

# Patient involvement in cancer care: a matter of choice?

Vikki A Entwistle

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# Patients are 'of course' involved

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- Policy focus is on more 'active' involvement
  - in decision-making
  - in self care
  - in ensuring safety

# Involvement as a 'good thing'

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Involving patients can be both:

- (intrinsically) the right thing to do
- (instrumentally) a means to improve outcomes

**BUT:**

- There are complexities
- There may be tensions
- Current ways of thinking about involvement don't all acknowledge or help with these

# Involvement in decision making

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What should it look like?

Why is it important?

- To respect patient's autonomy
- To ensure individually appropriate care
- To reduce waste
- Because it can contribute to good outcomes

# Respecting autonomy (the usual thinking in healthcare)

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IF patients are competent,  
health services and staff should  
respect their autonomous choices.

- Autonomous choices are:
  - Made deliberately
  - Informed
  - Free from controlling influences

(See Beauchamp and Childress,  
*Principles of Biomedical Ethics*, 2009)

# Implications of prevailing views of respect for autonomy

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- To involve patients, clinicians need to:
  - Offer (and inform about) options
  - Elicit and respect choices (or preferences)
- There can be a partnership...
  - ... but there is also a division of labour
    - Clinicians bring professional knowledge of options
    - Patients bring knowledge of their preferences
- If clinicians do more than ‘informing’, they may stray into ‘controlling’

# A scenario (part 1)

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- Mr Jones has prostate cancer
- The doctor tells him about three treatment options.
- The doctor asks which Mr Jones would prefer.

Is this a good example  
of involvement in decision making?

# A scenario (part 2)

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- Mr Jones isn't sure which option he prefers.
- He asks the doctor which he recommends.
- The doctor says all options are reasonable, they just have different benefits and risks.
- The doctor insists Mr Jones must choose.
- (But Mr Jones can take information away, think about it, and let the doctor know later).



Is this a good example...?

# A scenario (part 3)

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- Mr Jones sees the cancer nurse.
- He tells her he is unsure which option to choose.
- In fact, Mr Jones is very anxious about the choice.
- Mr Jones asks the nurse what she would do.
- The nurse acknowledges it is a difficult decision.
- But her preferences may differ from his. What she would do might not be what he should do.
- She said she wasn't well placed to advise.

Is this a good example...?

# A scenario (part 4)

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- The clinicians both saw Mr Jones' difficulties and felt uncomfortable about them.
- But they still thought they should not have helped Mr Jones further with the decision.
- Because (they reasoned):

Mr Jones is a competent adult.  
To respect his autonomy,  
we must inform him but we should not  
interfere with his preferences.

What happens if clinicians think recommendations are needed?

If there's a clear treatment protocol, what 'options' should clinicians give?

- Involvement / respect for autonomy as
  - giving patients options
  - then not influencing their choicesdon't always seem appropriate.

Which clinical team members can involve patients?

Are there other ways of thinking about involvement in decision-making?

# Thinking about involvement

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A bank robbery!



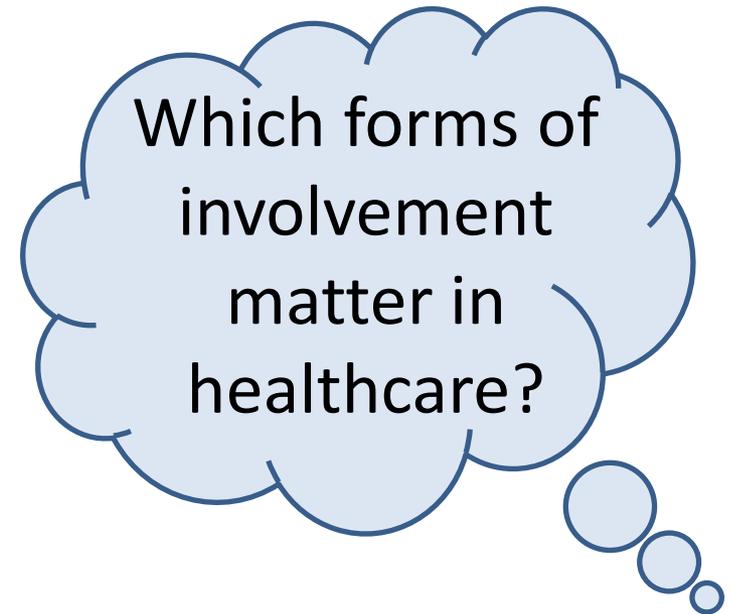
Who is involved?  
How?

