



# The Meaning and Measurement of Person-Centred Care

Using the Person-Centred Community Care Inventory (PERCCI) to evaluate the quality of care experiences

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Day Centre Research Forum 25<sup>th</sup> June 2020



# My aim for today

To address two questions.

- What are we talking about when we say that we want to achieve person-centred care?
- How can we demonstrate that care being delivered really is person-centred?

# 1. Meaning

Put simply, being person-centred is about focusing care on the needs of the person rather than the needs of the service.

Royal College of Nursing

Person-centred care moves away from professionals deciding what is best for a patient or service user, and places the person at the centre, as an expert of their own experience.

SCIE

Being person-centred is about focusing care on the needs of individual. Ensuring that people's preferences, needs and values guide clinical decisions, and providing care that is respectful of and responsive to them.

Health Education England

...care that is focused and organized around the health needs and expectations of people and communities rather than on disease

WHO

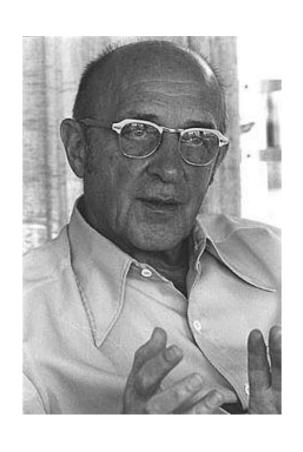
...people using a service have care or treatment that is personalised specifically for them.

Regulation 9: Care Act Regulations

### The challenge of being precise

- Definition by ...
  - ...what it's not
  - ...metaphor and imagery
  - ...generic principles and values, not what it looks like in practice
- Apparent simplicity, actual complexity
  - 'Easier to adopt the language of person-centred care as an alternative to practicing it'
- Lack of recognition of the history of person-centredness
  - Term is used as a neologism, not an idea with long history
- A literature-based "concept review"

### Carl Rogers: Person-Centered Therapy



- Humanistic psychology
- 1. Unconditional positive regard
- 2. Congruence: not hiding behind professional façade
- 3. Empathic understanding of person's frame of reference

"When functioning best, the therapist is so much inside the private world of the other that he or she can clarify not only the meanings of which the client is aware but even those just below the level of awareness. This kind of sensitive, active listening is exceedingly rare in our lives"

# A historical filtering process

Sociological critique of medicine

Social model of disability

Social construction of ageing

'Normalisation'

De-institutionalization

Sans Everything: A Case to Answer

"In our view, it is society which disables physically impaired people. Disability is something imposed on top of our impairments..." Growth of social gerontology

Anti-psychiatry

1950s 💛 19

₩ 1960s 1970s W→ 1980s

**1990s** 

2000+

Carl Rogers
Michael Balint

George Engels

John & Connie O'Brien Tom Kitwood

Biopsychosocial model

Client-centered counselling

Patient-cent(e)red medicine

Person-centred planning

"[Personhood] is a standing or status that is bestowed upon one human being, by others, in the context of relationship and social being"

