



Shifting boundaries of responsibility and contested judgements of good practice: facing up to the challenges of person-centred working

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In summary (to start)

- Moves to more person-centred working can be understood as shifting various boundaries.
- More person-centred working can entail some particular, sometimes ethical, challenges.
- What counts as working well through these challenges will be contested.
- We need to recognise, discuss and address the ethical challenges of person centred working.



Patient centred care

“Respectful and responsive to individual patient preferences, needs and values, and ensuring that patient values guide all clinical decisions”

Institute of Medicine, 2001



NHS Scotland

person-centred quality ambition

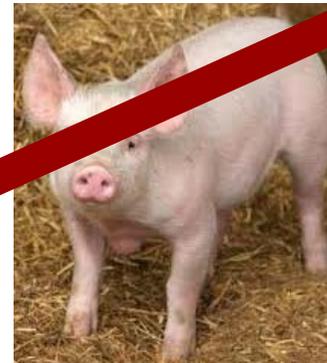


“Mutually beneficial partnerships between patients, their families and those delivering healthcare services which respect individual needs and values and which demonstrate compassion, continuity, clear communication and shared decision-making”



Person-centred working: the core idea

How should services treat people?



As humans!

As persons!



**What would count
as treating someone appropriately
as a person
in this situation?**



Person centred working: shifting boundaries (1)

Shifting 'divisions of labour'?

- **Share decision-making
(attend to person's preferences)**
- **Support self-management
(attend to person's knowledge,
skills, confidence, motivation)**



Person centred working: shifting boundaries (1)

Shifting 'divisions of labour'?

- **Share decision-making
(attend to person's preferences)**
- **Support self-management
(attend to person's knowledge,
skills, confidence, motivation)**

What else
about the
person needs
attention?

How is the
task bounded?
What does
this constrain?

A narrow view of task constrains...

Implic'n: / Task	Manage conditions well	Live (and die) well with conditions
Emphasis in judging success	Condition control (clinical perspective)	
Positioning of person	Risk of becoming a "means to clinical ends"	
Emotion, identity autonomy etc.?	Perhaps relevant, but not main purpose of support	
Patient led goal-setting?	Ask patient what they can do from condition control recommendations	

Based on: V Entwistle, A Cribb, J Owens. *Health Care Analysis*, online 28 November 2016.

A broader view of task enables...

Task Implic'n:	Manage conditions well	Live (and die) well with conditions
Emphasis in judging success	Condition control (clinical perspective)	Living (and dying) well (person's own perspective)
Positioning of person	Risk of becoming a "means to clinical ends"	Central focus/actor: the one doing the living (and dying)
Emotion, identity autonomy etc.?	Perhaps relevant, but not main purpose of support	Key aspects of living well, integral to purpose of support
Patient led goal-setting?	Ask patient what they can do from condition control recommendations	Ask patient what matters to them, and what they could do to improve that

Based on: V Entwistle, A Cribb, J Owens. *Health Care Analysis*, online 28 November 2016.



Person centred working: shifting boundaries (2)

What about a person should health professionals attend to, and why?

(Risk factors, disease... motivation... mental wellbeing... identity... autonomous agency... social positioning...)



Person centred working: shifting boundaries (2)

What about a person should health professionals attend to, and why?

(Risk factors, disease... motivation... mental wellbeing... identity... autonomous agency... social positioning...)

**Interventions for health
can harm or wrong people in various domains
even when not explicitly
attending to them**



Person centred working: shifting boundaries (3)

How far should the scope of health service interest flex in response to a person's agency, and why?



Person centred working: shifting boundaries (3)

How far should the scope of health service interest flex in response to a person's agency, and why?

How does person-centred working relate to safe, effective, fair, sustainable working?



Working with multiple considerations



Doing or trying to achieve one thing	...	“but without...” and “at the same time...”
Review timed information about a person’s blood sugar levels to help them understand how and why these fluctuate.		“You have to be careful that you don’t use results information to beat someone up about their diabetes”
Give people confidence that they can achieve [lower blood glucose]		“Prepare people for the possibility that it might not improve despite their efforts”



Striving for balance

Health service agenda

**Undue
biomedical
emphasis**



Person's own agenda

**Insufficiently
critical
responsiveness**

**Failure to respect
(autonomy).
Neglect or harm
other aspects of life.**

**Failure to support
(autonomy).
Neglect to help avoid
unwanted poor health**



You're constantly working with them for them to set their goals, really small goals. They come back, they haven't done it. So then you talk about the barriers... try and encourage them to think about [what they would be] confident to take on next time... But... the patient just keeps coming back and coming back, and you've got to be careful you don't almost collude with them that something's happening

Nurse consultant



So, something's saying you've got to be the person that supports them, and tries to encourage them to do well. And every little bit you try and say, "Well, that's good, that's great". But actually, there has to come a time when you have to *challenge* what they're doing...

Nurse consultant



We do have [professional] disagreements... Quite often if a patient isn't looking after themselves very well, the diabetes physician... will... sort of step in and say "Okay we need to help them. WE need to help them". But what needs to happen is THEY need to internally recognise that THEY need to help themselves more. And if that balance isn't there...

