Involving patients and the public in decision-making in health and social care in the UK

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Patient and Public Involvement Lead
Centre for Public Engagement
• Influence and be responsive to the health and social care agenda of the government, including policy and planning, with respect to patient and public engagement

• Ensure that patient and public engagement is integral to all aspects of research, education, service development and patient safety within the Faculty

• Become a national and international beacon of good practice and innovation
What do we do?

- Research
- Consultation
- Education and Training
- Seminars and workshops
What is Public and Patient Involvement?

Why are we doing it?

How do we do it?
Lots of terms...

- Lay involvement
- Patient-centred
- Public and patient engagement
- No decision about me without me
- Patient voice
- Co-creation
- Shared decision making
- Co-production
- Service user involvement
- Public and patient involvement

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‘Patient and public involvement often appears to be a nebulous and ill-defined concept, used as an umbrella term to cover a multiplicity of interactions that patients and the public have with the NHS.’

*House of Commons, Health Committee (2007)*
‘For me, one of the fundamental distinctions is between involving people as citizens in hard choice decisions, maybe in commissioning, in the policy process of government and, at the other end, involving them as service users who have had the experience and can feed something back.’

Celia Davis – evidence to House of Commons, Health Committee (2007)
Clinical Commissioning Groups

- **Individual**
  Patients and carers to participate in planning, managing and making decisions about their care and treatment

- **Collective**
  Ensure the effective participation of the public in the commissioning process itself, so that services provided reflect the needs of local people
Individual level
“... patients and relatives felt excluded from effective participation in the patients’ care.”

Collective level
“The arrangement of public and patient involvement, and for local government scrutiny in Stafford, were a conspicuous failure.”

Francis Report (2013)
Two levels of PPI

- **Individual**
  - Patient/service user/carer
  - Decisions about individual care

- **Collective**
  - Public
  - Service design and evaluation; prioritisation and planning e.g. commissioning decisions

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Hickey (1993) participation continuum

Information/explanation → Consultation → Partnership → User control

Choice → Voice

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Devolving
Collaborating
Involving
Consulting
Informing

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The NHS aspires to put patients at the heart of everything it does. It should support individuals to promote and manage their own health. NHS services must reflect, and should be coordinated around and tailored to, the needs and preferences of patients, their families and their carers. Patients, with their families and carers, where appropriate, will be involved in and consulted on all decisions about their care and treatment. The NHS will actively encourage feedback from the public, patients and staff, welcome it and use it to improve its services.

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You have gone to see your GP about a troublesome ankle. There are a range of treatments available including seeing a physiotherapist, having an injection and taking some tablets. In the decision about what to do how much say would you like?

Information/explanation: You are happy to be given information about what the options are and leave it to the GP to decide what is best for you
Consultation: You would like the GP to take into consideration your views but leave the decision to him/her
Partnership: You would like to decide along with the GP about the best options for you
User control: You would like control of the decision about what to do.
Happy Town clinical commissioning group is planning what health services the area needs for the coming year. The clinical commissioning group is made up of GPs from the local area and at least one registered nurse and one secondary care specialist doctor. They want to involve the public more.

How much would you like to be involved?

Explanation/information: Happy to be given information on what they decide.
Consultation: Would be happy to fill out a questionnaire or be asked my views and then let the commissioning group decide
Partnership: Would like to be on the clinical commissioning group working with the professionals
User control: I would like to be in charge, along with other members of the public, of this decision
Just to recap...

Choice

Individual

Collective

Voice
Why?
Drivers for PPI

- Emergence of the service users’ movement
- Distrust of professionals
- The professions
- Government policy
It's not new...

- Community Health Councils
- Patient Advice and Liaison Service
- Patient and Public Involvement Forums
- Local Involvement Networks
- Patient’s Charter
- Health and Social Care Act 2001
- NHS Act 2006
- NHS Constitution

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Healthwatch Croydon
1. Develop our brand and awareness of us
2. Establish ourselves as a body that people can engage with
3. Engage with the bodies planning and scrutinising health and social care in Croydon
4. Engage with commissioners and providers of health and social care in Croydon
5. Improve access to services in Croydon
6. Champion consumer rights in the world of Health and Social care

https://www.youtube.com/watch?v=lyhSMUyt7FA
Purpose of PPI

- Better services
- Better health outcomes
- Quality of life
- Improve accountability
- Value for money
- Address inequalities
Twinkleton-on-Sea clinical commissioning group (CCG) is in the process of developing its strategy and plans for the upcoming year. A report on the area has revealed that people from particular socio-economic groups have poorer health outcomes and are less likely to access many of the health services on offer.

The CCG have included members of the public on their commissioning board and are about to consult the public on views about where the CCG should be spending its money. What benefits do you think might arise from engaging the public?
Agnes is an 80 year old woman living in a nursing care home. The care home organises a range of activities for the residents including day trips to the seaside, evenings at bingo and trips to the theatre. Staff are making greater efforts to engage Agnes in the decisions about what activities she would like to participate in.

What might be the purpose or benefits of doing this?
Right thing to do

http://www.youtube.com/watch?v=NANgbOHGsZ8
How?

- Individual
  - Self management
  - Shared decision-making
  - Personal care planning

- Collective
  - Identify needs and aspirations
  - Develop priorities, strategies and plans
  - Design and improve services
  - Procure services
  - Monitor services

www.healthcare.ac.uk/cpe
PPI and the commissioning process

The Engagement Cycle

- Engaging communities to identify health needs & aspirations
- Engaging the public in decisions about priorities & strategies
- Patient centred procurement & contracting
- Patient centred monitoring & performance management

www.healthcare.ac.uk/cpe
Kingston CCG: Mechanisms for engaging with patients and public

- Patient reference group network and forums
- Stakeholder database
- Via front line staff
- Individual GP practice surveys
- Joint strategic needs assessment
- Local consultations around service change
- Large-scale service reconfiguration
- Kingston CCG Board meetings
- Via Kingston Healthwatch
- Via One Kingston
- Via voluntary organisations
http://www.youtube.com/watch?v=VZVIYLVvH6M
Conclusions

- What?
  - Individual/collective
  - Choice/voice

- Why?
  - Better services
  - Better health outcomes
  - Quality of life
  - Accountability
  - Vfm
  - Inequalities
  - Human right

- How?

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If you don't design your own life plan, chances are you'll fall into someone else's plan. And guess what they have planned for you? Not much.

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Making sense of the NHS