Fostering Acceptance in People Living with Chronic Pain

Professor Tamar Pincus

University of Southampton, UK

Conflict of interest

- I hold grants from Arthritis UK, NIHR RfPB, the Medical Research Council, ESRC.
- I provide consultancy activity contracted to The University of Southampton, training clinicians in Psychologically Informed Practice (PIP)

What is acceptance?

- Acceptance is the act of willingly receiving or acknowledging something without resistance, objection, or attempts to change it.(Dictionary)
- acceptance is the active and conscious embrace of private experiences (thoughts, feelings, bodily sensations) as they are, without unnecessary attempts to change their frequency or form, especially when doing so would cause psychological harm. (ACT)
- Pain acceptance is the willingness to experience pain without trying to control or avoid it, while continuing to engage in valued activities and life goals despite the presence of pain. (McCracken 1998)

- Pain willingness (not fighting or avoiding pain)
- Activity engagement (living meaningfully despite pain)

- The opposite of Avoidance-based coping:

Attempts to avoid, control, or escape pain and pain-related experiences (Vlaeyen,

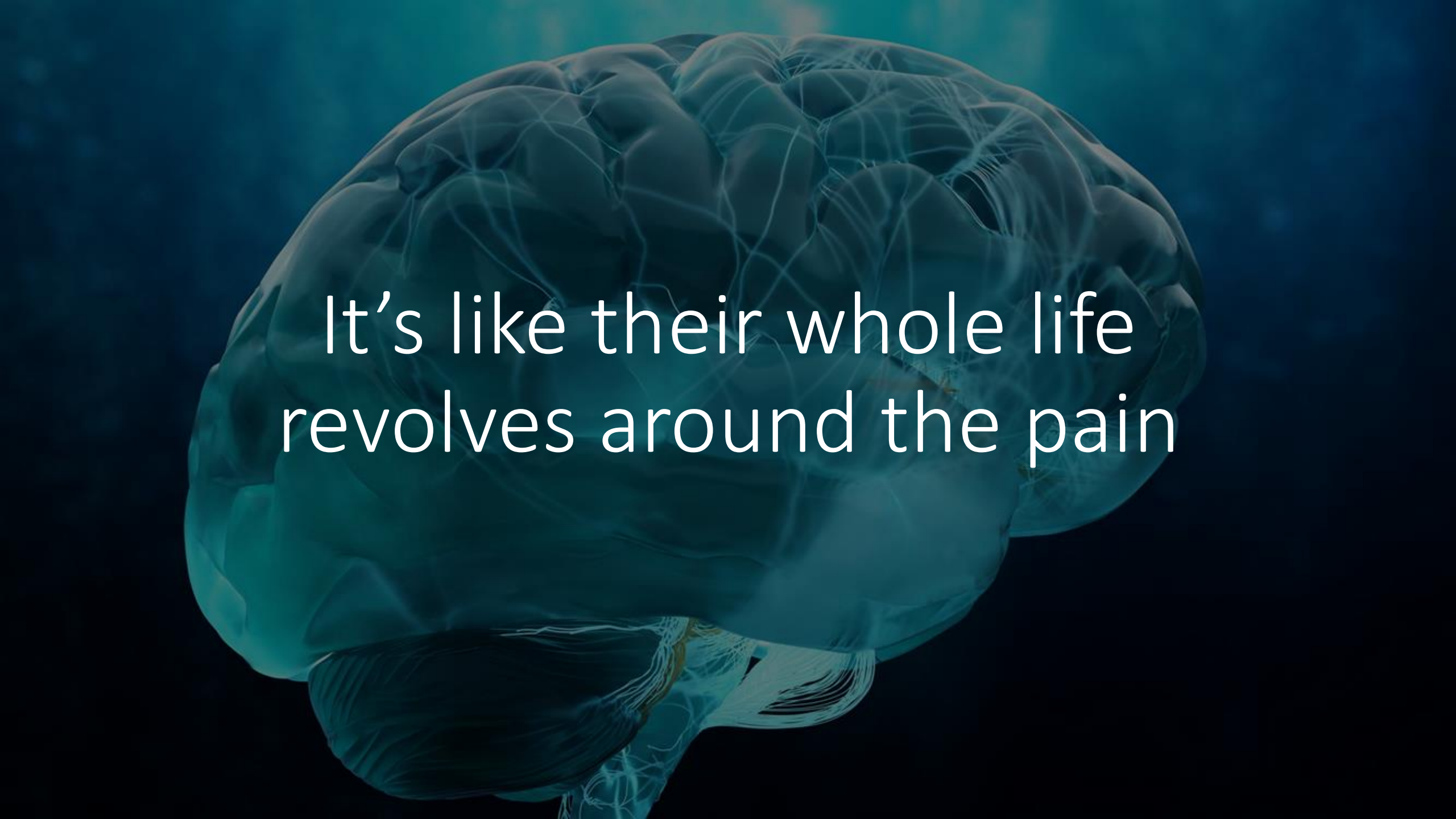
Aspect	Acceptance	Avoidance
Goal	Live well with pain	Eliminate or avoid pain
Approach	Willingness	Avoidance, suppression
Behaviour	Engagement	Restriction, control
Short term outcome	Hard, effort and possibly flare-ups	Pain relief
Long term outcome	Wellbeing	Reduced life, reduced being

So we all know what acceptance is, and why it is useful

But how do use it in practice?

Common themes

- How do I get my patient to stop chasing cures?
- How do I get them to self-manage?
- How do I get them to stop telling me the same thing over and over?
- How do I get them to understand how important physical activity is?
- How do I get them to stop believing something catastrophic is wrong but not yet detected?