# Differences between professions?

#### Social workers

Emphasis on person-centredness as empowering people

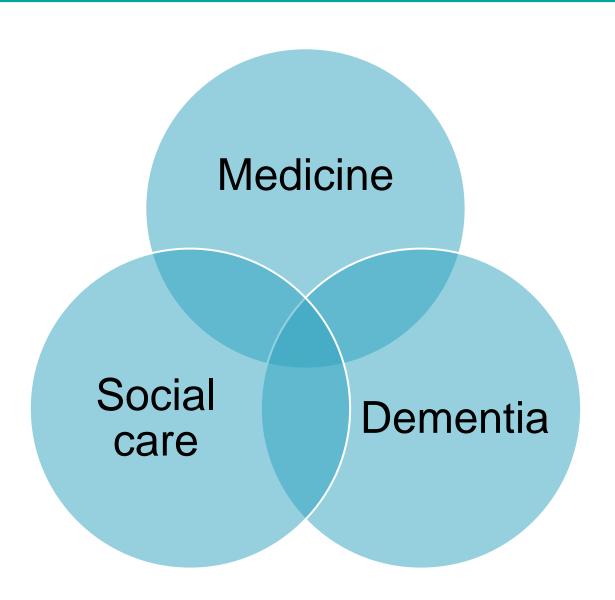
#### Nurses

 Emphasis on person-centredness as a means for developing rapport

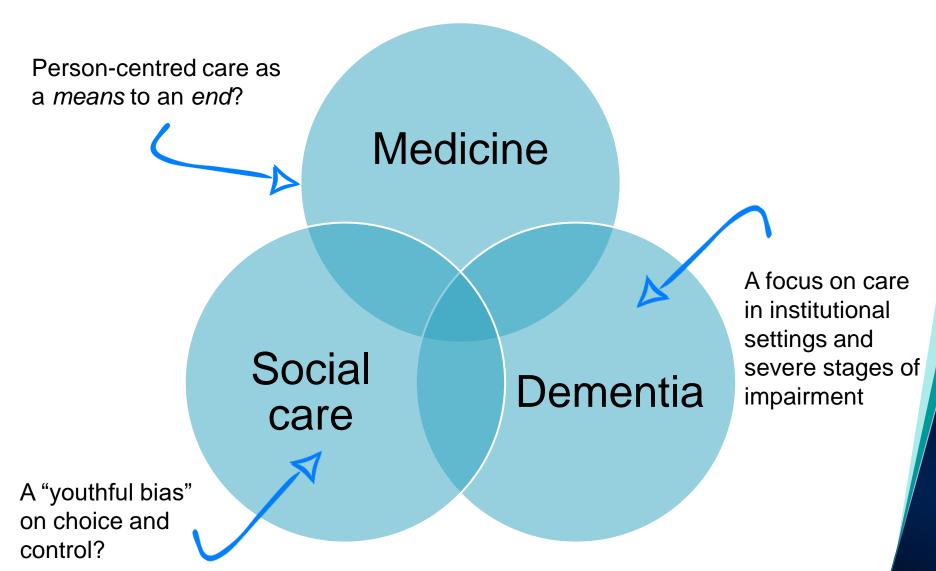
### Physicians

- Did not know how to define person-centredness...
- ... but not empowerment or rapport

# Different models of person-centredness?



# Some critique and contrasts



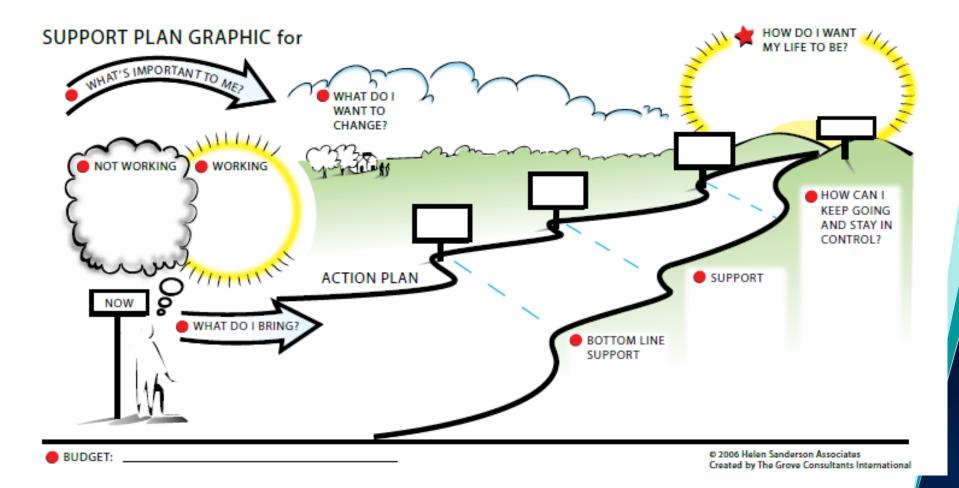
# Differences are not recognised

"The person-centred planning approach has ... a focus on supporting individuals to live as independently as possible, to have choice and control over the services they use and to access both wider public and community services..."

