The public’s challenge to a national treasure: responding to questions posed by patients and the public

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What does patient and public information mean to you?

Talk to the person next to you.
Today’s agenda

• Setting the health and care policy scene
• What PPI means to IKS at the King’s Fund – what we get asked
• What’s your approach?
• Breaking down barriers
• What else is at play that could help our role?
• Concluding thoughts
The ‘King’ in King’s Fund
What year? Quotes from the King’s Fund

“What is clear, however, is that any British government, of whatever political colour, is going to have difficulty funding the NHS at an adequate level.”

(Shaping the NHS for the 1990s”, (1989) Robert Maxwell, CEO, The King’s Fund

“The general aims in the reorganisation were that it should ensure a comprehensive and fully integrated health service in which care would be provided locally.”

(Tracing decisions in the NHS, 1980)

"concentrated efforts throughout the country to increase [...] the unification of services’ to ‘improve the service to the patient"

(Working together: a study of coordination and cooperation between general practitioners, public health and hospital services, 1968)

"Evidence shows that there are wide gaps between what patients want and what doctors think that patients want. When patients are fully informed about the risks and benefits of treatment options, they choose different and often fewer treatments."

(Transforming the delivery of health and social care: the case for fundamental change, 2012)
The political agenda

The public and the NHS
What’s the deal?

Overview
The NHS is under financial pressure with growing demand for services. As the NHS reaches its 70th birthday, The King’s Fund has been exploring how the public views its relationship with the NHS. In March 2018, in partnership with Ipsos MORI, we carried out three deliberative workshops to explore this issue.

- We found that the relationship between the public and the NHS is strong, and people were committed to its founding principles. However, there were several areas where the NHS could improve – not least around waste.
- While there was a feeling that some people take the NHS for granted and demand too much, participants felt that their expectations of the NHS were largely being met and that those expectations were realistic.
- Lack of funding was seen as a problem, and government was seen as responsible. Most people would be willing to pay more tax to maintain the NHS, and many people favour a dedicated NHS tax.
- There was recognition that NHS services were sometimes used inappropriately, which

House of Commons
Health and Social Care Committee

Integrated care: organisations, partnerships and systems

Seventh Report of Session 2017-19

Report, together with formal minutes relating to the report

Ordered by the House of Commons to be printed 23 May 2018

Two parliamentary committees have made history by being the first in the UK to ask a citizens’ assembly – a representative body of English citizens – to inform their work, and then throw their weight behind its bold recommendations.

Today’s social care report from the Health and Social Care, and Housing Communities and Local Government Committees closely mirrors the recommendations of the Citizens’ Assembly on Social Care, calling among other things for a tax on over 40s to help pay for social care.

The Citizens’ Assembly on Social Care

The report – which also echoes the Assembly’s aspirations for social care to be free at the point of use for both working age and older adults, be of higher quality, include better support for carers and use national earmarked contributions to help pay for the changes – calls for a cross-party commission to undertake reviews of the markets within the Assembly concluded...
Health and care policy landscape

STPs, HWBB, Trusts, LAs etc....

Integrated Care Systems...
NHS at 70
NHS at 70
“Acronym soup”...
Our challenges with public enquiries

Signposting

Stories

Opinions

Facts
What we get asked

Sue, cancer patient
- Feels abandoned by the health and care system
- NHS to pay more attention to the needs of cancer patients with long term side effects caused by their cancer drugs

Stan, member of the public from the South West
- Submitted a subject access request to NHS Digital for all the data relating to him and had some questions about the data
- Concerned that if any clinicians he is receiving care from see that he has a record in the MHSDS that this will colour their perception of him

Angela, member of the public from Devon
- Wanted to highlight inconsistencies of support for people she knows with dementia
- Were there national standards for support for people with dementia?
What we get asked

Henry, retired from Birmingham
- Aged 70, as old as the NHS
- Feels the NHS is not what it use to be
- Wanted to express his dissatisfactory of GP surgeries

Tom (80), retired social worker from Cambridge
- Commenting on a GP services report
- Offering his time pro bono
- Wants to contribute to common good (and a bit lonely)

John
- Immigration is the problem with the NHS – why aren’t you saying this?
The Kings Fund has obviously not spoken to the ordinary elderly receiving it [winter fuel tax].

