



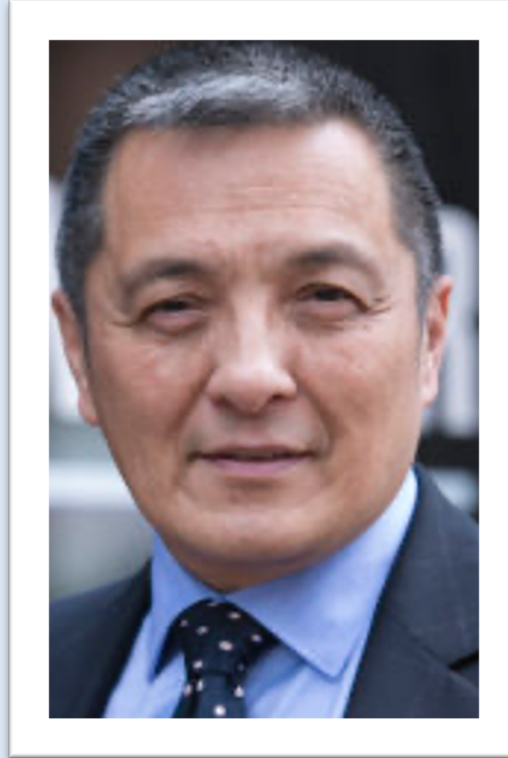
Working with patients, carers and the public: how to get it right

Monday 18 October 2021

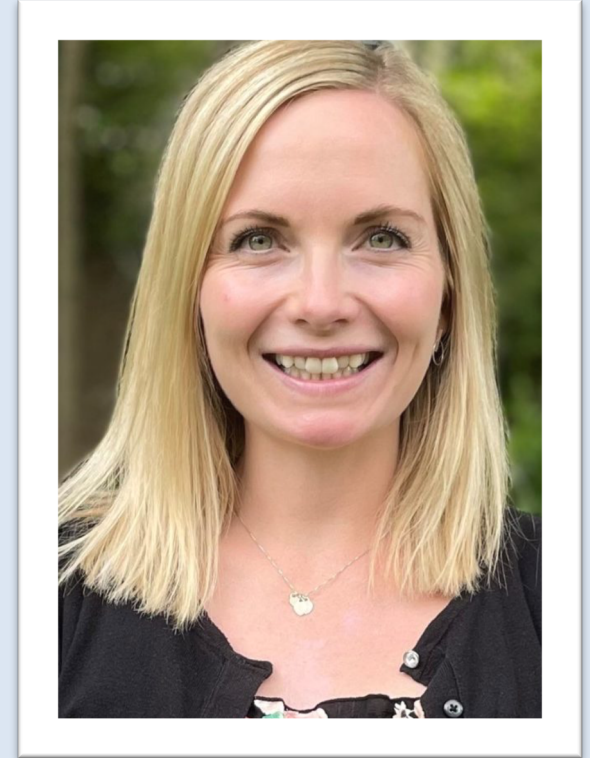
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**WORKING
TOGETHER**
Patient and Public Involvement
in the Thames Valley



NHS England and NHS Improvement



NIHR | Clinical Research Network
Thames Valley and
South Midlands

NIHR | Oxford Biomedical
Research Centre

NIHR | Oxford Health Biomedical
Research Centre

NIHR | Applied Research Collaboration
Oxford and Thames Valley

Oxford 
Academic Health
Science Network

What we will cover

- **What do we mean?**
- **Why do it?**
- **How to involve people**

What do we mean?



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?

Why does anyone do anything?



Because you are told to

It's the right thing to do !

It makes a difference !

Because we are told to



Integration and Innovation: working together to improve health and social care for all

Published 11 February 2021

The Department of Health and Social Care's legislative proposals for a Health and Care Bill



WE ARE THE NHS

People Plan



action for us all



Framework 15

Health Education England Strategic Framework

2014 -2029

Updated February 2017

General Medical Council

Regulating doctors
Ensuring good medical practice

Why do it?

Why does anyone do anything?



