Engaging the public in health system change

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Summary of findings of research by Britain Thinks

Background

- Change in health and social care that delivers the right outcomes for people should:
  - Be based on patient, service users and carers etc, assessment of what needs to change
  - Be co-produced with those it will affect
  - Be properly communicated to the wider patient (and potential patient) population
- Many patient groups and VCS orgs feel excluded from the STP process
- Good engagement and communication starts with understanding:
  - What matters to people
  - The language and concepts that will help people to engage

The research

- In 2014 the Richmond Group commissioned BritainThinks to undertake qualitative research amongst the general public to understand:
  - Their perceptions of the need for change in health and social care
  - How we could communicate changes that could benefit the people we support

- A lot has changed in two years - we decided to update and develop the 2014 research to understand :
  - If and how public perceptions have changed in the past 2 years
  - How to ‘demystify’ change – so people could more easily participate in local discussions and debates

Methodology

- This round of research was designed to allow comparability with the 2014 findings (i.e. Same samples)

2 Focus Groups of 8 people in South West England on the 9th of November

Group 1
- All men
- 30-55
- B/C1

Group 2
- All women
- 30-55
- C2/D

2 Focus Groups of 8 people in North England on the 3rd of November

Group 1
- All men
- 30-55
- C2/D

Group 2
- All women
- 30-55
- B/C1

4 Depth Interviews

2 interviews with individuals aged 60+ who care for people with long term conditions

2 interviews with individuals aged 60+ with long term medical conditions

How have things changed from 2014 to 2016?

Key findings 2014

- **Research showed a gulf between the public and the health community**

1. The general public did not have any interest in the process of health and social care delivery – **they were interested in the end benefit**
2. The public agreed there was room for improvement – but **they did not identify a change imperative for the NHS**
3. They were aware of problems in the system, **but their analysis of the cause was very different from that of the health community** (i.e. they attributed them to immigration and waste/inefficiency)
4. Many of the **proposals for change were accepted, but only because people thought they were common sense** - not as a radically new way of delivering health and social care. People wanted system improvement only as a means to an end: i.e. patient benefit

Changes in 2016

- There have been notable shifts in public opinion over the last 2 years

1. Awareness of social care has increased since this research was last conducted in 2014 (although the term is still not a familiar one)
2. Growing confusion over who can be trusted – on the state of the NHS/social care and for solutions in the public interest
3. The NHS is increasingly an issue of concern for participants (despite the dominance of Brexit in the news
4. A sense of mounting problems in the NHS and social care systems – some perceive a ‘crisis’
5. Funding pressures and staff shortages emerged as priority concerns – taking over from immigration and waste/inefficiency
6. There is concern about a perceived decline in the caring ethos NHS staff

1. Awareness of social care

- **When asked to consider the health and social care systems, the NHS dominates participants' thinking**
- However, participants *also* discussed social care - and in particular care homes – a significant shift from 2014
- Most still do not use the term 'social care' – they refer to 'elderly care', or 'care homes'
- They don't have a clear sense of how social care relates to the NHS, nor how it is funded

"People trying to keep the aged in the community, and being able to afford for carers to come in is a big issue."
(Female, Focus Group, South West)

"Quality of care in social care is not great, like where families have installed cameras in care homes."
(Male, Focus Group, North)

2. Confusion over who to trust

- **People struggle to assess what is happening in the NHS and social care – partly because they don't know who to trust:**
- 'Politicians'
  - Not trusted to tell the truth/ act in patient interest
  - Seen as result of careerism / election cycles
  - Amplified in the North – suspect Conservatives do not support the NHS (or are actively seeking to undermine it)
- The media
  - Negative media coverage of the NHS played a major role in shaping views
  - Participants who had good personal experience of the NHS, struggled to reconcile experience with media coverage
  - Many suspected the media of sensationalism

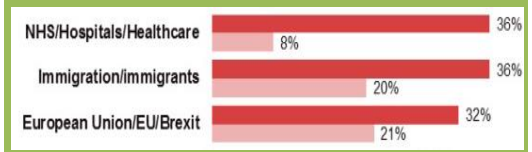
"The current government is not supportive of the NHS. They always say they've not got money for it, but they've got money for their expenses and wars. It's more money than care because the government are ruthless, they're just number crunchers and they don't really care."
(Male, Focus Group, North)

"The media do hype things up, and you wonder sometimes to what extent it all is hype. I never hear anything terribly bad about anyone locally having a bad experience."
(High Frequency Service User, South West)

3. High on the news agenda

- Despite the dominance of Brexit in the news, the NHS is increasingly an issue of concern

The October 2016 *Issues Index* revealed Healthcare, Immigration and Brexit as the top three issues for people in the UK currently. Healthcare was ranked as the third most important overall.