It’s like their whole life
revolves around the pain

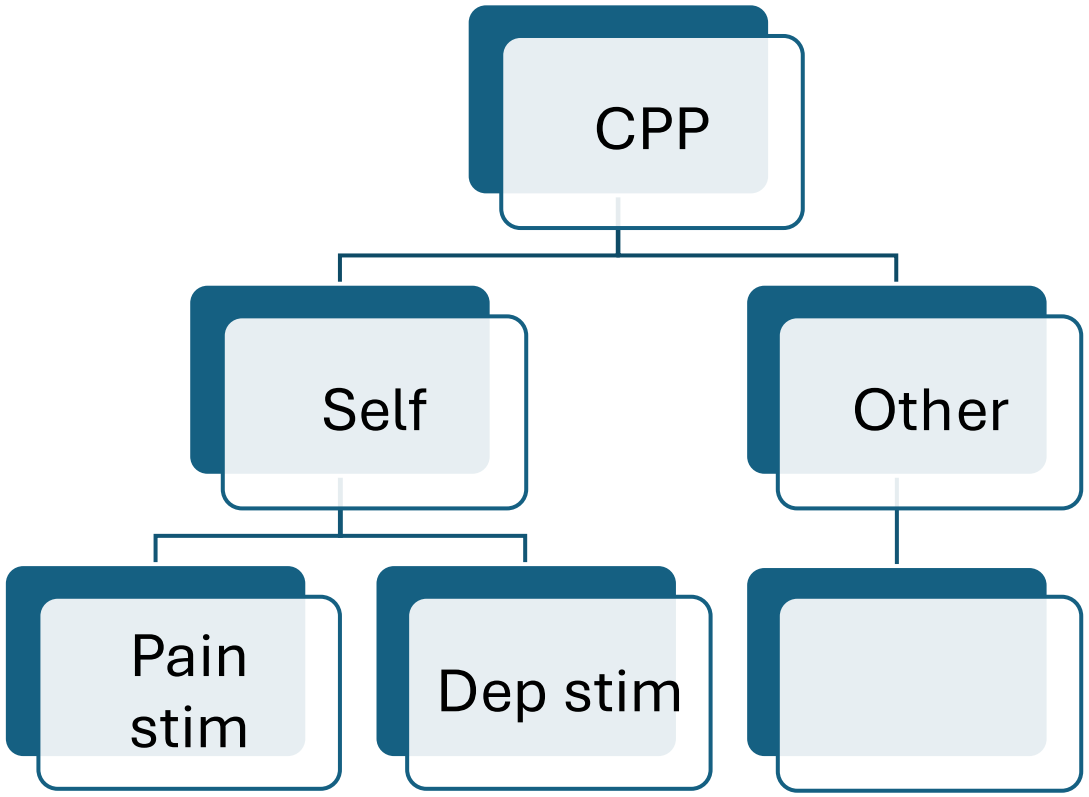
Thinking about The Self

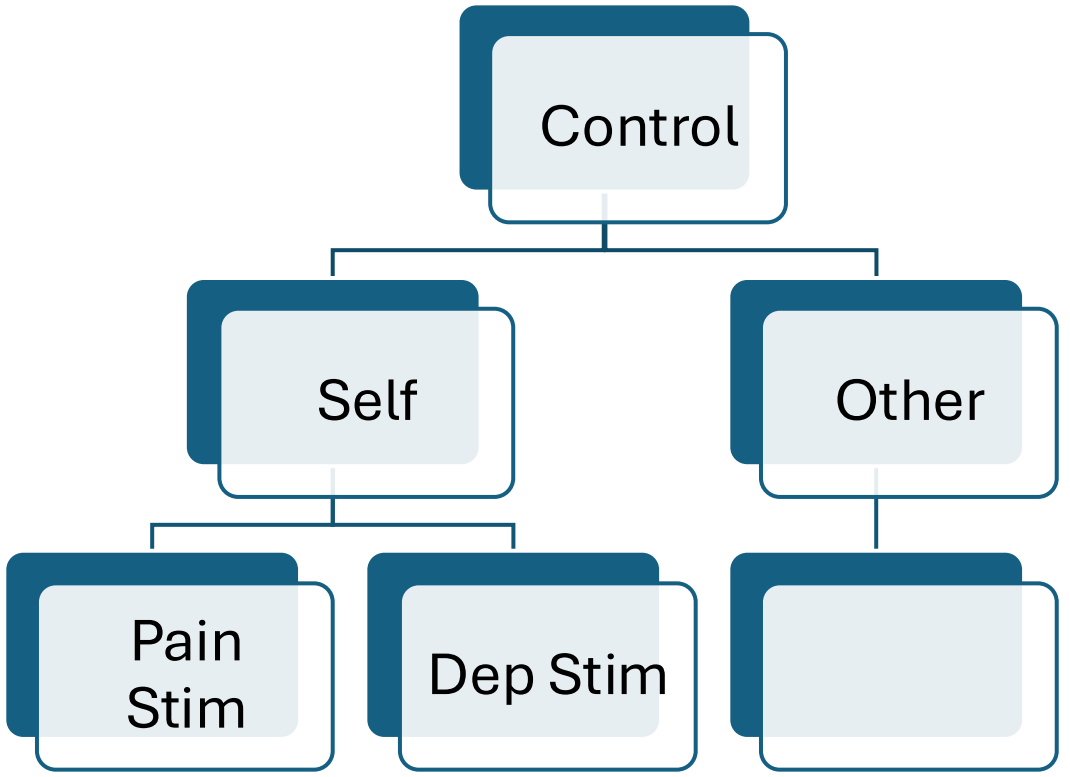
A few cognitive principles

- We process the world through a ‘filter’
- We select information relevant to self
- We select information that evokes emotions (fear, worry, anger- but also potentially excitement, joy)
- We develop biases to increase our selections

Could chronic pain bias us to select negative information relevant to pain, which will increase distress and worry, which in turn will increase our tendency to select such information?