Because you are told to

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

Concern	Patient	Clinician	importance
Keep your breast?	7%	71%	P<0.01
Live <u>as long as possible</u> ?	59%	96%	P=0.01
Look natural without clothes	33%	80%	P=0.05
Avoid using prosthesis	33%	0%	P<0.01

*It's the
right thing
to do !*

Sepucha 2008

Hiro Tanaka's mother

([Link to audio](#))

*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 !*



Organisational care




*It makes
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

How to involve people

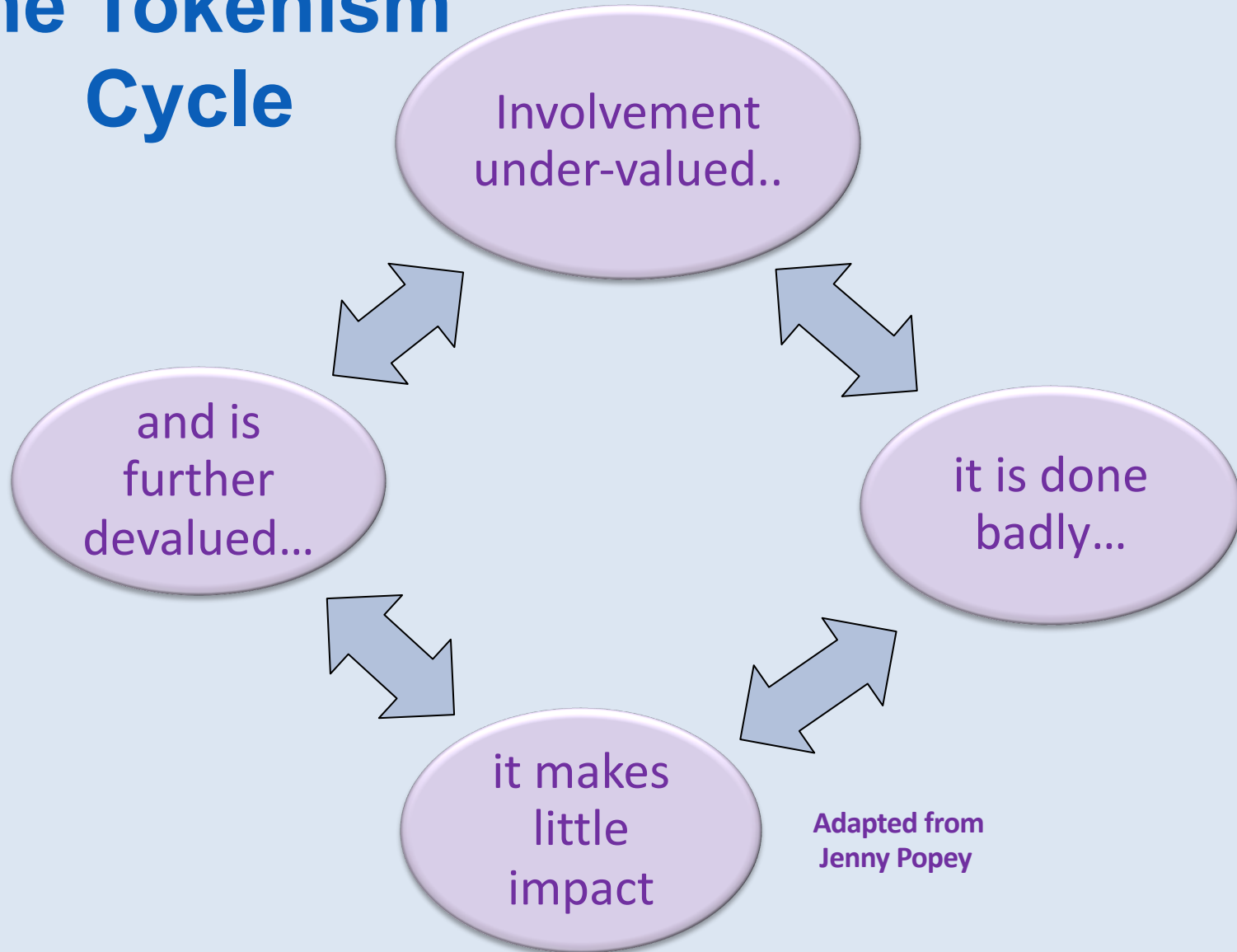


What skills or experience do you need?

