Person-centred care and evidence based practice

Dr Sara Demain, Associate Professor
Is that all that physiotherapy is about?

- Patient satisfaction?
- Quality of life?
- Motivation?
- Participation?
surveys and interviews with people using health services

surveys of clinicians

observation of clinical encounters.
Person Centred Care

What’s the matter with you?

What matters to you?
What outcomes matter
- People with LTCs
- Families and friends
- Health professionals

Hours with NHS professional
= 7 hours in a year

Self care / management
= 8753 hours in a year
Person Centred Care

The four principles of person-centred care

- Care is... personalised
- Care is... coordinated
- Care is... enabling
- Person is treated with... dignity, compassion, respect
Person Centred Care

- Healthcare which reflects the individual’s unique preferences, values and needs (DH)

- PCC aims to ensure a person is an equal partner in their health care (RCN):
  - respect and holism
  - power and empowerment
  - choice and autonomy
  - empathy and compassion.
Evidence Based Practice

The knowledgeable and compassionate practice of EBP should accommodate basic scientific principles, the subtleties of clinical judgment, and the patient’s clinical and personal idiosyncrasies.

EBM working group *JAMA* 1992;268:2420-5.
EBP in crisis?

- The volume of evidence and guidelines has become unmanageable
- Statistically sig benefits are often marginal in clinical practice
- Care becomes management driven rather than patient centred
- Evidence based guidelines don’t fit patients with multimorbidity
  
  Greenhalgh et al, BMJ 2014
Foci of PC research

- Definitions:
  - How patients or professionals define the components of person-centred care

- Preferences:
  - The type of care that patients want or professionals’ attitudes and values

- Experiences:
  - The extent to which care feels person-centred

- Outcomes:
  - The results of person-centred care
Resources for PCC

- http://www.health.org.uk/sites/default/files/HelpingMeasurePersonCentredCare_toolspreadsheet.xls
Person centred measures

- [Link](http://www.health.org.uk/sites/default/files/HelpingMeasurePersonCentredCare_toolspreadsheet.xls)

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Prioritising person-centred care - the evidence

In these pages you can find the evidence from 779 systematic reviews of ways to make person-centred care happen.

We provide accessible and accurate information so commissioners, health professionals and service-user groups can see what works best and how to invest time and resources.

Person-centred care involves placing people at the forefront of their health and care. It ensures people retain control, helps them make informed decisions and supports a partnership between individuals, families and services.

Some of the main components of person-centred care involve:

- supporting self-management
- supporting shared decision-making
- enhancing experience of healthcare
- improving information and understanding
- promoting prevention

These pages summarise the highest quality evidence about what works in each of these areas.

This page provides an overview. The page links on the left will take you to detailed information about each topic. On the right of this page are simple guides to the full evidence for you to download, take away and explore.

**VIDEO: Introduction to Evidence for Person Centred Care**

**Why is this important?**

Engaging, activating and involving people in their health and care is a key goal for health policymakers and is central to plans for the future of the NHS.

There is evidence that engaging people as active participants in their own healthcare can:

- improve people’s experience and the quality of consultations and care
- inform people about health and healthcare and build health literacy
- ensure that treatment is appropriately selected and tailored to the individual
- help people manage their own care and records
- build partnerships with health professionals
- promote public health and reduce health inequalities
- ensure that health systems are responsive and accountable to the people they serve
- reduce wastage and make better use of scarce financial resources
Main strategies for person-centred care

- Supporting Shared decision making
- Support Self-management
- Enhancing experiences of Healthcare
- Improving information and understanding
- Promoting Prevention
- Rhetoric or reality?
Stroke self-management: A focus group study to identify the factors influencing self-management following stroke

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ABSTRACT

Background: Self-management refers to the strategies, decisions and activities individuals take to manage a long-term health condition. Self-management has potential importance for reducing both the personal and health service impact of illness. Stroke represents a significant health and social burden, however there is a lack of clarity about the factors that
Health Warning

you may not like everything you hear
(Un)Supported self-care

- I think that’s one of the biggest problems actually [for self-management], coz when you first have your stroke there’s loads of help (Nathan)

- yeah, and then you get kicked out (Frances)

- you get kicked out basically, that’s it, isn’t it? (Nathan)

- yeah (Frances)
Managing Alone

I can go on myself all I like, it’s kick-starting other people that I find a problem with. You know, I just feel like I’ve got to a dead-end, and not through any fault of my own.
No clear plan

there should be a plan, and everyone should understand their part of the plan. It shouldn’t be up to me [points to self], as the patient to have the plan in my head, which is what happens.’
they give it [information] to you on paper, and they give you the names, the proper names of what’s happened to you....

and it’s so [pause]....you don’t really understand it......if it was in everyday language... a lot of people leave the hospital not fully conversant with what’s happened to them.
informational conflicts

- you get told one thing by one therapist, [sighs] another thing by another therapist

- yeah

- they don’t sing from the same hymn sheet

- Conflicting isn’t it? Everything’s conflicting
Don’t know why?