- Gang leader
- Gang members
- Bank staff
- Bank customers
- Gang leader's mother

# Lessons from a bank robbery (about involvement!)

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- People can be ‘involved’
  - *In* activities
  - *With* other people
- Thoughts and feelings, as well as actions, can matter for involvement.
- Involvement can be more or less
  - actively sought and welcomed
  - visible to others
  - influential ...



# Involvement: patients' perspectives

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## It's hard to feel involved when:

It's so impersonal

When you're told "This is what you need" and there you go, that is it'... When people do not take account of how you are feeling.

If I try and get involved in the discussion, are they thinking "Look, I'm the expert: don't question me!"? Am I interfering? You do sometimes feel that.

## It's easier to feel involved when:

She's so open and friendly, I always feel welcome

Things are explained properly... I'm asked how I feel about what they are suggesting...

They talk to you on a level

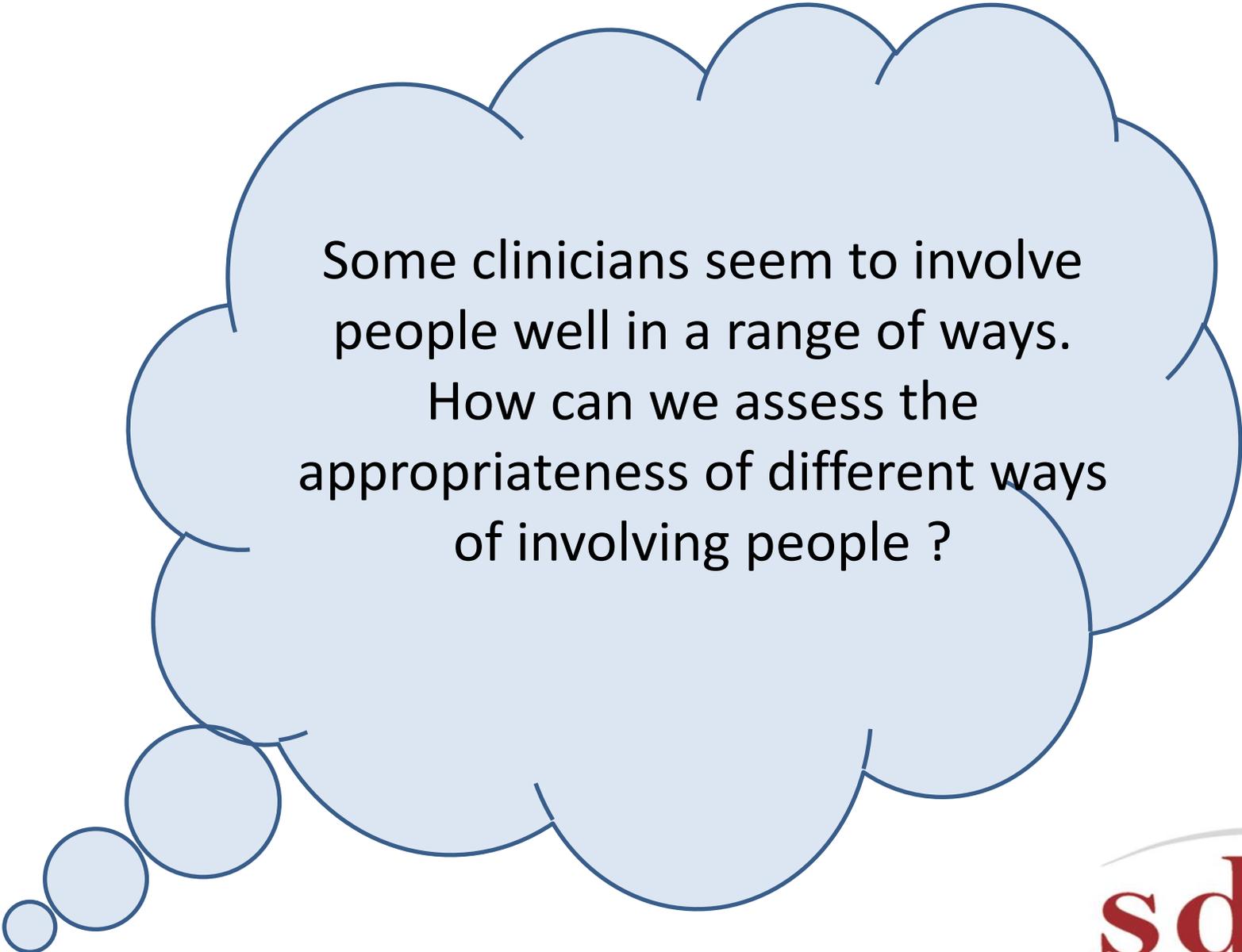
# Involvement 'in'