Example of experiment on cognitive bias





Some of the main features found

- Recall in CPP
  - Bias towards pain-related words or negative health words- not depression
  - But only when processed in reference to the self: (Pincus et al., 1993)
  - Only in CPP who were also distressed (Pincus et al., 1995)
  - In those with diagnostic uncertainty (Serbic & Pincus., 2014)

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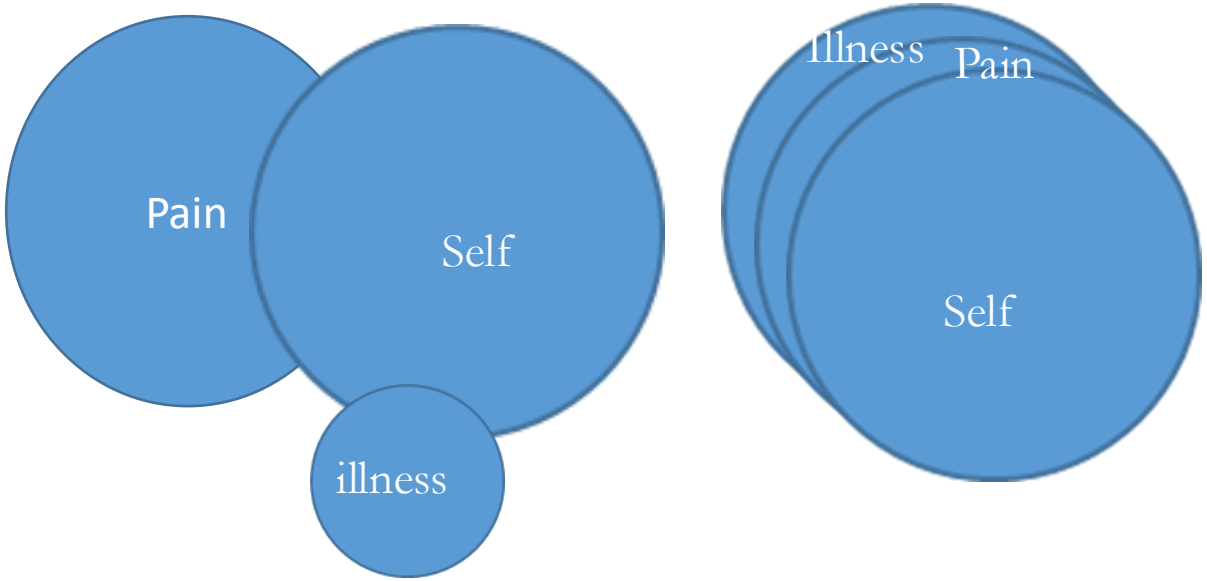
Self-Enmeshment Theory

(Pincus & Morley, 2001)

- Proposed three separate domains: Self, Pain and Illness (disability).



How we currently foster compliance and self-management

Current interventions in Chronic pain

- MANAGE your pain
- Increase your physical activity
- Do your exercises
- Pace yourself
- Reinterpret your automatic negative thinking
- Be aware (Beware) of catastrophic thinking

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YOU MUST

STAY PHYSICALLY ACTIVE

“squats and lunges were given to us by the devil”

T Pincus, life-time quote

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Talking about pain enhances enmeshment

MANAGING your pain= Thinking about pain all the time

Catching your automatic negative thoughts = stopping DOING to think about pain

‘Managing pain’ (PPI strong input)

- Exhausting
- Body misbehaving
- Takes up my day
- Becomes whom I am

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Other options

(The word OPTIONS here is very important)

Plasticine video: Pain and me, on YouTube

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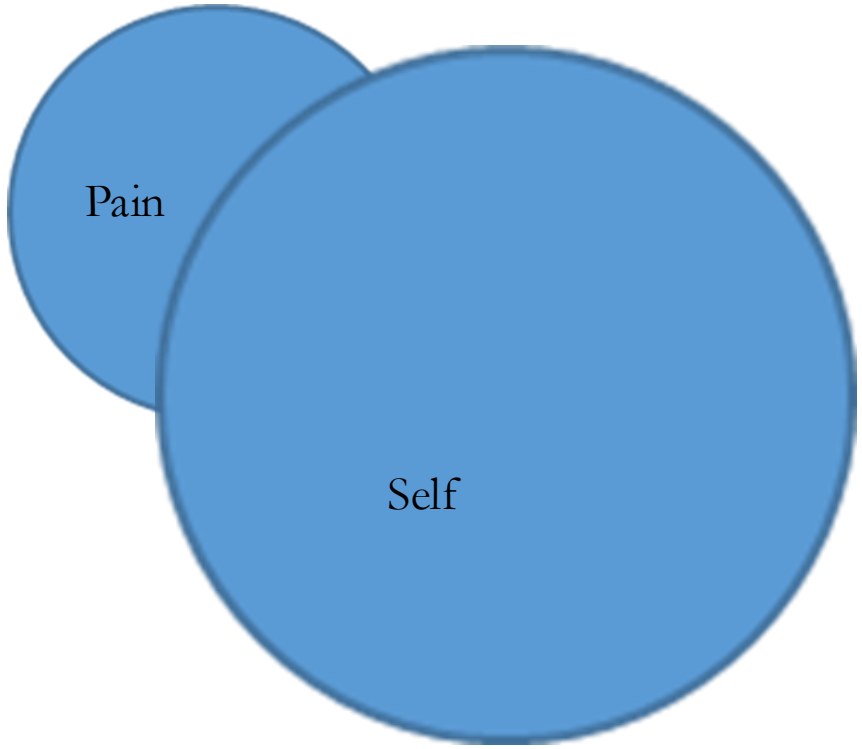
This gives us some ideas for interventions: how to de-mesh the self

- If we can't change the pain…



Behavioural Activation in Depression

Structured, brief psychotherapeutic approach that aims to:

- increase engagement in adaptive activities associated with the experience of pleasure or mastery
- decrease engagement in activities that maintain depression or increase risk for depression

These are all talk therapies.