The Prison's are full of people suffering from mental health and social issues. Who is the best person/organisation to try and change the system to care not custody, as it is a serious issue that needs dealing with.

Cannabis could help the NHS funding crisis.

A&E cost of dealing with sports injuries could be covered by an add on to the fee / subscriptions already paid by people participating in sports.

Could you tell me if there is any role for local councils in social care? Why not have local NHS commissioning groups control everything?

I was appalled to hear yet another dismissive response from the Government and the DOH concerning the dangers to patient safety as a result of the known shortage of nurses (and indeed Doctors) at/on the front line of service delivery.
Safeguarding

My treatment at ... health care service has been diabolical. I now do not trust the health service & would rather die than approach my GP.

I am deeply concerned and upset about if I may be removed from patients records if I abuse their [surgery] attendance policy for missing appointments without valid explanation.

I FEAR FOR MY LIFE SOMETIMES. I AM VERY SCARED AND FRIGHTENED.

There is an insidious Bullying Culture [at my trust].

PLEASE [help] from a loving mother who cannot go through this again, I don't know where else to go.

My life has been a long battle, and it's a long story, but I am hoping with your help I may at last get the help I need.

I thank you from my heart just to have replied to me, but I need the truth and these cruel people to answer WHY.
What’s your approach?

Discuss in groups the real-life enquiries that we have received.

- Where would you start searching?
- Who would you forward the enquirer onto?
- What kind of documents might hold this information?
Enquiry 1

I am trying to establish sources of information regarding the 'hidden' mental health needs of people living in Surrey. I am doing this on a voluntary basis with others in the voluntary, public and health sectors and we are trying to look behind the perceptions of the prosperity of those who live in the county to establish the current state of mental health/illness in the county.
Our initial response

Can I check that I understand what you mean by ‘hidden’ mental health needs – are you after information on the number of people with undiagnosed mental health issues? Or are you more interested in unmet mental health needs?
Our reply to enquiry 1

Hidden in plain sight
The unmet mental health needs of older people

There is a great deal of focus in the health and care system on measuring the quality of care being provided. But what about care that isn’t provided at all?

We have published several reports this year highlighting pressures in community-based services, including social care and district nursing. These pieces of research raised concerns about changes to the availability and quality of services as a result of rising demand and insufficient funding and staff numbers. The reports also raised concerns that these pressures might be leading to rising levels of unmet need.

Unmet need is difficult to define, and harder still to measure. This would be true in any setting, but particularly for services like district nursing that are delivered in people’s own homes. People who are not receiving district nursing care but would benefit from it, or those who are receiving some care but require more than they are currently getting, are often out of sight. There are no overcrowded waiting rooms or queues to bring this unmet need to light.

Local authorities are required to seek to identify unmet need for social care. But currently, monitoring arrangements are only in place in just over a third. Recent research from Age UK estimates that 1.2 million older people are not receiving the social care they need, a number they report has increased by almost half since 2010. This means that more people who have difficulties with activities of daily living – such as washing, eating or going to the toilet – do not have the support they need.
Enquiry 2

How are care homes funded and what percentage of places are LA funded or self funded?

What is the rate of closure/opening for care homes?

Can you say what % of care homes pass CQC inspections - is it known how many get average/good/outstanding and how many fail?
Our reply to enquiry 2

The King’s Fund database

Social Care Online
Our reply to enquiry 2
Enquiry 3

Everything I need to know about Dormant Hep C. My 7 year old child lives with a 50 year old addict who himself has dormant Hep C.
As a group discuss: how would you feel about answering this enquiry from your library service?
Our response to enquiry 3
Enquiry 4

Regarding STPS, - When tackling a financial failure of a CCG through special measures, how will this affect the NHS Patient in Hospital or at Home with their treatment and prescriptions in respect to the cost.
Our response to enquiry 4

Overview

NHS England is launching a public consultation on reducing prescribing of over-the-counter medicines for 33 minor, short-term health concerns.