4. Sense of mounting problems

- Negative media stories and personal experiences lead to a sense of a system experiencing pressures and struggling to cope. Issues relating to older people are a particular cause of concern

"You hear of patients being left in corridors, because there's no consultants ready to see them." (Female, Focus group, South West)

"It's a fact that we are living longer now, and with it comes illness, Alzheimer's and dementia, because people are living to that age where they are more prone to it." (Male, Focus Group, North)

"There's a bias against the NHS making it seem like it's in crisis, just because of the cuts and the funding isn't there to support the need."(Male, Focus Group, South West)

5. Changing sense of the 'issues'

In 2014

- There was a deeply ingrained belief that health system problems were attributable to:
  - Waste/inefficiencies
  - Abuse of the system by those 'who do not deserve to use it' as they do e.g. immigrants, health tourists, those who are reckless with their health
- There was a conviction that if these issues were addressed, all other problems would be easily solved without the need for radical change

> *"Whatever the fundamental change is we do need to look at what's happening inside before we look outside for the solution."*
> (Male, BC1, London, 2014)

- These issues now seem to resonate less

5. Changing sense of the 'issues'

Now, in 2016 the issues are seen to be..

Funding pressures	• Seen to be the major, overarching challenge • Perception NHS is not receiving sufficient funding to meet demand predominantly driven by media stories
Staff shortages	• Shortages impact quality of care – with patients waiting longer, and having less time with doctors • Driven by personal anecdotes and media stories
Ageing population	• Awareness that this is putting pressure on NHS and social care • Reluctance to see this as a negative – fear of 'blaming' older people
Mental health provision	• Seen as de-prioritised relative to physical health by many • Leading to serious concerns about the impact on patients
Poor quality social care	• In-home visits by carers seen as inadequate for 'caring' • 'Horror' stories in the media re abuse of elderly people in care homes generated concern

6. Concern about caring 'ethos'

- Participants believe most HCPs are trying to do the best they can for patients, often under difficult circumstances
- But there is concern that the traditional, compassionate approach to care is being eroded
- This commonly stemmed from personal experiences, though media stories about poor care were also seen as evidence of this trend
- Participants attributed this change to three factors: lack of time; less personal engagement between HCP and patient; some younger HCPs being less committed
- These concerns were amplified in the North

"Our practice had really good GPs, but they retired in the last year. Some younger ones have come in but they don't seem to have the care and attention for the people who have been there for a long time. I needed a really important letter, but the doctor told me 'I didn't go to medical school to be a social worker'."
(Female, Focus Group, North)

"My mother in law was in hospital, and they discharged her at 2:30am, they basically booted her out of the ward because they needed the bed. There was no care for her or anything."
(Male, Focus Group, South West)

So what…?

- **A sense that the challenges facing the NHS are growing, creates a new openness to change**
- Most participants think pressures in the NHS have meant that the quality of care has declined over the last 5 years
- For some, this has now reached crisis point. Though others – particularly in South West – were very resistant to this language
  - Because their personal experiences are good and act as a counter narrative to negative media coverage
  - Or because talking of a ‘crisis’ in healthcare feels disloyal to the NHS
- Overall – the sense of decline meant that participants were much more willing to consider changes to the NHS than in 2014

So what…?

- **Perceptions of the NHS as an institution that should be outside politics shape how willing people are to accept change**
- In line with other research, participants demonstrated a strong emotional attachment to the institution of the NHS
- This led to a sense that it should sit outside politics
- And limited the *justifications* for change they were willing to accept
  - Cost saving is not an acceptable reason for change, as this is seen to be a political choice
  - It has to be about the benefit to the patient
- And the *changes* that they were willing to consider
  - There are clear ‘red lines’ (most notably the closure of hospitals)

Talking about change

Talking about change: Why?

- ✓ Sustains the founding principles of the NHS
- ✓ Relates to the issues people have experienced locally (not the system)
- ✓ Relates to the wider context which means health and social care has to adapt – e.g. an ageing population
- ✓ Is substantive, and decisive enough to tackle the problem - but an 'evolution'.

- ✗ About 'cost saving' - this undermines any message about patient benefits
- ✗ "Blaming" people for growing demand – especially older people
- ✗ Radical / revolutionary – suggesting system might not be recognisable afterwards

"That's positive to me – because its starting with a truth, saying that they want to do something and take action."
(Female, Focus Group, North)

"That's perfect, that's the best one. Its more direct, and puts a time frame on it. It's not wishy washy."
(Female, Focus Group, South West)

Talking about change: What?

- ✓ Clear about the end benefits for patients
- ✓ Related to what people expect from the NHS – clear about how it will continue to deliver this
- ✓ Clear about how the system (especially how people access it) will still be recognisable
- ✓ Clear enough so people can 'picture' the end results
- ✓ Clear that the plan has been carefully considered by relevant experts (e.g. HCPs) and people with a stake in the system (e.g.