They are effective in reducing depression (moderate ES for individual, large effect for group)

Psychology led- expensive

Stein, et al., (2021). Psychological Medicine

Cuijpers, et al., (2023) Psychotherapy Research

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Environmental Enrichment

- Animal models (Greenough and Black)
  - New
  - Complex
  - Combining motor and sensory
  - Reward circuits
- Results in growth of new neurons and synapses AT ANY AGE (Experience dependent rather than Experience expected)

“ I know I should do more, get out more, but its just too intimidating to try”

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Identifying the Orange

- At home and away
- Alone and with others
- Exploring new avenues (Green, Learning, Creative, Spiritual-as well as Physical)
- Side-step the “I’m not good enough” trap
- Be realistic and pragmatic (cost, travel- Side-step the yearning to who-we-were)

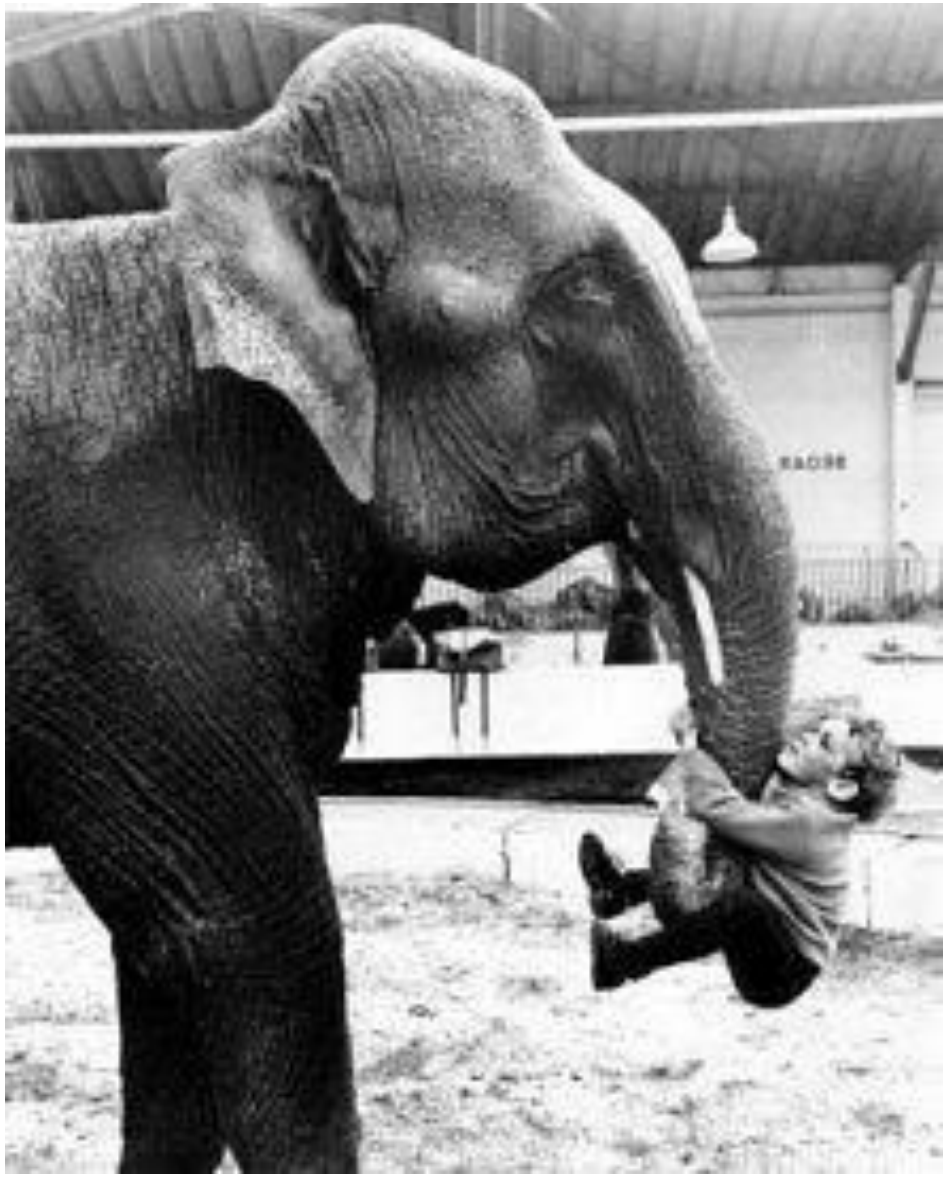
You as an agent for change

No ‘should’

Exploring possibilities- flexible, iterative

Supporting the ‘how’

People do what they want to do



Do patients need to realise they have exhausted all avenues for cure before they accept?

Creative hopelessness is never as strong a motivator as JOY

The urge to express pain and have it Recognised and validated is

OVERWHELMING

"why does she keep repeating herself?"

"why doesn't he do what I told him to do?"

What do people want?

- A solution, cure, management plan
- A clear and credible explanation of why they have pain
- A recognition of the impact of pain
- To be heard and believed.

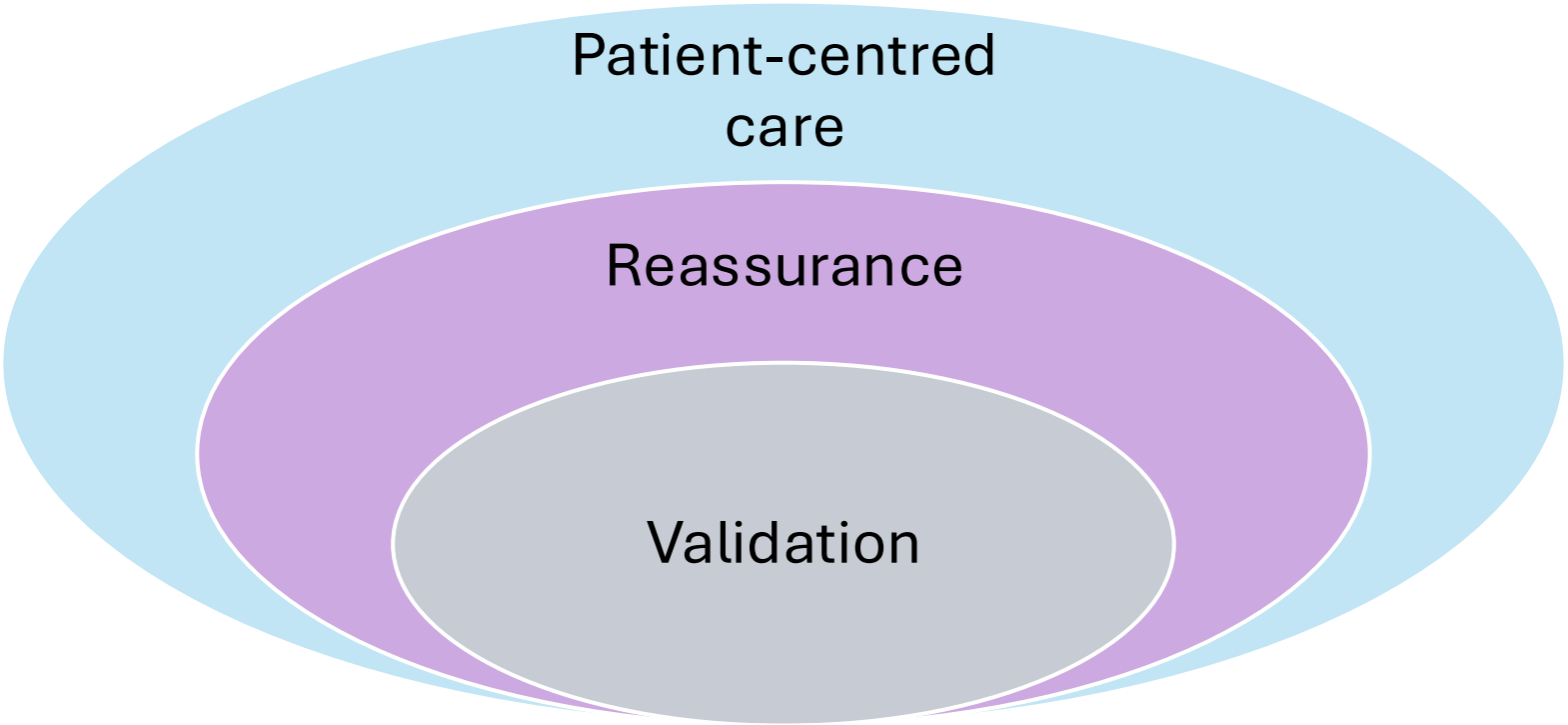
Why do we struggle to believe pain?

