

### Where are the stakeholders in implementation science?

Annette Boaz

Centre for Health and Social Care Research

St George's University of London and Kingston University

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### What patients do and their impact on implementation

An ethnographic study of participatory quality improvement projects in English acute hospitals

Annette Boaz, Glenn Robert, Louise Locock, Gordon Sturmey, Melanie Gager, Sofia Vougioukalou, Sue Ziebland and Ionathan Fielden



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Original Research Paper

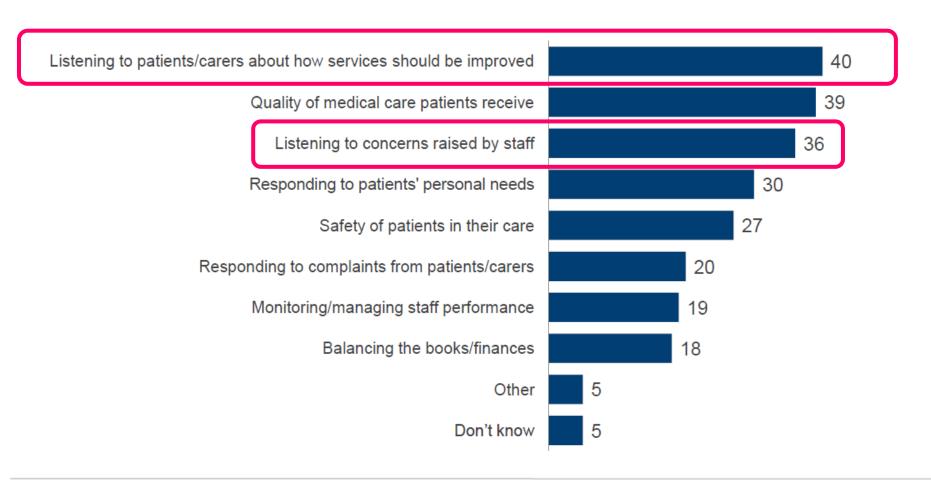
Rethinking the relationship between science and society: Has there been a shift in attitudes to Patient and Public Involvement and Public Engagement in Science in the United Kingdom?

Annette Boaz BA MSc PhD ☑, Despina Biri MA MSc, Christopher McKevitt BA (Hons) PhD



#### Where the NHS needs to improve

Based on your personal experience of the NHS, which two or three of the following do NHS hospitals most need to improve?



Base: All (1,010), 13TH - 16TH April 2013

#### Ipsos MORI

Social Research Institute





Following

#### What is patient and public involvement in research and why does it matter? bit.ly/1WI6WiV



RETWEETS

6

LIKES











### Parallel or connected?

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#### Patient and Public Involvement in Research



Why Public Involvement in Research?

The experience that researchers and clinicians have of healthcare services often comes from a specialised and expert point of view. Patients and members of the public provide a different way of looking at things that can ground the discussion in practical experience. The lay perspective can make clear things that are so obvious the professionals have stopped noticing them and ask 'naive' but important questions that the experts are too well trained to think of.

Development of Patient and Public Involvement (PPI)

Interest in the role of 'stakeholders' in promoting implementation and improvement

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Update on PenCLAHRC's research prioritisation process

Posted on December 14th 2016

## Understanding the relationship between research, policy and practice

Linear models



Relationship models



Systems models

Quality Improvement Science and technology studies

Evidence based medicine Evidence based policy and practice Knowledge transfer (and exchange)