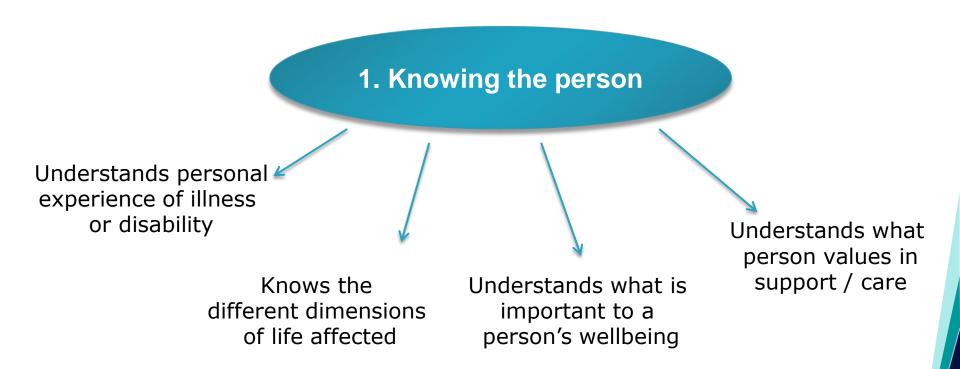
"...Person-centred care has the same meaning as person-centred planning, but is more commonly used in the field of dementia care and services for older people".

