Overcoming Challenges in Patient and Public Involvement

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Introducing patient and public involvement

Objectives

1. Consider the purpose of involvement, what to achieve and why?
2. Reflect on the influence of complaints
3. Be introduced to the core values for involvement including the need for plain English
4. Identify groups and individuals to involve
5. Reflect on the importance of building relationships and developing roles
6. Be introduced to approaches to involvement
7. Learn how to capture the difference involvement can make
Learning together

Take 5 minutes

1. Why should we work together with patients, carers and families?
2. What could the benefits be?
3. What are the risks?

Get ready to report back
Why?

Individual
• To improve the quality of care and patient’s experience
• To ensure appropriate and effective treatment and care
• To reduce complaints and litigation

Collective
• To increase public understanding of health issues
• To promote efficient use of resources
• To promote health and reduce inequalities
(Coulter, 2011)
Balance

Benefits
• Knowing rather than assuming
• Gaining insight from both the patient and staff perspective
• Building trust
• Demystifying how healthcare works

Risks
• Raising expectations
• If not done well, reinforcing adversarial relationships

Risks can be mitigated by being clear, systematic and by managing expectations.
What’s the difference?

Engagement
Providing information, can be a one-way flow.

Involvement
Active, being part of something which you can shape and influence.

Complaints
Critical learning opportunity. When resolved can support further involvement.
Values – How to work together

(from National Involvement Standards 4Pi)

A commitment to:

• Improve services
• Listen with respect and openness
• Make changes in response to the views of service users and carers
• An open-minded approach to cultural differences
• Inclusivity, equality of opportunity and fairness
• Clarity and transparency
• Sensitivity about language and actions
Guidance

"Nothing about us without us"

4Pi National Involvement Standards

Public involvement in research: values and principles framework

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Plain English

What is the task of involvement? PPI….?

Our problem
We notice that patients are not receiving…

We need your help
To understand what is actually happening…

So that we can improve
What happens for similar patients…
Learning together

Take 10 minutes

What could the task of improvement with patients and carers be in this collaborative?

1. Is it about clinical care?
2. Could it be about safety?
3. Could it be about the experience of care?
4. Who needs to be involved?

Get ready to report back
Getting started
National Involvement Standards

• A framework to enable people to think about and implement the involvement of service users and carers in any aspect of services, organisational governance and research.

• The 4PI Standards: Principles ~ Purpose ~ Presence ~ Process ~ Impact – provide a simple framework with which to approach involvement, in almost any activity and in diverse fields.
Have target groups (to involve) been clarified by the theme/project team? (Presence)

If yes, then:

- Look at existing data such as Hospital episodes statistics, Prevalence statistics, or local variations in patient experience can be useful to help you understand the characteristics or demographics of target groups.

- Break down people who need to be involved by thinking about who has knowledge/skills/networks important to achieve the theme/project aim.

If no, then:

- Think about whether these groups need to be involved and engaged on an ongoing basis, or periodically. This may help you understand the "process" – how you will involve and engage them. It may help you understand whose experiences can help shape the improvement and/or those who should be involved on a more ongoing basis.

- Which people can offer local knowledge? (e.g. involve porters & other staff, or patients/carers who access related services)
- Who can offer more strategic knowledge (e.g. Healthwatch, community & voluntary sector, CCG representatives)

Tips:

- When involving patients/public/carers, the evidence shows the need for:
  - Preparation meetings/time
  - Ensuring patient/public/carers getting involved with the theme have this, helps manage expectations & clarify roles
  - Strength in numbers

Roles should be created by the team but these examples have been adapted from roles in the 4PI document:

1) Ambassador (i.e. committed to the ethos of the work stream or programme, promoting it, spreading the word, engaging others)
2) 'Critical friend' (i.e. people able and prepared to engage in meaningful debate to strengthen the improvements being made and the work programme)
3) Co-worker (i.e. working directly with programme members to deliver the work of the programme)
4) Community Champion (People who engage communities in their own health, and build bridges between them and services); (see http://communitychampionsuk.org/)
5) Expert by experience (this could be someone who has direct experience of using the service/or has a health condition related to the improvements you are making)
Process – How?

• 1:1 Informal conversations
• What matters to you?
• Small group work
• Surveys – use with caution
• Social Media
• Events

Consider resources, experience and time
Impact

The ‘so what’?

• Be systematic – Plan, Do, Study, Act
• In planning make predictions, what do you think will happen?
• In studying, what actually happened?
• What did you learn together?
• What would you do differently next time?
More information?

Patient and Public Engagement and Involvement eLearning Module

QI4U

Action effect diagram
Plan Do Study Act cycles PDSA
Public and patient engagement/involvement
Process Mapping
Long Term Success
Measurement for improvement
Mental and physical wellbeing
Stakeholder engagement
Thank you

Any questions?

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