Knowledge mobilization

Using research evidence

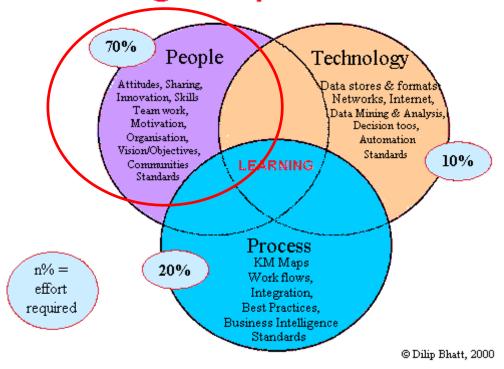
Implementation science

Ways of understanding the relationship between research, policy and practice

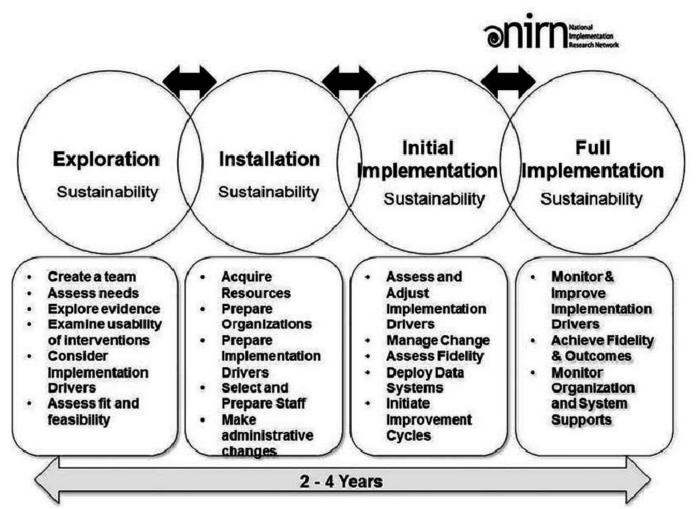
## Where are the stakeholders?

Knowledge transfer (and exchange)

#### **Knowledge Components**



## Implementation science: where are the stakeholders?



### In terms of what we know might work we have a lot going on:

1. **Absorptive capacity**: (incl. Changes in the structure of institutions, changes in human capital

Training/updating staff, enhancement of group and individual behaviour

- 2. Improvements in the processes of care related to conducting a specific trial
- 3. Organisational mechanisms within health-care systems
- 4. Collaborative approaches between organisations, teams and individuals
- 5. **Action research and participatory research** as mechanisms that improve relevance, understanding of research and willingness to use research

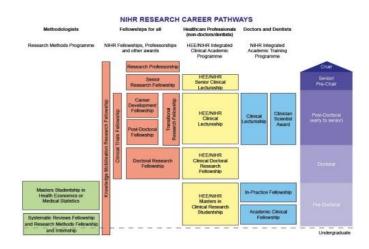


### Developing systems



**Clinical Research Network** 





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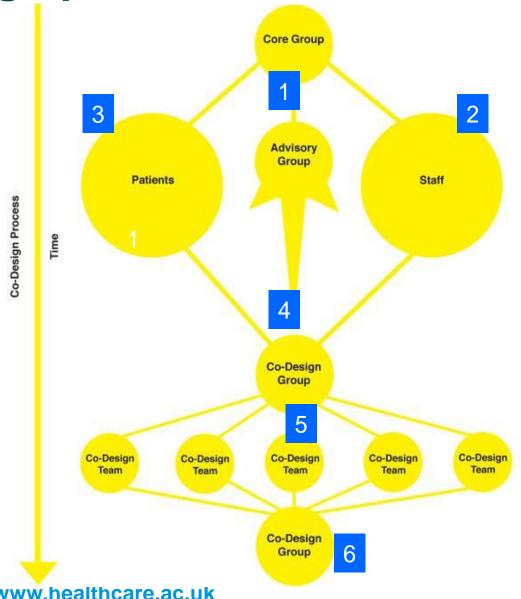




# Learning for experience based codesign: An example of participatory action research

A 6-stage design process

- 1. setting up
- 2. engaging staff & gathering experiences
- 3. engaging patients and gathering their experiences
- 4. bringing patients and staff together to share experiences & begin co-design
- 5. detailed co-design activities
- 6. coming back together: celebration, review & renewal



### Experience based co-design

#### Two key themes emerge from the data:

- A range of different roles were adopted by patients
- Changes championed by patients and carers were often small scale
- As co-designers patients provided innovative ideas and solutions
- Through their involvement and contributions they also acted as catalysts for broader change

All required on-going, skilled facilitation on and flexibility



## Participant roles in EBCD at different stages of the process

		Particip ant roles					
		Sharing experiences	Identifying improvement priorities alongside staff	Developing potential solutions with staff	Helping implement & evaluate solutions		
Intervention Stage	Patient event						
	Joint event						
	Co-design group						
	Celebration event						
	Follow-up quality improvement activity beyond the formal stages of EBCD						

## Types of change identified by clinical theme

'I wondered what, if anything, will be taken on board. To be honest with you, everything has been taken on board, and that in itself was a complete surprise.' (Patient interview)