SCIE (2012) p3, emphasis in original

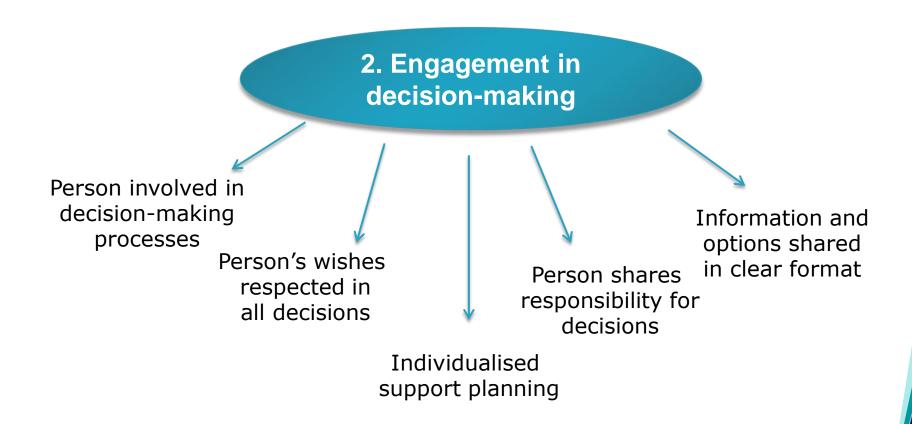
### **Variations**



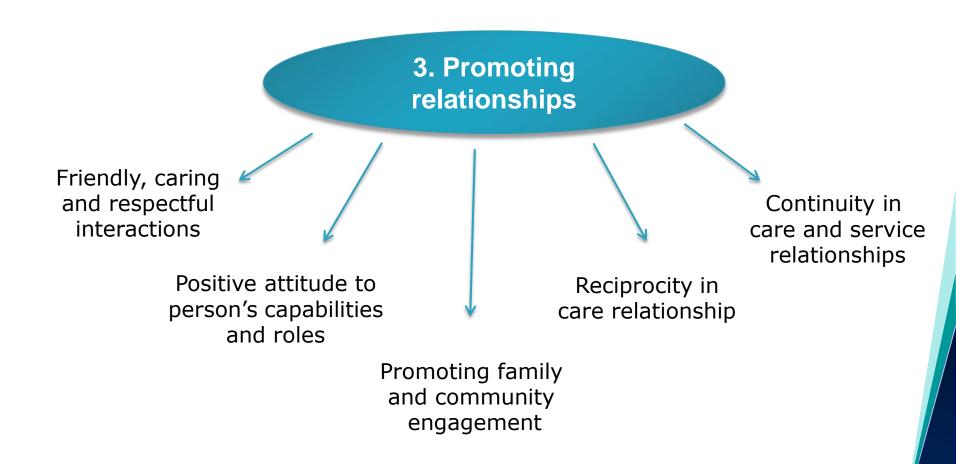
### **Three Shared Attributes**



### **Three Shared Attributes**



### **Three Shared Attributes**



### 2. Measurement

Measurement is a process of finding a number that shows the amount of something

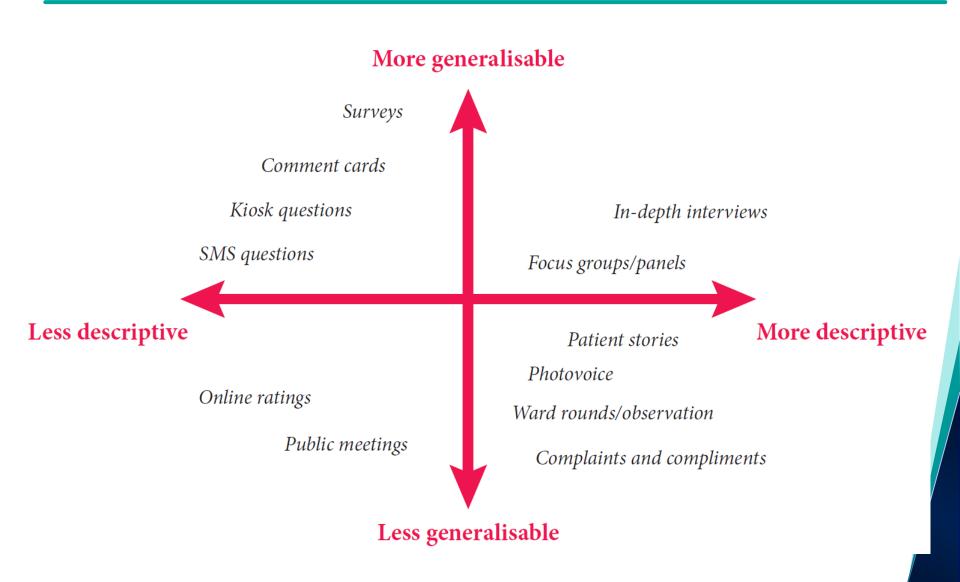
It can be a group or ranking (e.g. coming 1<sup>st</sup>, 2<sup>nd</sup> or 3<sup>rd</sup> in a race)

But usually we are interested in a refined level of measurement (so the exact time it took to reach the finish line)

### Why do we measure?

- To add to our understanding of a phenomenon
- Three common reasons for measuring:
- To classify people/groups
- 2. To discriminate between people/groups
- 3. To evaluate change over time
- Most valuable when used alongside other sources of understanding and knowledge

### Sources of information?



# Why we avoid bad measurement

### Effectiveness of treatment for schizophrenia

|                        | Using <u>published</u> scale<br>(n, col %) | Using <u>unpublished</u> scale (n, col %) |
|------------------------|--|---|
| Found treatment had    | 52   | 38  |
| significant benefit    | (15.8%)                                    | (30.0%)                                   |
| Found treatment had no | 277  | 89  |
| benefit                | (84.2%)                                    | (70.0%)                                   |
| Total                  | 329 RCTs                                   | 127 RCTs                                  |
|                        | (100%)                                     | (100%)                                    |

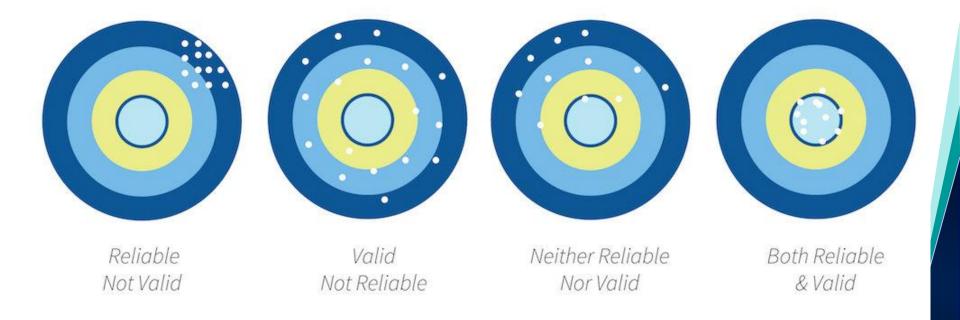
### What does a good measure look like?

#### Validity (or accuracy)

Does it measure what we want it to measure?