How do conversations sometimes go?

- The 11 second window
- The three strikes conversation
- Bailing out, getting lost

Putting validation in context

- Evidence on consultation-based reassurance suggests that it is associated with patient' outcomes, after adjusting for clinical factors, interventions, and individual differences.



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What is validation?

- Defined in dialectical behaviour therapy (DBT), communicating to patients that what they are thinking, feeling, or doing makes sense and is understandable.
- In pain, we add a clear and explicit indication that they are believed.
- Emphasising how feelings, no matter how extreme and negative, are normal, in response to the circumstances.
- Thought to work through improved emotional regulation and reduced distress (though I think there are other mechanisms in play)

Edmond & Keefe,

Pain. 2015

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"Being believed, validated, acknowledged, heard and feeling seen and understood – that was life changing because a burden was lifted that I didn't even know was there. There was immense relief in no longer having to 'prove' that I was in pain, that I was deserving of care, that I was a worthy human being. I was not fundamentally flawed. I was not to blame for my pain. I was not overreacting or too emotional. My pain was not 'all in my head'. My pain was real. And once my pain was validated, once I, as a human being, was validated, it opened up capacity to take on new information. "

Belton J, Birkinshaw H, Pincus T.
Patient-centered consultations for persons with musculoskeletal conditions. Chiropr Man Therap. 2022

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A bit of empirical stuff

Isolating specific measurable outcome: recall

- The opportunity to influence healthy behaviours emerges in consultations, in which health care providers can reassure and provide information and education to patients

- But patients often struggle to recall information accurately, and (Butow et al, Pain, 2013)

- Compromised recall, poor concentration, difficulty with attentional processes, and reduced executive function (e.g. planning, organization, thought control, self-regulation, goal-directed actions) in people living with chronic pain (Khera and Rangasamy, 2021).

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Possible mechanisms for validation to improve recall

Pain interrupts, interferes

- Emotional regulation (Attention narrowing)
  - Reduce anxiety
  - Reduce arousal
  - Reduced rumination

  = improve processing

  =improve recall

Social survival drive

- Evolutionary explanation (persistence model)

"until I know you heard and understood the impact of pain on me, my primary (survival-driven) goal is to make you understand, and this will over-ride any other use of my cognitive resources"

"There was immense relief in no longer having to 'prove' that I was in pain"

Does validation improve recall?

- Participants received either validating (N=25) or invalidating responses (N=25) from the experimenter during a pain provoking task (lifting and holding with straight arm a bucket of sand, with distressing sound)

- Followed by self-report measures of interference (affect, situational pain catastrophizing) and recall (accurate and false memories of words).

- Validated group exhibited higher accurate recall and less false recall of word list.

Carstens etal., 2017

Scand J Pain.