	Examples of changes identified by clinical themes			
Lung cancer	Acquiring more comfortable V-shaped pillows for post-operative patients			
Lung cancer	Identified and modified private room for receiving support after the diagnosis			
Lung cancer	Patient support group established			
Lung cancer	A new process for effective transfer of patients belongings (including dentures and frames) from theatre to the recovery ward			
Lung cancer	Patients made aware of support available through clinical nurse specialist			
Lung cancer	Consultants agreed to send summary letter to patients after consultation			
Intensive Care Unit	Sign created to enhance dignity and privacy			
Intensive Care Unit	Promoting the involvement of families in personal care via team news			
Intensive Care Unit	Promoting the washing of patients' hair more regularly via team news. New wash basin to be trialled			
Intensive Care Unit	Encouraging wards to send patients wash bags to ICU – email to all sisters and managers. Infection control view sourced			
Intensive Care Unit	Sourcing appropriate clocks to aid patient orientation			
Intensive Care Unit	Encouraging nurses to brush patients' teeth more regularly – via team news and through sourcing new toothbrushes to trial			
Intensive Care Unit	Promoting the correct application of CPAP (continuous positive airway pressure) masks. Creation of a guide and teaching on team days			
Intensive Care Unit	Informing patients about the potential for hallucinations – via rehab and therapies booklet			

## Patients and carers as catalysts for broader change

'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.'

(Nurse, intensive care, fieldnote of conversation)



### Participation in implementation science?





Eable A.5 Complex standard errors and confidence intervals of selected variables sometiment)								
Attitudinal variables		Complex	eenti-					
(face-to-face interview)	25 000	error of p	interval	DEFT	Sens			
Q. 270 Benefits for the unemployed are (	full samp	ne)						
too low	10.0	0.0	17.1-20.2	1.178	3311			
too high	62.2	5.5	60.1-64.4	1,289	3311			
Q. 391 How serious a problem is traffic con	gestion	n towns, ci	ties (full sam	npie)				
A very nericum problem	11.2	0.6	10.0-12.6	1.180				
A perious protects	29.5	0.9	97.8-01.2	1.107	3371			
Not a very serious problem	39.8			1.110	3371			
Not a problem at all	19.3	0.9	17.6-91.1	1.306	3371			
Q. 277 Who should mainly be responsible fo to live on if they become unemployed (full s	er ensuri	ng that peo	gle have en	ough				
Mainly the government	59.9	1.0	57.0-61.6	1.267	3371			
Mainly a person's employer	4.0	0.4	3.9-5.5	1.005	3371			
Mainly a person themselves and their family	33.4	3.3	31.3-35.5	1.297	3311			
Ex-Service personnel more likely Civilians more likely Ex-Service personnel and civilians equally likely	51.8 6.6	0.7	48.9-54.6 5.4-8.1	1.170	near road			
equally likely	38.3	1.4	35.5-41.1	1.170	AGA4			
Attitudinal variables (self-completion)								
A46a Government should redistribute incor who are less well off (full sample)	ne from 1	he better o	iff to those					
Riztia Agree strongly	8.0	0.6	6.0-0.2	1.127	2545			
CD4s Agree Neither agree nor disagree	29.5	1.0	27.0-01.0	1.180	2042			
Disagree	97.5	0.0	25.6-29.4	1.155	2041			
Disagree strongly	6.1	0.6	8.1-7.3	1,241	294			
B16 C15 Which of these statements comes general elections? (2/3 sample)	closest	a your view	w about					
Ds not really worth votes	16.0	1.0	14.4-18.0	1.709	1000			
People should vote only if they								
care who wins	20.7		18.6-22.8	1.137	1906			
It's everyone's duty to vote	62.0	1.4	50.1-64.5	1.202	1906			
Q. 365 Whether support or oppose National with lower incomes (1/3 sample)	Health I	iervice sho	suld be availe	able only to th	1050			
Support this idea a lot	6.4	0.9	4.8-8.4	1.216	109			
Support this idea a little	19.9	1.2	17.5-92.4	1.030	1000			
Oppose this idea a little Oppose this idea a lot	20.0	14	17.4-22.9	1.151	N096			
					-1906			
A36a People should be able to travel by pla								
Agree	61.5	1.0	57.9-64.9	1.113	83			
Nether agree nor disagree	22.0	3.0			936			

Detecting a subtle shift in core team attitudes to stakeholder engagement over time...

### Are we ready to share power?

'The defensive power' of the academic community

I don't think there is a lot of humility in the scientific community about their own need to be exposed, to..., because there is a certain elitism that floats around these circles in which people think they know the truth... So it's not that they're dying to get input from others and widen their perspectives.'

Sue, Research Fellow, Health Services Research



### Some questions....

- Will these concepts (implementation and participation) blend?
- Are there important differences between professional and lay stakeholders?
- Can we promote participation at a systems level?
- Can we be more creative to support participation?
- Is more consultation better than nothing?

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