#### Reliability (or precision)

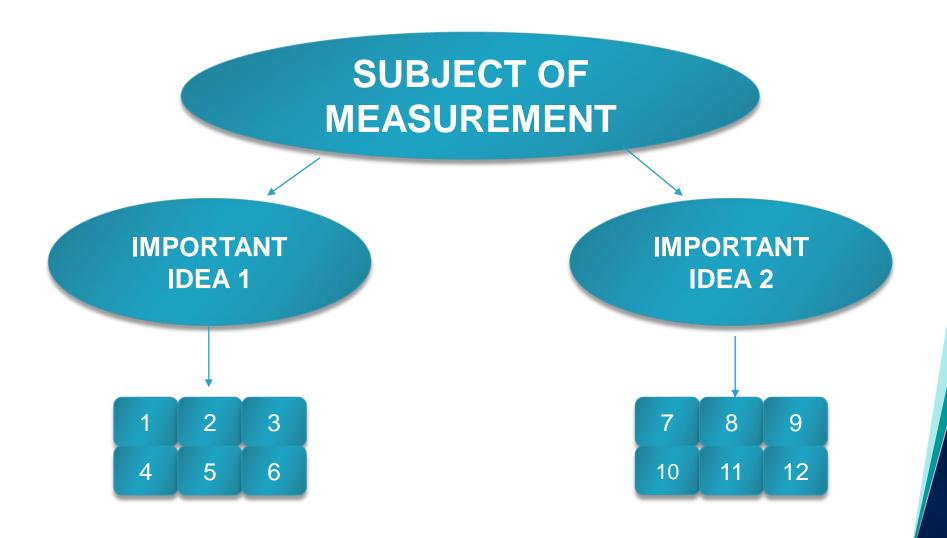
Do we measure it closely and consistently?



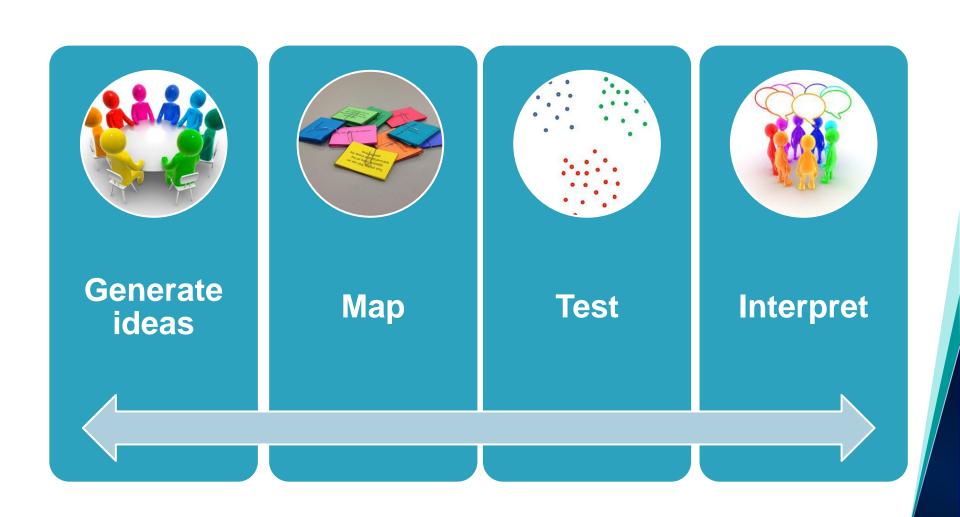
# Can we measure subjective things?

- Yes –we measure many subjective things
  - Class
  - Well-being
  - Job satisfaction
  - Political orientation
  - Depression
  - Personality traits
  - Quality
  - Person-centred care???

# Forming scales



# Coproduction of a questionnaire



### Generate ideas

Two groups of older people and carers using community day services

One group in deprived, predominantly white, community

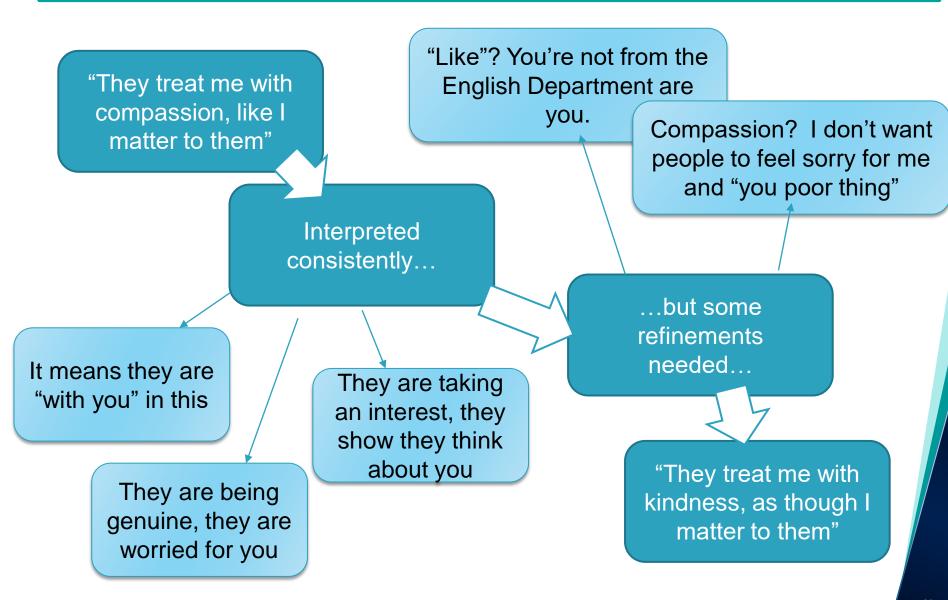
One group in deprived, predominantly South Asian, community

What words and statements best describe a good care experience?