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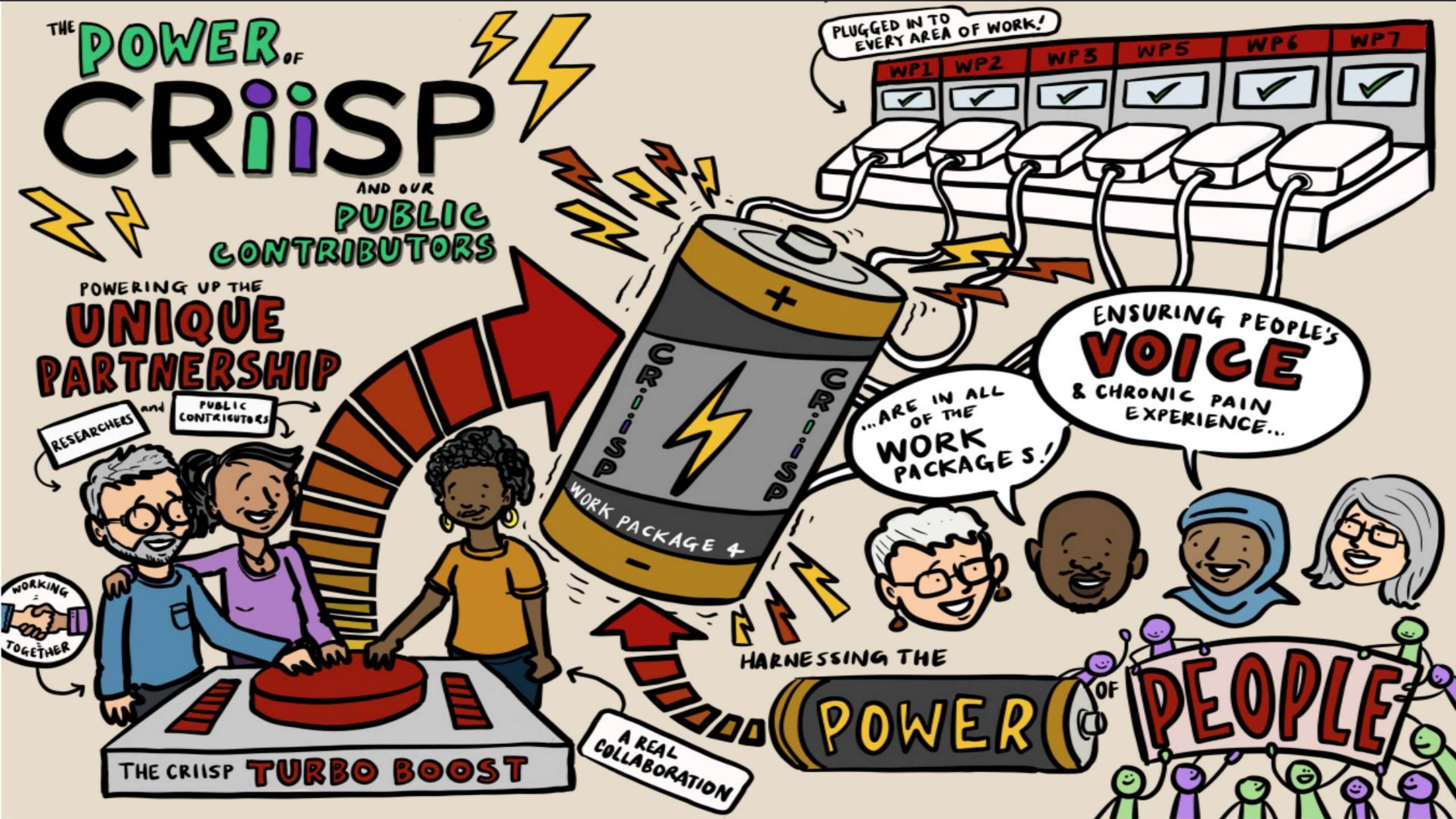
CRiiSP

Consortium to Research Individual, Interpersonal & Social Influences in Pain

Recounting Past Experiences of Clinician Validation/Invalidation: Impact on Chronic Pain Patients' Psychological Well-being and Recall Capacity

Charlotte Lee, Hollie Birkinshaw, Matt Garner & Tamar Pincus


THE POWER OF CRiiSP AND OUR PUBLIC CONTRIBUTORS
PLUGGED IN TO EVERY AREA OF WORK!
WP1
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POWERING UP THE UNIQUE PARTNERSHIP
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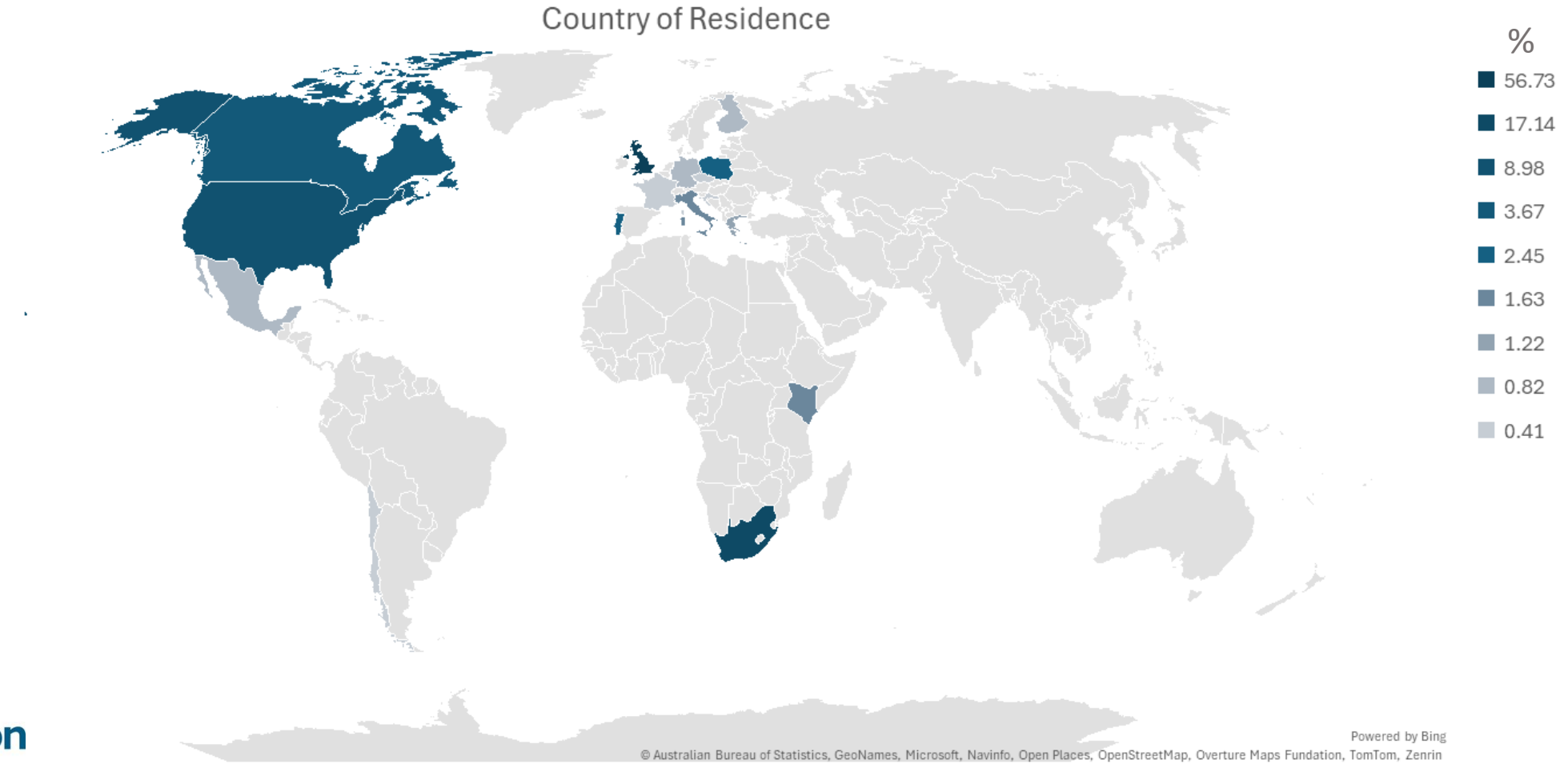
WORK PACKAGE 4
ENSURING PEOPLE'S VOICE & CHRONIC PAIN EXPERIENCE...
...ARE IN ALL OF THE WORK PACKAGES!
THE CRIISP TURBO BOOST
A REAL COLLABORATION
HARNESSING THE POWER OF PEOPLE

