Patients, communities and the NHS: building a person-centred health care system

Dan Wellings – King’s Fund
@danswellings
Any service needs to understand the people it serves by hearing from them
Why is patient/user/citizen perspective important?

“The confidence that individuals have in their beliefs depends mostly on the quality of the story they can tell about what they see, even if they see little. We often fail to allow for the possibility that evidence that should be critical to our judgement is missing – what we see is all there is”

Daniel Kahneman
Thinking, Fast and Slow
Why do we need it?

- ALBs, CSUs & CCGs
- 5YFV
- NCMs
- STPs
- IPC (PHBs & IPBs)
- PACS
- SCRs
- MCPs
- BCF
- UEC
- ACOs, ACSs, ICSs, ICPs
- CCG IAF

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“In other sectors of the economy, there are severe consequences for knowing so little about what people you serve want. It’s called bankruptcy. In healthcare it’s called unsustainability.”

Dr Al Mulley, MD for Global Health Care Delivery Science - the Dartmouth Institute

“It’s more important to know what sort of person has a disease than to know what sort of disease a person has”

Hippocrates (460-370BC)
What are we talking about?
The challenge of nomenclature?

Patient and public involvement policy

Patient and public engagement: a practical guide for health and wellbeing boards

Arnstein (1969) Ladder of citizen participation

- Citizen control
- Delegated power
- Partnership
- Placation
- Consultation
- Informing
- Therapy
- Manipulation

Degrees of citizen power

No power

Degrees of tokenism

Co-production in social care: What it is and how to do it

What is co-production - Introduction

PATIENT INSIGHT:

The King's Fund

Ideas that change health care

GP PATIENT SURVEY

We want to hear the views patients have about their GP services.

www.gp-patient.co.uk
The ‘Ladder of Engagement and Participation’

There are many different ways in which people might participate in health depending upon their personal circumstances and interest. The ‘Ladder of Engagement and Participation’ is a widely recognised model for understanding different forms and degrees of patient and public involvement, (based on the work of Sherry Arnstein³). Patient and public voice activity on every step of the ladder is valuable, although participation becomes more meaningful at the top of the ladder.

<table>
<thead>
<tr>
<th>Level</th>
<th>Description</th>
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<tr>
<td>Devolving</td>
<td>Placing decision-making in the hands of the community and individuals. For example, Personal Health Budgets or a community development approach.</td>
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<td>Collaborating</td>
<td>Working in partnership with communities and patients in each aspect of the decision, including the development of alternatives and the identification of the preferred solution.</td>
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<td>Involving</td>
<td>Working directly with communities and patients to ensure that concerns and aspirations are consistently understood and considered. For example, partnership boards, reference groups and service users participating in policy groups.</td>
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<td>Consulting</td>
<td>Obtaining community and individual feedback on analysis, alternatives and / or decisions. For example, surveys, door knocking, citizens’ panels and focus groups.</td>
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<td>Informing</td>
<td>Providing communities and individuals with balanced and objective information to assist them in understanding problems, alternatives, opportunities, solutions. For example, websites, newsletters and press releases.</td>
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Key policy in this area
Ways the NHS hears from patients and the public
Matrix of insight methods from *Measuring patient experience: evidence scan* Health Foundation, June 2013
Purpose?
It has to mean something

“It’s great that our colleagues in the NHS and the public sector are seeing that there’s real value in understanding and utilising the experiences of staff and consumers of services, but what worries me is how much – or how little – of this work is focused on clear objectives using systematic data collection methods. For some, I’m concerned the most valuable evidence PPI generates is the occasional lightbulb moment or, failing that, the pictures of engagement events that are posted to social media to show others we’re listening. This type of PPI might feel valuable at the time. After all, hearing people’s stories is emotionally rewarding and most of us come away feeling good. But we shouldn’t conflate this good feeling with value – six months later, we’ll probably find this engagement hasn’t led to any meaningful actions.”

Rich Stockley, Head of Research and Engagement, Surrey Heartlands
Where is NHS insight and feedback now?

Insight and feedback in current system
- No single home
- Siloed
- Seen as a ‘nice to have’
- Lack of clear purpose
- Seen as ‘soft’ data
- Not always believed
- Distinction between ‘engagement’ and ‘insight and feedback’

What’s missing?
- Joined up view of patient
- Putting patient voice on an even keel with other data
- Capability and capacity
- Focussing on the use of insight data rather than collection
- Everyone’s business
- Effectiveness and efficiency
Wigan: a case study
A citizen-led approach to health and care
Lessons from the Wigan Deal
Questions for today...

• Reflections on what you have heard

• Do you feel this area is prioritised in the health and care system? Why/why not?

• What are your experiences of this area?

• What is the potential?

• Which areas would you like to know more about?
Thank you

Dan Wellings
d.wellings@kingsfund.org.uk

www.kingsfund.org.uk