Working with patients, carers and the public: how to get it right

Monday 18 October 2021

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Your hosts

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What we will cover

• What do we mean?

• Why do it?

• How to involve people
What do we mean?

Working with patients, carers and the public
A few definitions.....

Involvement

• Working with patients, carers and the public to improve care delivery, research, innovation and education for the whole population
• Aims to improve everyone’s care, by making it more personalised, more person-centred

Engagement

• Taking ideas out to patients, carers and the public
• First contact, rather than involving or working with e.g. at festivals or community events
Experience

• Listening to, and acting on, what patients, carers and the public think and feel
• Collecting, understanding and using patients’, carers’, the public’s and staff’s thoughts and feelings about care, research, education and innovation

Coproduction (Social Care Institute for Excellence co-production charter)

• “A relationship where professionals and citizens share power to plan and deliver support together, recognising that both have vital contributions to make in order improve quality of life for people and communities”
Why do it?

Because you are told to

It makes a difference!

It’s the right thing to do!
Because we are told to
Why do it?

Because you are told to. It makes a difference!

Why does anyone do anything?

It’s the right thing to do!

It makes a difference!
Why do it?

- It’s the right thing to do!
- Who knows best?
- No decision about me without me!
## Top three goals and concerns for breast cancer decisions

<table>
<thead>
<tr>
<th>Concern</th>
<th>Patient</th>
<th>Clinician</th>
<th>Importance</th>
</tr>
</thead>
<tbody>
<tr>
<td>Keep your breast?</td>
<td>7%</td>
<td>71%</td>
<td>P&lt;0.01</td>
</tr>
<tr>
<td>Live as long as possible?</td>
<td>59%</td>
<td>96%</td>
<td>P=0.01</td>
</tr>
<tr>
<td>Look natural without clothes</td>
<td>33%</td>
<td>80%</td>
<td>P=0.05</td>
</tr>
<tr>
<td>Avoid using prosthesis</td>
<td>33%</td>
<td>0%</td>
<td>P&lt;0.01</td>
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"It’s the right thing to do!"
It’s the right thing to do!
You don’t know what you don’t know!
Why do it?

It makes a difference!
Patient experience is positively associated with:

- self-rated and objectively measured health outcomes
- adherence to recommended medication and treatments;
- preventative care such as use of screening services and immunisations;
- healthcare resource use such as hospitalisation and primary-care visits;
- technical quality-of-care delivery
- adverse events

It makes difference!

BMJ systematic review Stacey 2011
How to involve people
### Why?

#### What skills or experience do you need?

| Skills or experience                                                                 |  
|-------------------------------------------------------------------------------------|---|
| • What it is like to have a specific condition, use a specific service, or part of a particular community? | Experts by experience |
| • Representation for a specific condition or community                                 | patient/public orgs or groups eg charities |
| • Views outside the system                                                             | General public, citizens, lay people |
| • Involvement methodology                                                              | professionals who work in involvement |
## Ways to reach people

<table>
<thead>
<tr>
<th>Type of person</th>
<th>Ways to reach them</th>
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</thead>
<tbody>
<tr>
<td><strong>Experts by experience</strong></td>
<td>• Healthcare professionals</td>
</tr>
<tr>
<td></td>
<td>• Voluntary organisations and charities</td>
</tr>
<tr>
<td></td>
<td>• Organisational website</td>
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<tr>
<td><strong>Patient/community groups</strong></td>
<td>• Local Council and Voluntary Services</td>
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<tr>
<td></td>
<td>• Local groups eg PPGs a BME community group</td>
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<td></td>
<td>• Consumer health groups eg Healthwatch</td>
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<tr>
<td></td>
<td>• National Voices - coalition of charities</td>
</tr>
<tr>
<td></td>
<td>• Association Medical Research Charities</td>
</tr>
<tr>
<td><strong>General public, citizens</strong></td>
<td>• Personal connections, social media, public engagement events or even people on the street etc etc</td>
</tr>
<tr>
<td><strong>Involvement methodologists</strong></td>
<td>• INVOLVE (public participation charity)</td>
</tr>
<tr>
<td></td>
<td>• NHS engagement/experience leads</td>
</tr>
<tr>
<td></td>
<td>• National Institute for Health Research</td>
</tr>
</tbody>
</table>
The Tokenism Cycle

Involvement under-valued...

it is done badly...

it makes little impact

and is further devalued...

Adapted from Jenny Popey
Know **why** you want to involve people

.......and then decide on

**who** and **how** you want to involve them
The payment question

No Decision About Me Without Me

Healthwatch

Inform
Patients, carers and the public informed about what is happening

Involve
Active members of focus groups, projects, working groups, etc.

Partner
Members of strategic groups or boards

The Public

Voluntary & Community Sector

Involvement, Engagement, Experience

Not paid

Travel & Expenses

& time
How to involve people
Stages of involvement

Co-Evaluate
Co-Define
Co-Distribute
Co-Design
Co-Decide
Co-Deliver

Why?
Start Here
Measure and use experience data

THE WAY I FEEL IS HARD TO QUANTIFY!

HOW HARD - ON A SCALE OF ONE TO TEN?
‘So I can see that this person is not only a human being, but he is also a father, he is a son, he is a brother, he is a friend, he is a cousin, he’s a plumber or an electrician, he is a sportsman, he has an interest in horse riding, whatever it happens to be. He has a dog, he has a budgie, he has plans, he has expectations, he has regrets, he has feelings.’

‘I have already changed the way I think and care for patients even though we haven’t started implementing changes yet. I have a better understanding now of how things are from the patients’ perspective.’

‘An extremely valuable learning experience. I am a better nurse because of it.’
Experience is not the same as satisfaction

“The other thing I didn’t raise and I should have done because it does annoy me intensely, the time you have to wait for a bedpan. ….elderly people can't wait, if we want a bedpan it’s because we need it now. I just said to one of them, ‘I need a bedpan please.’ And it was so long bringing it out it was too late. It’s a very embarrassing subject, although they don't make anything of it, they just say, ‘Oh well, it can't be helped if you’re not well.’ And I thought, ‘Well, if only you’d brought the bedpan you wouldn't have to strip the bed and I wouldn't be so embarrassed.’

Patient survey

Overall, did you feel you were treated with respect and dignity while you were in hospital?

Yes, always

Overall, how do you rate the care you received?

Excellent
Patient and staff shadowing
Appreciative Inquiry

Asset Based

Look at what we've got!!

Look at what we're missing!!

Deficit Focused

© J. Logan 2012
Appreciative Inquiry: key ideas

• Whatever you want more of already exists in a group or an organisation

• What is working well around here?
  • In every group or organisation, something works

• What we focus on becomes our reality, if we look for problems, we will find them and….
….and there are multiple realities

My doctor’s mug.... My mug....
The Language of Health

A video of the importance of using language that is accessible and easily understood by patients, carers, and the public.
Top Tips.....

• Be mobile and prepared to go where people are
• Don't expect people to come to you
• Find out what people are interested in and work from there
• Be open to new ideas
• Beware the 'gatekeepers'
• Take a broad view of what is representative
Top Tips (2).....

- Be aware of your *language* and how you communicate
- Manage *expectations*
- Keep a handle on the *practical* and *often small*
- Remember to *feed back*
In summary .....
Thank you for joining us
Any questions please
email us at
community.involvement@oxfordahhsn.org