126 statements between two groups

# Refining questionnaire items



### The PERCCI

- Q1: ... take what I have to say seriously
- Q2: ... treat me with kindness, as though I matter to them
- Q3: ... can tell my good days from my bad days
- Q4: I feel I have developed a close connection with ...
- Q5: ... understand the areas of my life that I need help with
- Q6: I am given enough time to say everything that I want to say
- Q7: I have a say in decisions taken ....
- Q8: I am helped to keep in touch with my local community
- Q9: I get help with the things that are most important to me
- Q10: My opinions about my care are support are respected
- Q11: ... helps me to feel optimistic about what I can still do
- Q12: ... helps me to build confidence.

### How did we test it?

- ~600 people with mental health and social care needs using community support
- Validity
  - Comparing with our expectations
    - 1. People would experience more person-centred care, the longer they have been with a service
    - People would experience more person-centred care if they attended day centres rather than received domiciliary care
  - Testing correlations with other measures
    - Moderate correlation with other satisfaction measures
- Reliability
  - Test-retest experiment

### Results

|  | Coeff.  | Robust s.e. | t     | P     |
|--|---------|-------------|-------|-------|
| Aged under 70  | 3.899   | 1.118       | 3.49  | .001  |
| Dementia diagnosis/other<br>organic                                | - 3.502 | 1.263       | -2.77 | .006  |
| Referred < 6 months ago  | -5.905  | 1.714       | -3.45 | .001  |
| Sees registered practitioner                                       | 8.670   | 2.157       | 4.02  | <.001 |
| Sees registered practitioner *<br>Sees support worker <sup>1</sup> | 2.782   | 1.116       | 2.49  | .013  |
| Receives homecare  | -2.074  | 1.200       | -1.73 | .085  |
| Attends daycentre  | 2.093   | 1.131       | 1.85  | .065  |
| Constant   | 35.611  | 2.319       | 15.36 | <.001 |

n=410,  $R^2=.186$ , Adj  $R^2=.170$ . Shapiro-Wilk z=5.721 (p<.001); RESET test F(3,395)=1.95, p>.05

### Results

|   | Coeff.  | Robust s.e. | t | P  |
|---|---------|-------------|---|--|
| Aged under 70   | 3.899   | 1.118       |   |  |
| Dementia diagnosis/other<br>organic                             | - 3.502 | 1.263       |   | f you started using                        |
| Referred < 6 months ago   | - 5.905 | .714        |   | the service within                         |
| Sees registered practitioner                                    | 0.670   | 2.157       | t | the last six months<br>you reported        |
| Sees registered practitioner * Sees support worker <sup>1</sup> | 2.782   | 1.116       |   | significantly poorer<br>erson-centred care |
| Receives homecare   | -2.074  | 1.200       |   |  |
| Attends daycentre   | 2.093   | 1.131       |   |  |
| Constant  | 35.611  | 2.319       | 1 | 5.36 < .001                                |

n = 410,  $R^2 = .186$ , Adj  $R^2 = .170$ . Shapiro-Wilk z = 5.721 (p < .001); RESET test F(3,395) = 1.95, p > .05

