



educational programmes for people delivering healthcare

Why involve? why partnership?

Content notes

This session enables participants to explore their antagonisms as well as their fears, and share their own experiences about sharing decisions with patients.

It explores what affects the relationship and the factors contributing to imbalance.

Background to involvement

The emphasis on public involvement is not new, there have been numerous attempts over the years. There have been language changes to reflect the value base of those promoting it.

Participants need to understand a little about previous initiatives and discuss the language used so that they feel comfortable about the language that they use now.

The movements are described in skeletal form.

Public Service: when the NHS was established in 1948 it drew its ethos from the climate of the times. Public service was new and built on the belief that it would facilitate cohesion in society. Services were shaped by professional interest. Few checks and balances were included.

Example: special interests of individual consultants often shape service delivery rather than the needs of the community.

Planning: By the 1960s there was a reaction to the pre-eminence of technology and central planning. Campaigners sought a greater say for communities in the decisions made on their behalf, which included a campaign for the patient voice when a new management system for the NHS was being discussed.

As a result, in the 1974 re-organisation of the NHS, Community Health Councils (CHCs) were established. CHCs and Councils for Racial Equality were the only two agencies established by statute. Other user groups, such as tenants associations, were established by Local Authorities.

CHCs were pioneering, bold, and very radical. They facilitated involvement and were perceived as a threat to managers and professionals. The NHS Plan, July 2000 proposes changes to existing, and new, structures for representing patients.

Community Development: the movements of the late 70s were about challenging the knowledge base of professionals and valuing lay/users knowledge.

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Example: the development of self-help, advocacy and community development projects working to build on community wisdom.

Consumerism: the Thatcherite concern with consumers and markets introduced the language of consumerism to the public sector so passengers became customers and patients consumers. This model sees service users as individuals and there was a shift from the group representation of the 70s.

Charters defining rights were introduced together with the use of patient satisfaction surveys by managers. This resulted in the greater visibility of the user of services. Considerable resentment was caused among professionals by the requirements to have a charter, and its emphasis on patients' rights of consumerism, and little change of culture followed.

Empowerment: this was a response to the perceived passiveness of consumerism in health care and the recognition that this was in part the result of the huge power imbalance between professionals and users of services. The focus was on finding ways of giving patients the confidence to challenge.

Most work was done in the learning disability field and with mental health users. Within the acute care sector it focused mainly around obstetrics and paediatrics.

Partnership: In the documents put out by the NHS Executive in the mid-90s, user participation and empowerment are used interchangeably.

Partnership has increasingly begun to be used for relationships between institutions suggesting a relationship of equality. Still widely used by commercial and professional groups that are engaging with issues that require user legitimisation.

Example: 'partnership in medicine taking' a strategy to get patients to take medicines as they are prescribed, relabelled concordance.

Involvement: 'Patient and Public involvement in the new NHS' 1999 says that Health Improvement Programmes and Health Action Zones are founded on the notion of partnership. The language in this report is not prescriptive and the examples cover work described as partnership, involvement, participation, community development and although the word is not used, it draws heavily on work which identified patients as consumers. It is also part of the government's concern to develop active citizenship.

Modernising relationships: The NHS Plan 2000 says "the relationship between service and patient is too hierarchical and paternalistic. It reflects the values of 1940s public services. Patients do not have their own health records or see correspondence about their own healthcare. The complaints system in the NHS is discredited. Patients have few rights of redress when things go wrong". "When the NHS was created it gave Britain a healthcare system in tune with the times. Today its values and principles hold good but NHS practices have become outdated. Too much of what the NHS does and how it does it belongs to a different era.

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The challenge for the NHS is to prove it can reform its practices to match the high ideals of its principle to remove the fault lines it inherited from 1948”.

So, public service comes full circle.

Section 11 of the Health and Social Care Act 2001 put a new statutory duty on all NHS Trusts to involve and consult patient and public in service planning, operations and the development of proposals for change *not only* when a major change is proposed but in ongoing service planning, and decisions about general service delivery. *Not just* in consideration of a proposal but in the development of that proposal.

There a raft of new bodies including the Commission for Patient and Public Involvement in Health. A series of policy guides outline these at <http://www.4ps.com/programmes/resources/topics/topicindex.htm>

Staff often feel overloaded by the need to respond to initiatives. It is vital that patient involvement is not simply seen as something extra to do.

Some exercises

Why do we need involvement?

This works well in small groups and engages participants in debate, helping them to clarify their own views.

What language do we feel comfortable with when describing the users of our service?
What language do we use to describe ourselves when we use services?
What words are we comfortable with when discussing the involvement of users?

People need to recognise that

- there is no right answer
- a given situation may make some descriptions inappropriate or alienating
- careful attention must be given to language used.

Looking at who shapes the partnership

Discuss

- ways a workplace adapts to the needs of its users
- which patients are too demanding and demonstrate with examples
- who shapes the partnership? who has power to shape it?

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Learning from being a patient

Start with a whole group mental exercise, asking participants to close their eyes and visualise their GP practice or a recent hospital visit

Then work in pairs describing to neighbour

What did you see?

What first strikes you?

Is there something that makes you feel good?

Something that irritates? etc. etc.

Then give them a magic wand to change one thing.

Work in groups to look at what they learnt.

- to what degree can we empathise with patients?
- can patients trust the unit you visualised?
- does it adapt to the needs of users?
- where are the stress points?

Patient Friendly Criteria for Why involve, why partnership?

The health care team should

- be able to describe what it means by patient and public involvement
- demonstrate effective and reflective team working
- practise in a way that meets the needs of both patients and staff

Baseline for working towards accreditation: be able to describe what it means by patient and public involvement.