Sample

245 people living with chronic pain via Prolific (online study platform)
28 nationalities living in 16 countries. 175 Female, 70 male.
Between 19 and 76 (*mean age* 40.6)



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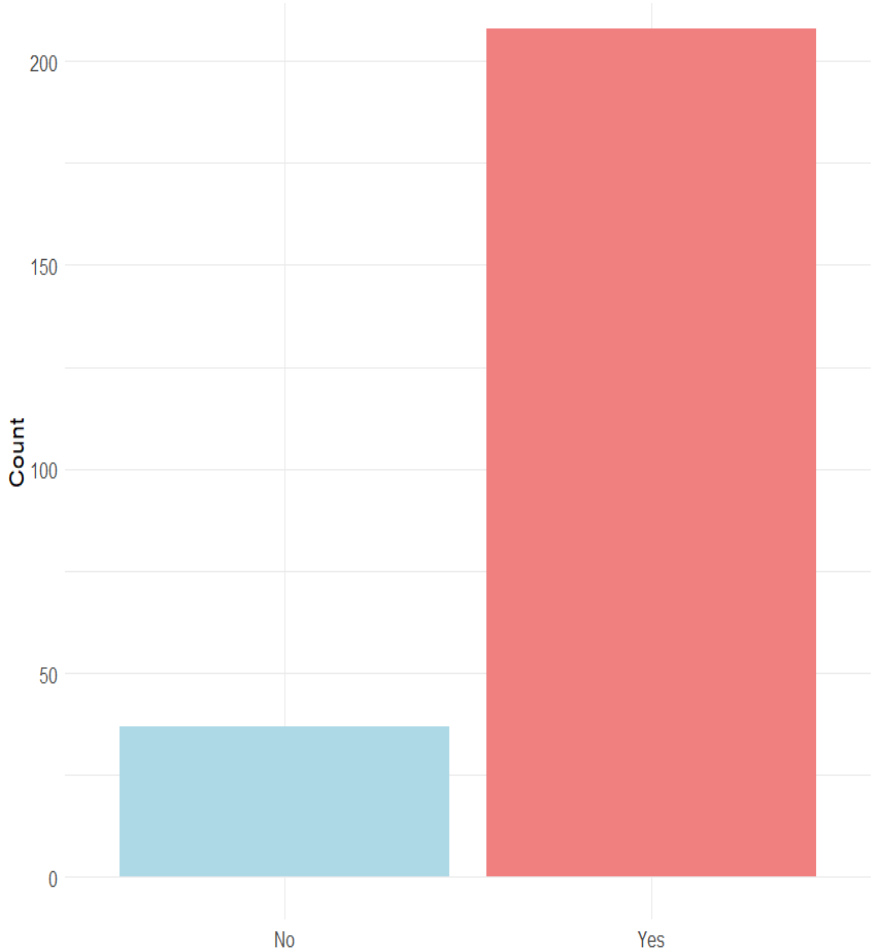
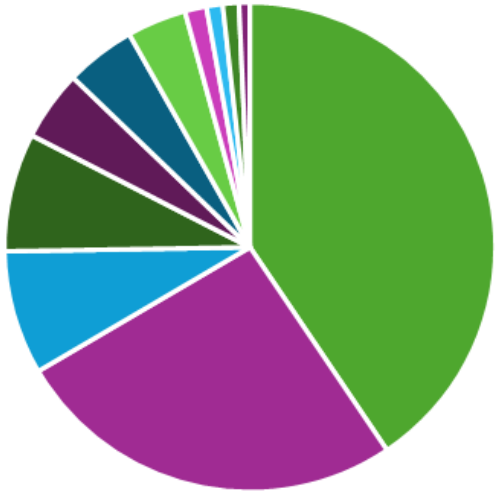
Sample