You know how important it is to keep doing things.... coz they [HCPs] just tell you to do it....but they don’t tell you why.
Health-care relationships affect self-management and adherence
What are the outcomes of self-management that matter to stakeholders? Study protocol for the Self-Management VOICED project

Sara Demain, Emma Boger, Sue Latter, Matthew Hankins, Anne Kennedy, Claire Foster, Fiona Jones, Ian Kellar

Abstract

**Background:** The number of people living with a long-term health condition is increasing. Self-management has been identified as a significant way of managing the burden of long-term health conditions for patients and for health services. It has been highlighted that increased support for self-management is needed and that services should be commissioned to underpin this. However, little is known about which outcomes of such support are meaningful to differing stakeholder
I don’t want to feel like the *naughty school child* because they *tell me off* because my HbA1C [blood sugar] is high (patient)

I think the truth is most patients, if they're not doing well, don't want to see a health professional because they feel they'll be judged.” (HCP)
“should do” doesn’t work

Lots of different [HCP] say “no you must not eat this, you must not do this, and you have got to take these tablets.”

You don't get anywhere - you have to kind of talk to them on their level and have an understanding with them. Because it’s not something you can sit here and tell them what to do, it’s for them to understand what they need to do for themselves. (HCP)
HCP creating a safe space

Sometimes I will see them because, they've got wound infections…I'll say, "You seem to be having loads of thrush. What's going on? What's driving this?"

They haven't been taking their drugs, and you find out it's because they couldn't get the lid off. It can be really simple things…they only can open it when their husband's home…

they don't want to tell you, because they feel they're letting you down, or they're not being a good person, or, you know.

So it's the health professional's skill to unearth that, really, and help the person to feel comfortable enough to tell you”
(HCP)
An equal relationship changes behaviour

- [Julie, previous HCP] used to chase me. I had to go in and I’d cancel appointments and just…it’s horrible.

- [Mary], she’s the practice nurse, ….she was non-judgemental about it all and accepted that.

- I wasn’t going to lie to her…as we got to know each other I would tell her how it is

- I think it re-engaged me a bit because she actually was then trying to find things and then eventually mentioned [the self-management course] which I did two years ago. And that was just a revelation”
Giving patients control

- [A patient] said,

  “Well tell me off. I know that's what you're going to do.”

- And I said, "What on earth are you talking about?"

- So his view, from the nurses he'd seen before, was - he was a diabetic; he wasn't well-controlled - every time he came in to see somebody he got told off……
He said he didn't even want to take any of his drugs.

So I said, "Right, let's take you off your drugs then." Because he probably wasn't taking them at home; he didn't want to take them. He was just emptying them.
Giving
patients control....

- And then once we got back to basics I said, "What would you be willing to take?"
- So he told me what he was willing to take, so I prescribed that and we gradually got him back on all his drugs and his diabetes was really well controlled within a year” (HCP)
A need for a change of focus?
Research evidence is still key to making the right decision—but it does not determine that decision.
Need for stronger evidence that PCC is effective and efficient

How can EBP tools (e.g. guidelines) be adapted to support rather than counter PCC?
Nick’s self-management wish-list…. 

- I don’t want to be **blamed or dictated** with a broken record,
- I want the professionals to be **listening and learning from me**, to feel like I’m listened to and **involved** and that my **experience and knowledge has some value and respect**, not that I’m right, but that they’ll listen to it.
- And that the people I’m talking to **understand the challenges** that we’ve got, that it’s ‘not just that easy; that it is difficult’
- and that they give us **options and flexible responses**, and not just the same old thing, kind of, “Go back and do it again”.
- And the thing that matters most to me, that’s crucial to me, is to feel that **what I’m doing makes a difference** because if I don’t feel it makes a difference I won’t do it. I can’t sustain doing it for decades unless I know it makes a difference.