## broader aspects of decision-making

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- Recognise and clarify a health problem
- Identify potential solutions
- Appraise potential solutions (options)
- Select a course of action
- Implement the chosen course of action
- Evaluate the course of action



Some clinicians seem to involve people well in a range of ways.  
How can we assess the appropriateness of different ways of involving people ?

# Relational accounts of autonomy

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- Personal autonomy is basically about:
  - being our own person, shaping our own life
  - (not living under the oppressive control of others)
- Social contexts and relationships matter for this.
- We need to think *how social contexts and relationships affect capabilities for autonomy*
- Accounts variously encourage attention to, e.g.:
  - power relationships, motives, trust / self-trust
  - identification with, ownership and authorisation of decisions

# Implications of relational accounts

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- Include less 'competent' people
- Don't assume '> informing' is [bad] 'controlling'
- Can in principle justify more clinical support, for different forms of involvement...
- ... but not just anything goes!
- (Exploring options is often important)
- Think how clinicians *support* (or undermine) autonomy capability

# A scenario

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- Mr Jones has prostate cancer
- The doctor tells him there are several options...

What can follow and be a good example of involvement in decision making?

# Patient involvement

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- **NOT a matter of choice (for services and staff)**
  - Patients are always involved in some senses
  - Supporting appropriate involvement
    - is a matter of doing the right thing (ethics)
    - is important for good quality care
- **MORE THAN a matter of choice (for patients)**
  - Being offered a menu of options is not enough
    - To respect / support autonomy
    - To ensure appropriate experiences of involvement
  - Involvement *with* staff and *in* healthcare matter
- **Needs to be facilitated carefully, underpinned by appropriate theory**

# Healthcare relationships shape patients' capabilities for involvement

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Thank you.  
Questions and discussion welcome!

[v.a.entwistle@dundee.ac.uk](mailto:v.a.entwistle@dundee.ac.uk)

# Patient involvement in patient safety



- Formal permission is not enough!
- Patients' capabilities are shaped by healthcare contexts.
- Support for involvement in one domain can support involvement in others.

Patients' and family members' ability to 'speak up' depends on how health care staff relate to them.

# Professional woman, after surgery for breast cancer

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I tried to [challenge]  
when somebody didn't use the hand gel  
when they came to change my drip,  
but I made such a hash of trying to say  
'It says on that notice that I can challenge you',  
and he misunderstood and brought me some hand gel,  
still went ahead and did me,  
and I thought I'm not going to ask again.  
I tried and got it all wrong...  
I obviously didn't express it in a way he understood...  
I could see he hadn't used any...  
he was rushing here, there and everywhere...  
but I blurted it out in a way he didn't understand,  
and I felt too embarrassed to say,  
'No, that's not what I meant.'

# Professional woman, returned to hospital concerned about possible infection

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I'm just sat there....  
and time went on  
and you could see how busy they were ...  
and then you start to think "Is it that bad?"  
...and you begin to query that to yourself...  
"Maybe I'll come back at the end of the day"  
...I was feeling upset by then as well  
and I think it was this thing of feeling  
– not knowing –  
whether it was something to worry about,  
having to assert yourself  
and I didn't feel great that day