Psychiatrist



If the physicians aren't able to step back... they get enmeshed in a kind of process where they put them on technology... give them more monitoring, ... lots and lots of input. And the core thing is... that the person... isn't able to recognise the fact that their lives could be different... to think "I could be doing better with this"...

Psychiatrist



Striving for balance



**How much and what kind of support ?
(The paradox of intervening to enable agency!)**



**Person-centred working
involves dealing with
personal, interpersonal and social
complexity and uncertainty**



People say "... I want to enjoy myself now, I'm not caring if it makes me ill later". I wouldn't mind that, except I know that [some] of the patients saying that are feeling insecure and scared and guilty as hell... So they have developed a rationalisation, a bluster around how they're coping, but they're sometimes hurting badly and are badly intimidated by the condition they've got

Diabetes specialist



**So there's always this dilemma:
how far do you interfere with someone's head
when they tell you one story and you worry
that the truth is maybe a different story?**

Diabetes specialist



Sometimes it's difficult because patients want to please you..., so they tell you all the right things... And then suddenly you get the results and things are not matching. So people actually lie about their blood sugars. They write all these perfect readings down ... And it's really hard because then you have to challenge them... At the same time you don't want to break that rapport you have with them, but you want to challenge what they're doing a little bit.

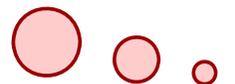
Diabetes specialist nurse



With a service commitment to person-centred working:

- The scope of interest broadens
- Various things that matter can be in tension
- Professionals have to make (sometimes difficult) judgement calls in practice
- Best practice is essentially contestable

How can health professionals be supported to navigate the judgement calls well?





“Making difficult decisions”

Making Difficult Decisions
in NHS Boards in Scotland
Report of a short life working group



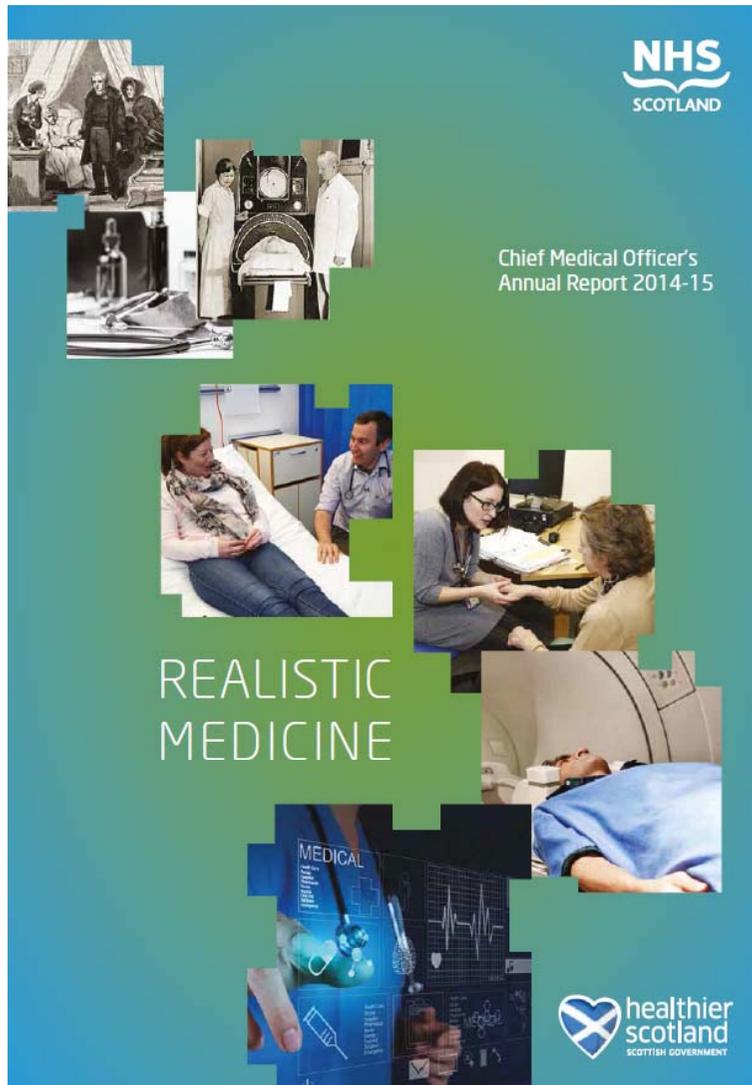
March 2010

“Difficult decisions are made at all levels of a healthcare organisation on a regular basis...”

“There may be several ethically justifiable outcomes to any given dilemma”



“Realistic Medicine”



“Doctors tread a difficult path, with the expectation that they will make robust decisions balanced against criticisms of being overly paternalistic.”



Some related reading

A Cribb, V Entwistle. **Shared decision-making: trade-offs between narrower and broader conceptions.** *Health Expectations*, 2011, 14: 210-9.

V Entwistle, I Watt. **Treating patients as persons: a capabilities approach...** *American Journal of Bioethics*, 2013, 13: 29-39.

V Entwistle, A Cribb, J Owens. **Why health and social care support for people with long-term conditions should be oriented towards enabling them to live well.** *Health Care Analysis*, online 28 November 2016.

H Morgan, V Entwistle et al. **We need to talk about purpose... self-management support...** *Health Expectations*, 2017, 20: 243-59



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Thank you for listening

For discussion beyond the conference:

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