In the year prior to June 2017, the NHS spent approximately £69 million on prescriptions for medicines which can be purchased over the counter from a pharmacy and other outlets such as supermarkets.

These prescriptions include items for a condition:
- That is considered to be self-limiting and so does not need treatment as it will heal of its own accord;
- Which lends itself to self-care, i.e. that the person suffering does not normally need to seek medical care but may decide to seek help with symptoms relief from a local pharmacy and use over the counter medicine.

Vitamins, minerals and probiotics have also been included in the consultation proposals as items of low clinical effectiveness which are of high cost to the NHS.

NHS England has partnered with NHS Clinical Commissioners to carry out the consultation after CCGs asked for a nationally co-ordinated approach to the development of commissioning guidance in this area to ensure consistency and

Items which should not be routinely prescribed in primary care

In 2015/16, 11.1 billion NHS prescription items were dispensed to patients in primary care at a cost of £2.2 billion. With the number of prescriptions increasing by 1.9 per cent a year, it was important that the NHS acted to achieve the greatest value from the money that it spends.

NHS Clinical Commissioners (NHSCC) – the organisation that represents CCGs – originally approached NHS England with a proposal to reduce prescription of ineffective medicines in primary care. As part of its national commissioning role, NHS England started working with NHSCC to review such products, set out an evidence based and consistent approach for patients, and coordinate a national consultation process on behalf of all CCGs.

The intention is to produce a consistent, national framework for CCGs to use, while taking account of local circumstances and their own impact assessment and legal duties to advance equality and have regard to reduce health inequalities.

In partnership with NHSCC, NHS England appointed a joint clinical working group to review the available evidence and identify medicines that should not be routinely prescribed.
Our response to enquiry 4
Enquiry 5

I wish to ascertain whether effort is being put in to healthcare becoming viewed as a ‘bargain’ or contract between the provider (NHS) and the receiver (patient); meaning that there should be expectations of both parties to the bargain. eg 90% of type II diabetics can be controlled or cured by self discipline of the patient saving the NHS billions per annum.

It seems to me the fewer steps the patient takes to stay healthy....correct diet, exercise etc the quicker they jump to the top of the queue because their conditions require immediate and expensive treatment. NHS is rewarding bad behaviour.

Is there change happening to try to get patients held to account if they don’t deliver their side of the bargain?
Our response to enquiry 5
Response to enquiry 5

Understanding NHS financial pressures: how are they affecting patient care?

This report examines the impact of NHS financial pressures on patient care across four different parts of the health system. Download the full report or read a summary below.

Overview

- Financial pressures on the NHS are severe and show no sign of easing. However, we know relatively little about their impact on patient care.
- This study sought to investigate the impact of financial pressures in four very different areas of the health service: geri-urology medicine (GUM), district nursing, elective hip replacement, and oncology services.
- Our research used data analysis and interviews to explore different experiences across the system.
- We found that GUM and district nursing services were under particular strain. Both access to services and quality of patient care have been affected in ways that are difficult to detect with currently available metrics.
What are the barriers to providing patient and public information?
What would help break down these barriers?

Breaking down barriers to better health and care

The journey from fragmented services to local partnerships and integrated care systems, designed to meet our needs today and tomorrow
What else is at play that could help our role?
Examples of best practice

Knowledge for Healthcare ideas bank

BMA Patient information awards
Strategic PPI priorities for libraries?

• Securing our role in the PPI agenda
• Build confidence in our ability
• Overcoming system barriers
• Working in collaboration across sectors
• Involvement in joining up health with social care
• Empowering people to self manage conditions and care
The winning solution (my utopia)

We will talk about population outcomes or individual outcomes
We will actively share best practice
All health information will be evidence based
Actively refer queries across sectors
For IKS – that we are the 'go-to' place for health and care policy information
Thank you

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