Experiencing Pain at Baseline



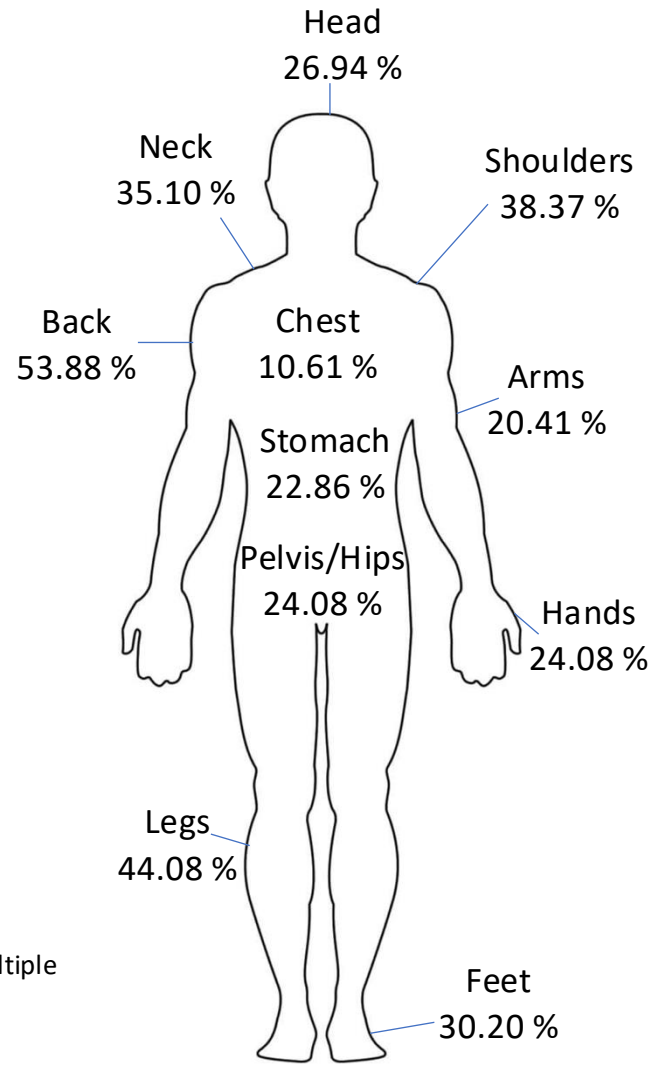
Diagnoses*



- MSK (n = 114)
- Neurological (n = 73)
- Other (n = 23)
- No diagosis (n = 22)
- Gastrointestinal (n = 13)
- Gynaecological (n = 13)
- Autoimmune (n = 11)
- Cancer (n = 4)
- Cardiovascular (n = 3)
- Respiratory (n = 3)
- Endocrine (n = 2)

*total n = larger than sample size because some participants have multiple conditions or a condition that falls in 2 categorical areas

Area(s) of pain



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Method

Pre-screening

n = 245

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Describe a past experience…

Participants were assigned to experimental conditions based on the past experience they reported :

Validation (n = 124) or Invalidation (n = 121).

Those who had experienced both were randomly assigned.

Next, we would like you to tell us about a time in the past where you felt a healthcare provider **validated** your pain experiences.

Pain **validation** can be described by the following statements:

A healthcare provider made me feel that what I told them **was understandable.**
A healthcare provider made me feel that what I told them **made sense**.
A healthcare provider made me feel that what I told them **was reasonable.**
A healthcare provider **listened to my concerns.**
A healthcare provider made me **feel heard.**
A healthcare provider made me feel like **I was believed.**

For the next few minutes we would like you to describe in as much detail as possible the things that made you feel **validated**.
(What did the doctor/nurse/clinician say? What was their body language like? etc.)

Please do not include any identifying information about yourself, the hospital/clinic/GP or the healthcare provider.

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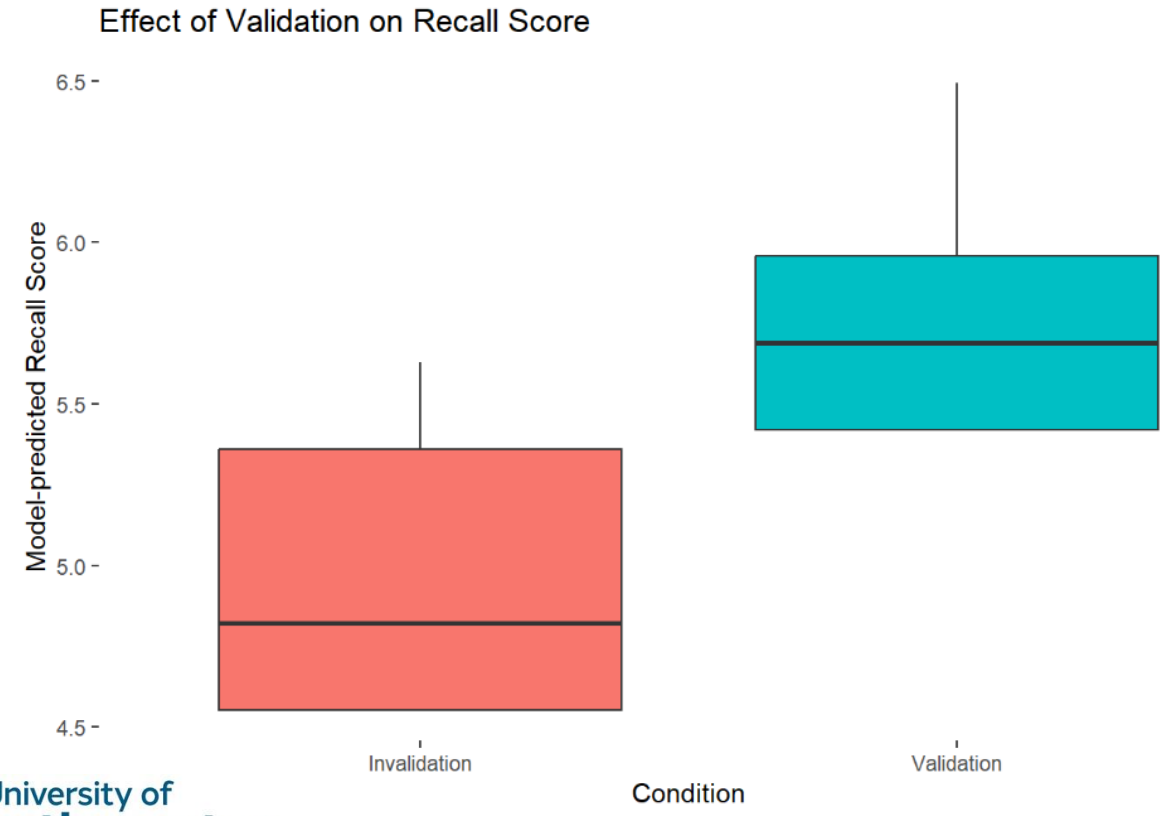
Results – *Recall Score*

Recounting a past experience of clinician ***validation*** was associated with significantly **higher** **recall scores** than recounting a past experience of ***invalidation*** (those in the validation condition remembered **0.87** more items compared to those in the invalidation condition). The best fitting model accounted for systematic differences in diagnostic uncertainty.



Public Contributors' thoughts:

"Remembering one more thing might not sound like a lot but is really important."

"One thing you never think to take to a consultation is a pen and paper!"

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Summary- tools in your box

- Listen to the narrative (resist chasing hypothesise, resist telling the patient they're wrong; resist coming up with a management plan while they are talking)
- Validate (with integrity- possibly iteratively; resist moving on to 'solutions')
- Explore the Orange (resist squats and lunges, rights and wrongs)
- Possibly resist using the term Acceptance

Huge thanks

To our funders,
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To participants!

To our PPI!

To the team!

- Dr. Charlotte Lee
- Dr. Hollie Birkinshaw
- Prof. Matt Garner
- Amanda Lillywhite

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