Skills or experience	
<ul style="list-style-type: none">• What it is like to have a specific condition, use a specific service, or be part of a particular community?	<p>Experts by experience</p> 
<ul style="list-style-type: none">• Representation for a specific condition or community	<p>patient/public orgs or groups eg charities</p> 
<ul style="list-style-type: none">• Views outside the system	<p>General public, citizens, lay people</p> 
<ul style="list-style-type: none">• Involvement methodology	<p>professionals who work in involvement</p> 

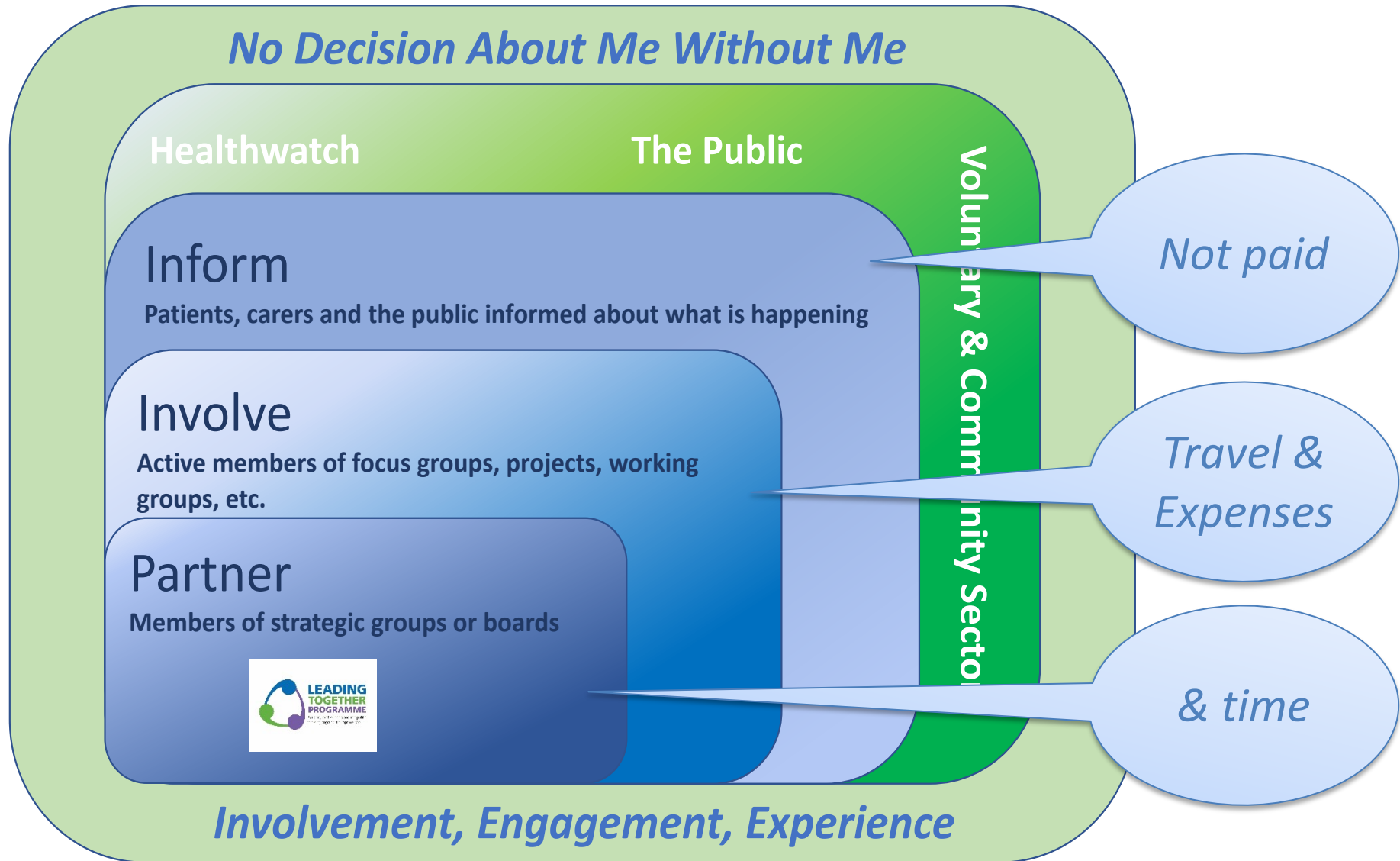
Type of person	Ways to reach them
<ul style="list-style-type: none">• Experts by experience	<ul style="list-style-type: none">• Healthcare professionals• Voluntary organisations and charities• Organisational website
<ul style="list-style-type: none">• Patient/community groups	<ul style="list-style-type: none">• Local Council and Voluntary Services• Local groups eg PPGs a BME community group• Consumer health groups eg Healthwatch• National Voices - coalition of charities• Association Medical Research Charities
<ul style="list-style-type: none">• General public, citizens	<ul style="list-style-type: none">• Personal connections, social media, public engagement events or even people on the street etc etc
<ul style="list-style-type: none">• Involvement methodologists	<ul style="list-style-type: none">• INVOLVE (public participation charity)• NHS engagement/experience leads• National Institute for Health Research