- ✗ Focus on processes or 'behind the 'scenes wiring' – people don't know what this means and can't tell if it will meet their needs
- ✗ Jargon, emotive language, unsubstantiated claims
- ✗ Changes that lead to reduced services – hospital closures are a "red line" – they don't seem like a logical answer to the challenges

"But what if they got a shortage of hospitals, what if they're not near enough
If you want to risk losing a hospital for two clinics…Why not leave the hospitals and have additional clinics? Keep the hospital and the pressures taken off it."
(Female, Focus Group, North)

Clear and practical language

- **People struggle to 'picture' what it would mean to 'move care into the community' or 'deliver more care closer to home'**
- People like the word 'community' – but relate it more to who is there, than where it will be – 'local' communicates location more effectively

> *"Community hospital has got a nice feel to it – like a smaller version of a hospital. Sounds as if they know what they're doing, but it depends on whether you've got that community feeling where you live."*
> (Female, Focus Group, South West)

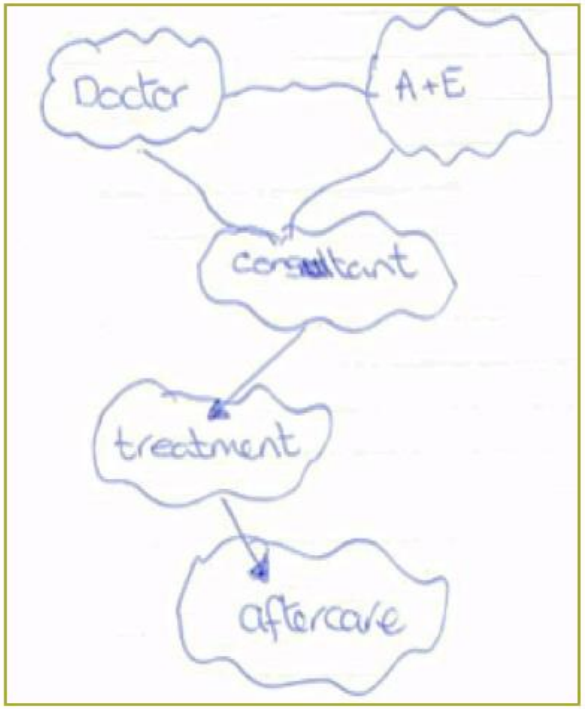
- The phrase 'local healthcare centre' was the best way of capturing 'care in the community'
- The word 'clinic' means different things to different people – e.g. Some thought it meant a mobile service.
- The word 'hospital' has strong associations - a place for surgery / that you would stay overnight / security – a place filled with experts

> *"Well-being centre sounds too vague*
> *I quite like health care centre, but clinic sounds like you're going under the knife."*
> (Male, Focus Group, South West)

- The word 'wellbeing' not well received - associated with a 'softer', less effective type of healthcare

Professional vs. public language: e.g. emergency care

- **A&E (and language around other types of urgent care) is understood differently by professionals / the system and the public**
- For example, people assume an Urgent Care Centre would be:
  - Open 24/7
  - Staffed by doctors
  - The place to drive to in an emergency
- Access to urgent care in an emergency is one of the highest priorities for people
- Most important for people is that they can get urgent help from a doctor (and other professionals) in an emergency in ways that are easy to access and close to home



Talking about STPs….

- **People haven't heard of STPs - the 'full title' leaves them none the wiser!**
- Once explained participants thought the approach sounded sensible – they thought:
  - plans would be long-term and thought-through
  - They involved the right sort of people to get plans right - i.e. those with frontline experience, a close knowledge of the system, the interests of patients at heart, and without political affiliation
  - being regionally/locally-based would mean local needs would be recognised and addressed

Plans for changing the NHS in your local area are being drawn up by committees of local doctors, hospital CEOs, patient groups and councils. The plan they will devise is called the STP (Sustainability and Transformation Plan).

"I haven't heard anything about the STP. It's probably a good idea that you've got the relevant people taking part in it."
(Care giver, South West)

Who do people want to hear from?

- **People were clear they wanted to hear from people with a working knowledge of the healthcare system and real experiences to share**
- There was a desire to hear from people within the healthcare system; primarily doctors and senior nursing staff
- Some want to hear ‘real life stories’ from patients, explaining the positive impact that changes had/ would have had for them
- People perceived to have a ‘vested interest’ of any kind or as being ‘careerist’ would not be accepted as a credible voice
- The VCS and patient groups speaking *collectively* is also seen as a helpful indication of whether plans serve patient and public interest

“A normal person…Someone who’s had a bad experience with healthcare that turned good. It would be good to hear from a member of the public who’s been through it.”
(Female, Focus Group, South West)

Contact us...

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