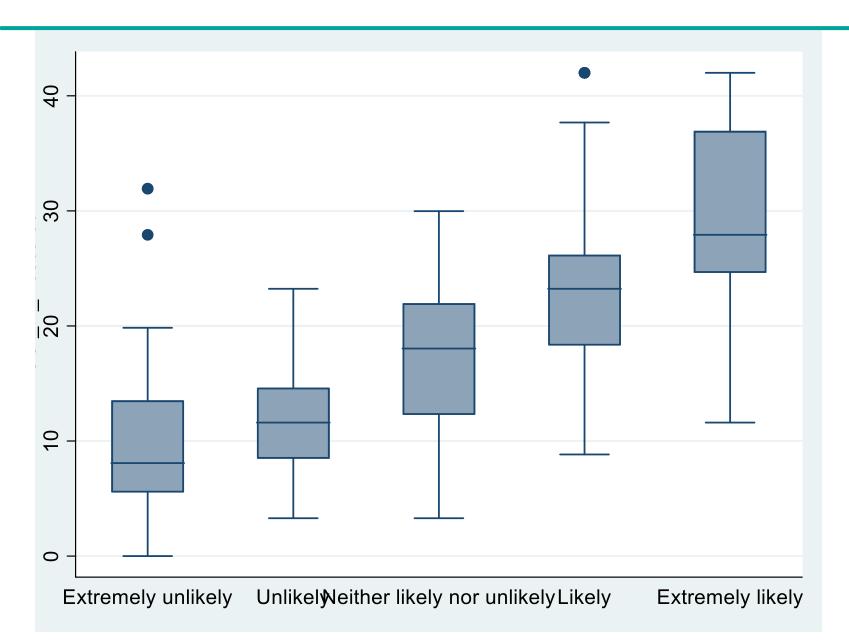
### Results

|   | Coeff.    | Robust s.e. | t   | P                        |  |  |
|---|-----------|-------------|---|--------------------------|--|--|
| Aged under 70   | 3.899     | 1.118       | 3.4   | 49 .001                  |  |  |
| Dementia diagnosis/other<br>organic                             | - 3.502   | 1.263       | -2.   | 77 .006                  |  |  |
| Referred < 6 months ago   | -5.905    | 1.714       |   |                          |  |  |
| Sees registered practitioner                                    | 8.670     | 2.157       | Person-centred ca<br>tended to be:<br>- Poorer if you |                          |  |  |
| Sees registered practitioner * Sees support worker <sup>1</sup> | 2.782     | 1.116       |   |                          |  |  |
| Receives homecare   | -2.074    | 1.200       |   | received                 |  |  |
| Attends daycentre   | 2.093     | 1.131       | homecare  |                          |  |  |
| Constant  | 35.611    | 2.319       | -   | Better if you attended a |  |  |
| $n=410, R^2=.186, Adj R^2=.1$                                   | 70. Shapi | ro-Wilk z   |   | daycentre                |  |  |

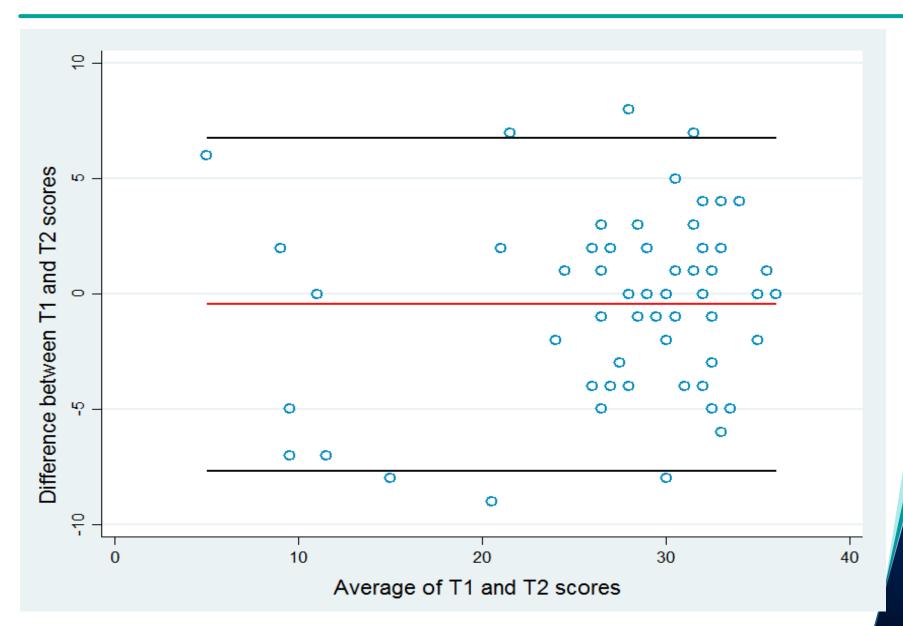
RESET test F(3,395) = 1.95, p > .05

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### **Expected relationship with satisfaction**