The Tokenism Cycle



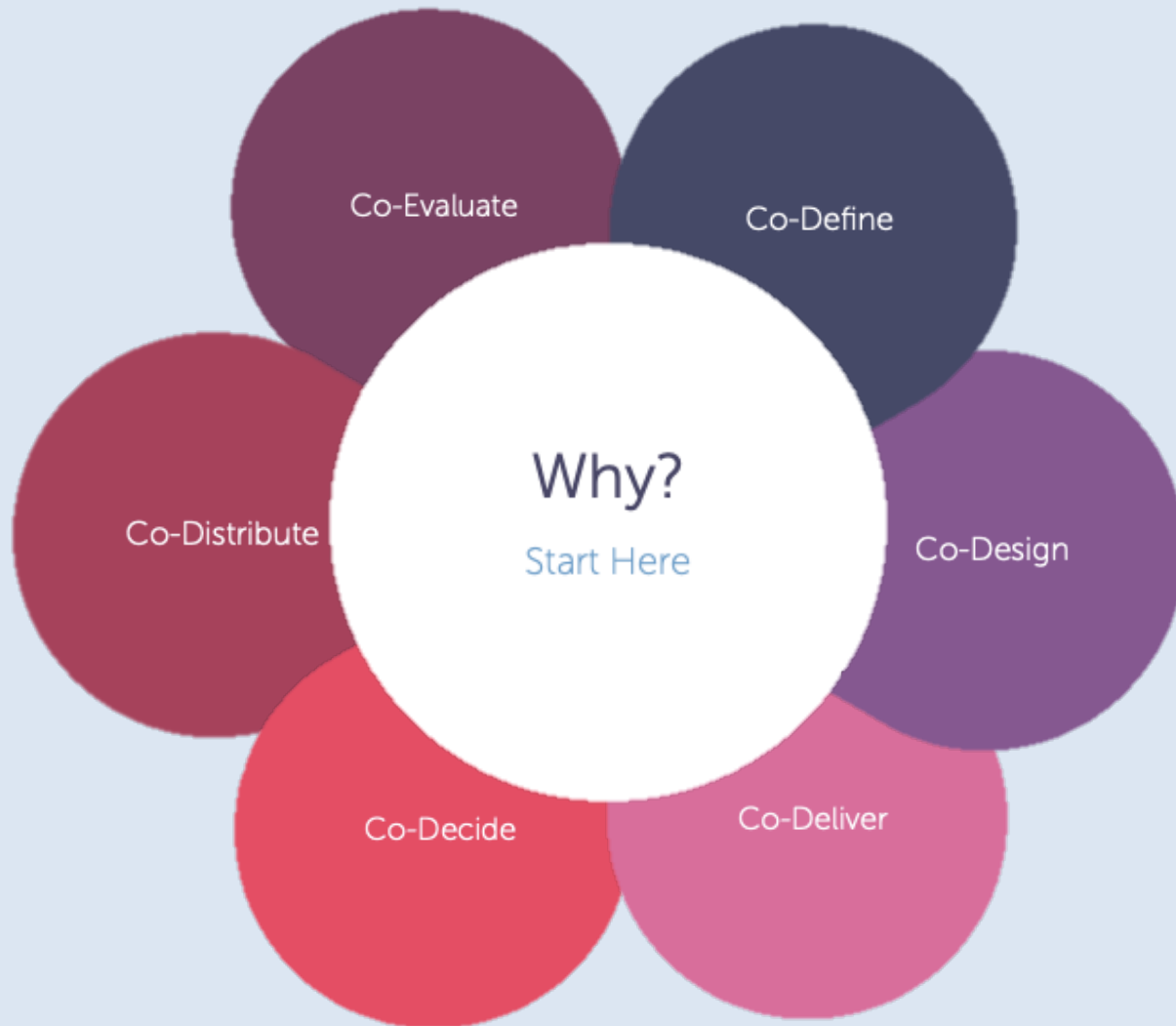
Know **why**
you want to involve people
.....and then decide on
who and **how** you want to
involve them

The payment question



How to involve people

Stages of involvement



Measure and use experience data



'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.'

