders in the new system (in the East Midlands): Healthwatch chief executives and volunteers; Health and Wellbeing Board chairs (complete: 31 interviews)
  – In-depth case studies of PPI in two ‘transformation’ programmes (ongoing)

• This paper draws on the first stage, particularly interviews with Healthwatch chief executives and nominees

• Analysis informed by theoretical perspectives and potential challenges noted above, while retaining inductive sensitivity
Findings

1. **Building a platform**
   Challenges of resourcing and the emergent new system of health and social care governance meant Healthwatch had to give careful consideration to the boundaries of their role.

2. **Finding a niche**
   Participants described the emergent strategies they were using to secure the financial resilience and legitimacy that would secure Healthwatch’s future in the new system.

3. **Negotiating the conflicts**
   But these strategies brought their own tensions, which had to be managed in maintaining and enhancing Healthwatch’s position as the voice of local people.
Combination of broad set of responsibilities and constrained resources posed challenges

Prioritisation of tasks inevitable, with 'non-core' activities excluded or used as opportunities for income generation

A sense that nominal 'hardwiring' counted for little – Decisions not made in the formal public space of the Health and Wellbeing Board but in corridors and back rooms – Expedient, perfunctory forms of PPI predominant

Building a platform

"It is three-year funding and we are about to go into year three, and we don’t know what the settlement is going to be from national government to local authorities and what happens. Three years is quite a short period of time to establish something very new, so that is a challenge."

(Healthwatch 6)

"Inevitably the amount of money available’s going to go down. So I think sustaining something that’s viable and doable. Sitting alongside that is an expectation that we’ll become income-generating organisations, which in and of itself is not a bad thing, but I think it’s quite a big ask for an organisation that’s not even two years old. We just feel like we’re getting going and we don’t even know what we’re really good at yet, and yet we’re having to say, ‘Well what might people pay us to do so that we can actually sustain the core activity?’"

(Healthwatch 5)

"There’s a separate group that sits under the Health and Wellbeing Board locally, and one of the things that we have been saying as Healthwatch is at the moment that group makes commissioning decisions, holds the purse strings, it is effectively the key commissioners, whereas the Health and Wellbeing Board is the great and the good really."

(Healthwatch 1)

A separate group sits under the Health and Wellbeing Board locally, and one of the things that we have been saying as Healthwatch is at the moment that group makes commissioning decisions, holds the purse strings, it is effectively the key commissioners, whereas the Health and Wellbeing Board is the great and the good really.

The CCGs and Healthwatch have a totally different definition of what consultation is. The CCGs do it because it is a legal duty, and they do it in a way that meets that legal duty. We on the other hand see consultation—they almost do it when they have got the proposals already set up, whereas we see consultation as a way to get the right way of going forward. So before anything else is sorted you have listened to what people have to say."

(Healthwatch 6)
Finding a niche

“It was very well received by [the hospital trust] and by the commissioners. I think, understandably, the provider of patient transport was a little more guarded about it, but I think everybody felt that it was a good opportunity to find out more about the system that we were engaging with. That’s made some people a little bit more aware of the issues and the problems that we were experiencing.”

(Healthwatch 5)

“We just work really closely with them. Our social care working group, it is a mix of service users, carers, but also organisations like the [Locality 2] Association for Blind People, the Alzheimer’s Society, Age UK: local organisations that provide services. And because [local voluntary-sector umbrella group] is one of our partners we work really closely with them in terms of getting views from voluntary and community sector organisations, because they have still got that traditional collective advocacy role.”

(Healthwatch 2)

“[The hospital] got quite a bit of stick for it […] so then we got loads of stick for it from the commissioners. The actual service providers themselves were fine, because we had gone to them first with the information, but the CCG weren’t very happy about it.”

(Healthwatch 6)
Negotiating the conflicts

• Resolving some problems could create new ones
• Commercial activities could carry a taint: required a clear financial and presentational firewall
• Other voluntary sector groups not always so keen to lend Healthwatch their representational legitimacy
• Ability to (appear to) speak for 'seldom-heard' groups dependent in large part on cadre of volunteers:
  – Self-selecting
  – Inherited from predecessor LINks
  – Not necessarily demographically representative of marginalised groups
  – Used to a freer hand in deciding what to do

“What we need to be is clear about what our core role is. It may well be, in terms of our own financial sustainability, that people can buy from us, but in a sense what they're buying...”

 “[Volunteers] used to do what [they] wanted to do and it is slightly different now. You can't just decide your own agenda, so some of the volunteers have had a freer hand than they have now because of the difference in the contract [compared to LINks].”

(Healthwatch 9)

“...but we'd expect to be funded separately from that because it's not core.”

(Healthwatch 1)
Discussion

• Hardwiring short-circuited?
  – But other routes to influence available
  – Bilateral relationships a valuable means of gaining traction, demonstrating worth, and confirming role as ‘local voice’

• ‘Structured freedom’?
  – Able to determine their own agenda to a large extent
  – Constantly conscious of the need to legitimise themselves according to others’ (sometimes incompatible) criteria of what Healthwatch should be (and haunted by ‘ghosts of PPI past’)

• The right kind of independence
  – A position to be filled
  – The need to be “predictable and thus responsible, in other words, competent, serious, trustworthy—in short, ready to play, with consistency and without arousing surprise or disappointing people’s expectations, the role assigned to them by the structure of the space of the game” (Bourdieu 1981)
Thank you.

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References