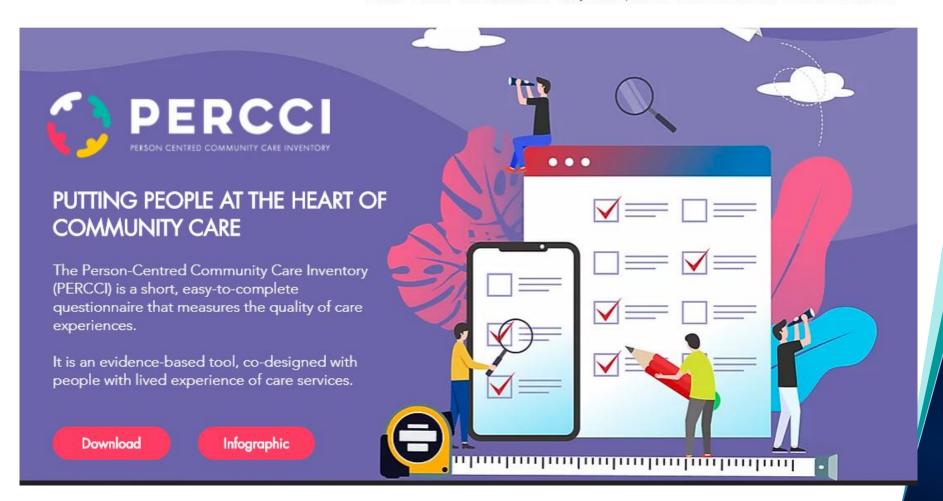


# **Excellent test/retest reliability**



# www.percci.org (it's free!)

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# www.percci.org (it's free!)



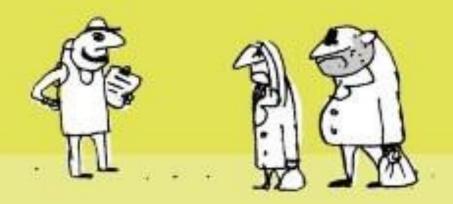
| PERCCI   | PERCCI  These questions are designed to show whether your care and support is person-centred.  For each statement, please tick one box to show how often you feel that each quality is shown. |                 |           |       |        |  |
|--|---|-----------------|-----------|-------|--------|--|
| The first six statements are about support you   | care workers that   | Never or a      | Sometimes | Often | Always |  |
| My care workers take what I  | have to say seriously   |                 |           |       |        |  |
| They treat me with k   | indness, as though I<br>matter to them  |                 |           |       |        |  |
| They can tell my good day  | s from my bad days  |                 |           |       |        |  |
| I have developed a close of  | onnection with them   |                 |           |       |        |  |
|  | and the areas of life<br>hat I need help with   |                 |           |       |        |  |
| I am given en  | ough time to say the<br>things I want to say  |                 |           |       |        |  |
| The final six statements are about support overall   | t your care and   | Never or rarely | Sometimes | Often | Always |  |
| My care and support helps abo  | me to feel optimistic<br>ut what I can still do   |                 |           |       |        |  |
| 8 I have a say in decis  | ions taken about my<br>care and support   |                 |           |       |        |  |
| I am helped to s   | tay in touch with my<br>local community   |                 |           |       |        |  |
| I get help with the  | things that are most<br>important to me   |                 |           |       |        |  |
|  | about my care and<br>pport are respected  |                 |           |       |        |  |
| My care a  | nd support helps me<br>to build confidence  |                 |           |       |        |  |
| For enquiries about PERCCI please contact Mark Wilberforce at mark.wilberforce@york.ac.uk, or visit percci.org |   |                 |           |       |        |  |

We too often asks insufficiently penetrating questions, insufficiently often, of too few people... and our regular surveys, asking if people are satisfied with the care they receive, sound too much like asking people whether they are grateful

### Potential value

- PERCCI is an evidence-based measure of person-centredness, and can be used (freely) to evaluate quality
- It is very short and quick to complete
- It has been co-produced with people using services
- It helps to identify people with poor experiences so you can examine why that might be
- Over time you can monitor service quality
- It does not tell you what problems might be you need to follow-up for more details.

#### on a scale of 1 to 10 how happy are you?



he's done this before and you're gonna need a much more sensitive calibration area down the bottom end of the scale



# Thank you

- If you are interested in using the PERCCI, or are interested in its further development, please contact me
  - mark.wilberforce@york.ac.uk
  - @M\_Wilberforce
  - www.percci.org

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