What staff said..

'An extremely valuable learning experience. I am a better nurse because of it.'

'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.'

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

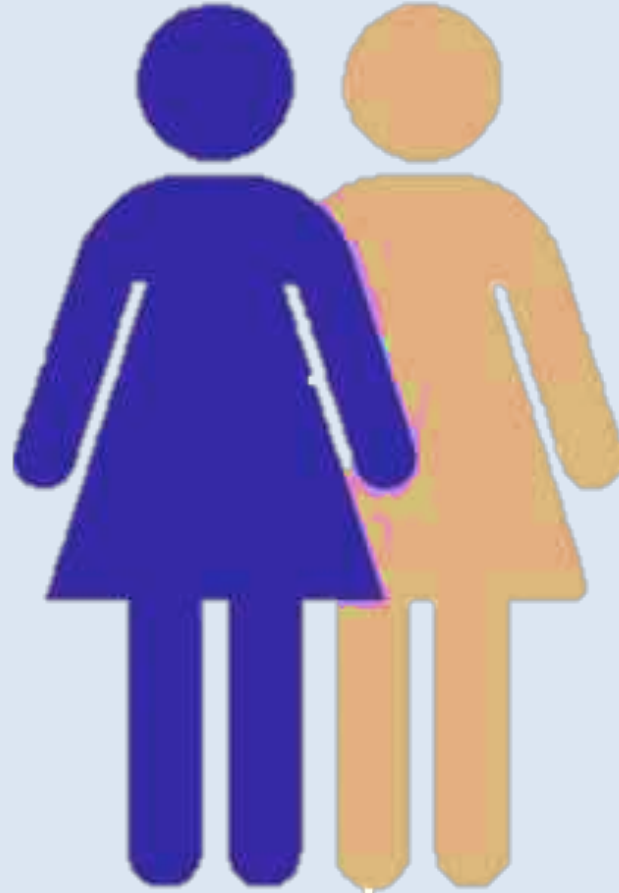
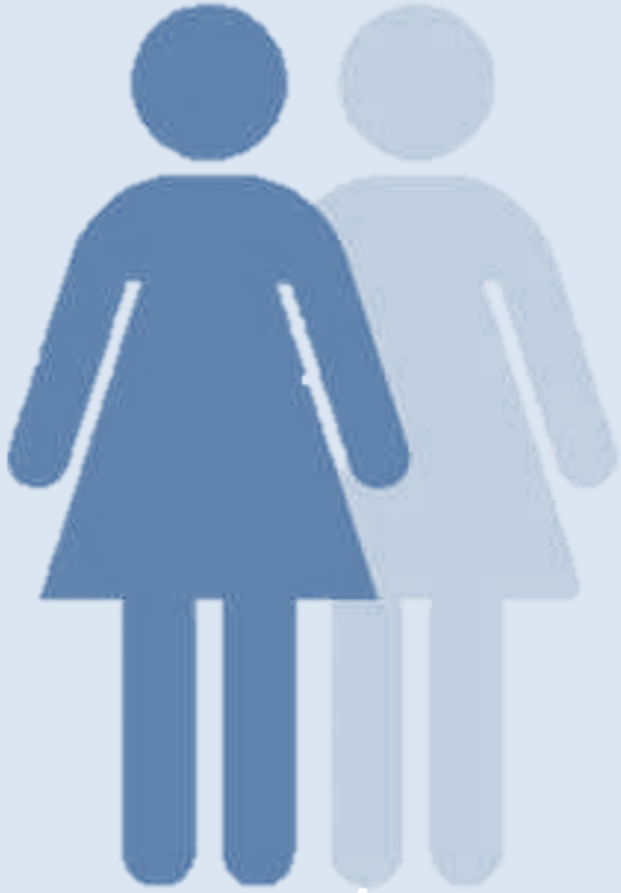
Overall, did you feel you were treated with respect and dignity while you were in hospital?

Yes, always

Overall, how do you rate the care you received?

