Genuine patient engagement or tokenism

Seeking to understand the patient & service users perspective

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Things are changing in healthcare

- We are living longer
- Have complex comorbidities
- Are better informed
- Access to expert information
- Greater expectations to be involved – design, planning & delivery
- Oh and there is less money!
8. Citizen Control
7. Delegated Power
6. Partnership
5. Placation
4. Consultation
3. Informing
2. Therapy
1. Manipulation

Citizen Power
Tokenism
Nonparticipation
National picture

- Driven by:
  - CQC surveys
  - Plethora of information – Picker Europe
  - Kings Fund
  - Healthwatch
  - Local Medical committees
  - CCG
Value of engagement / involvement

- Expert insight
- The majority are committed to the NHS
- Shared responsibility to using NHS responsibly
  - DNA rates
  - Mutually agreed dates
- Increased rapport – not just a conveyer belt
- Imaginative use of resources
- Participation & commitment
Variation in involved

- Some often happy to engage
  - LGBT
  - LD
  - Expert patient groups

- Others sometimes harder to reach
  - Teenage carer’s
  - Gypsies & travelers
  - Illiterate
  - Those who don’t speak English
What do patients want

- Confidence
- Trust
- Rapport
- Consistency
- Empathy
- To feel heard
- Information's & Explanations
  - They EXPECT us to have the technical skills & knowledge
Methods of engagement

- FFT
- Bespoke surveys
- Interviews
- Groups
- Social media
- Shadowing
- Diaries
- Complaints
- Letters
- Public meetings

- Peer reviews esp. cancer
- Panels
- Drop in café’s literature reviews
- Mystery shoppers (staff)
- Videos
  - Young cancer patients / family experience
Staff perspective

- Variable
- Lack understanding of rational beyond national directive
- Don’t believe it more than a token gesture
- Has little impact
- Staff are invested
Complaints

- Offer insight into the darker side

- How do we respond emotionally when we hear of a complaint
  - T
  - Olly
Staff are stakeholders too

Trained to understand benefits of engagement

How to listen without judgment

Perhaps the biggest resource of information on our services

What about those who retire!
**Arnstein’s Ladder of Participation**

http://lithgow-schmidt.dk/sherry-arnstein/ladder-of-citizen-participation.html#d0e70

![Ladder of Participation Diagram]

**CITIZEN CONTROL**
Stakeholders have the idea, set up the project and come to facilitators for advice, discussion and support. Facilitators do not direct, but offer advice for citizens to consider.

**DELEGATED POWER**
The goal is likely to have been set by the facilitator but the resources and responsibility for solving the problem are passed to the stakeholders. There are clear lines of accountability and two-way communication with those giving away the power.

**PARTNERSHIP**
Stakeholders have direct involvement in the decision making process and actioning the decision. Each stakeholder has a clear role, set of responsibilities and powers – usually to achieve a shared common goal. Two-way communication is vital.

**PLACATION**
Stakeholders have an active role as shapers of opinions, ideas and outcomes, but the final decision remains with the facilitators. Two-way communication is essential.

**CONSULTATION**
Stakeholders opinions and views are sought through various means, but final decisions are made by those doing the consulting.

**INFORMING**
Stakeholders are kept informed of what is going on, but are not offered the opportunity to contribute themselves. Communication is one way.

**THERAPY**
To educate or cure the stakeholders. The idea is defined and the participation is aimed only to gain public support. ‘If we educate the stakeholders, they will change their ill-informed attitudes and they will support out plans.’

Source: Adapted from the original by S. Arnstein
Your journey

Being aware of time

☑ Share something extraordinary about patient / service user engagement from your experience
☑ KISS

☑ Tell your story – what did other hear & learn
What % of your true potential are you working at?

What will you do if you take 51% responsibility for making a change?
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