Excellent

Patient and staff *shadowing*

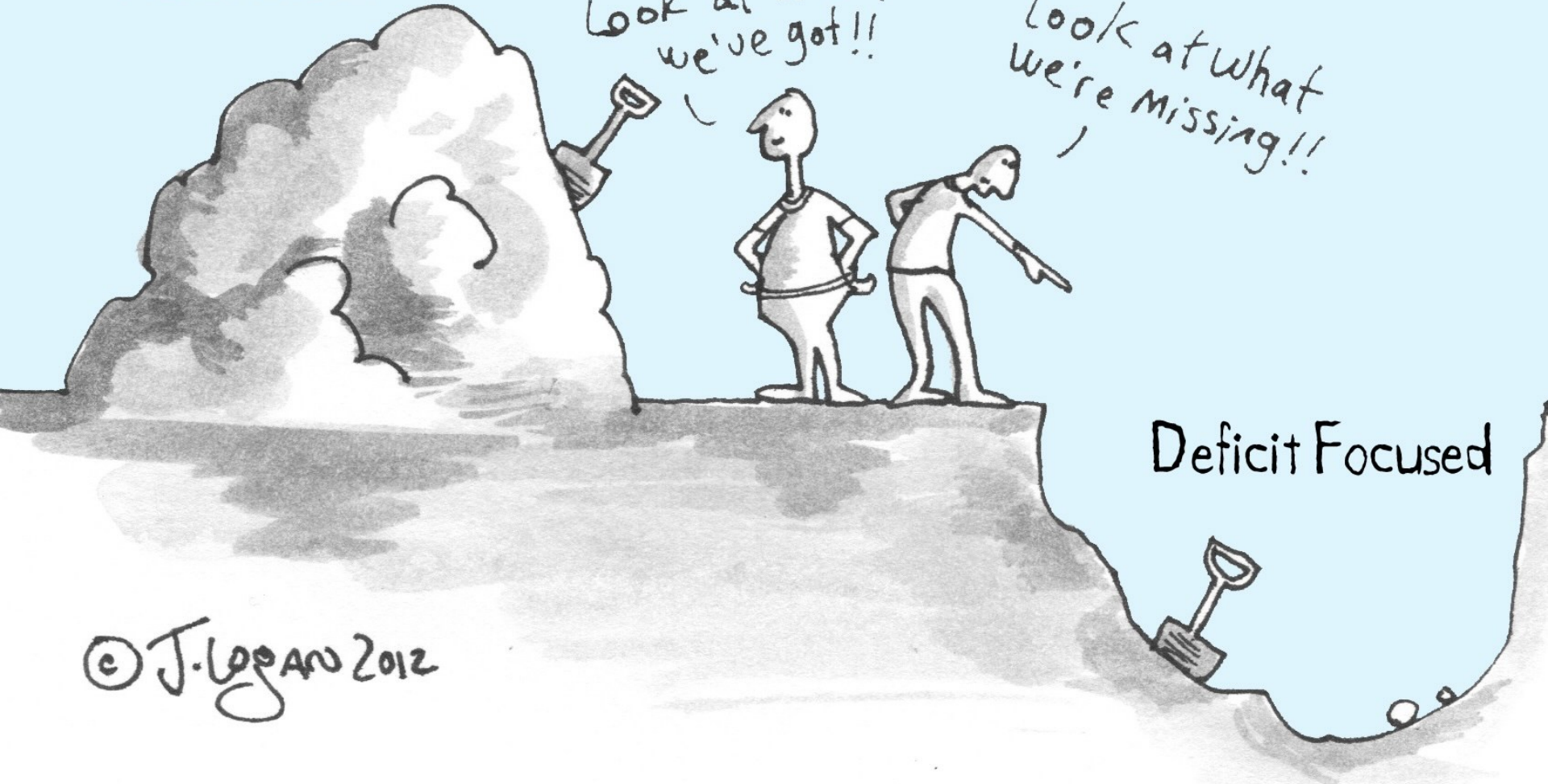


Appreciative Inquiry

Asset Based

Look at what we've got!!

Look at what we're missing!!



© 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 importance of language

(Link to video clip)

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


TRY TO INVOLVE AS DIVERSE A GROUP OF PEOPLE AS POSSIBLE




DO YOUR BEST TO ACCOMMODATE DIFFERENCES



CONSIDER THE TIMING & LOCATION OF MEETINGS



BE PREPARED TO MANAGE PEOPLES' EXPECTATIONS



THE AVERAGE READING AGE IN THE UK IS ABOUT 9 YEARS



Thank you for joining us

Any questions please

email us at

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