

Research Update & Results of the experience of PoTS interviews

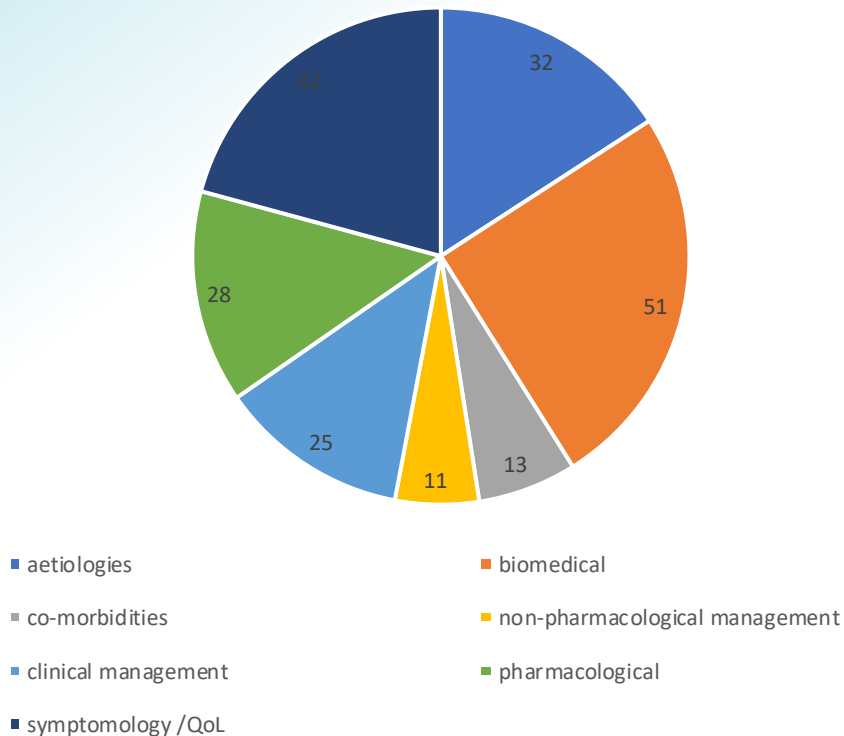
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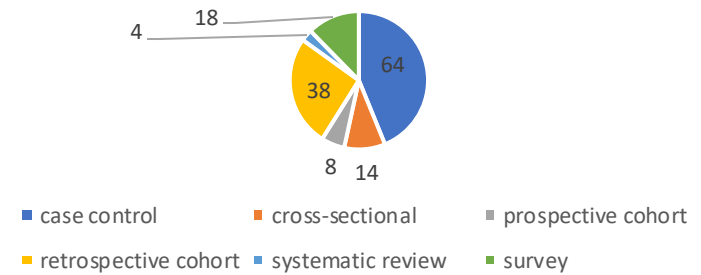


Mapping the Evidence Base The PoTS Research Studies (to Sept 2017)

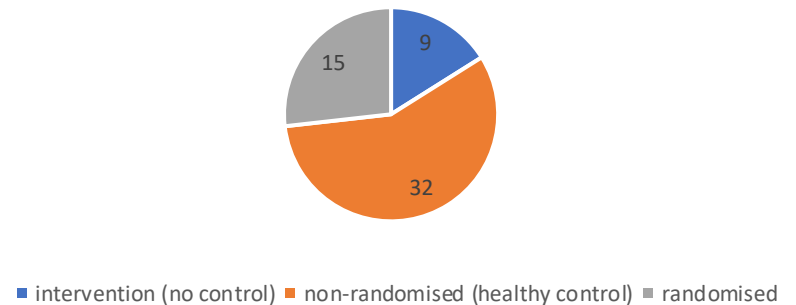
Theme in the PoTS research n=202



Observational studies in PoTS Total n=146



Experimental studies In PoTS Total n=56



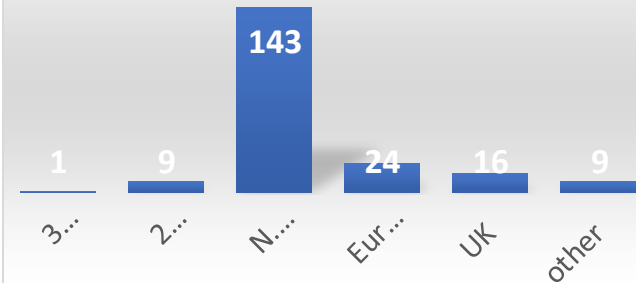
What does mapping the PoTS Evidence Base reveal



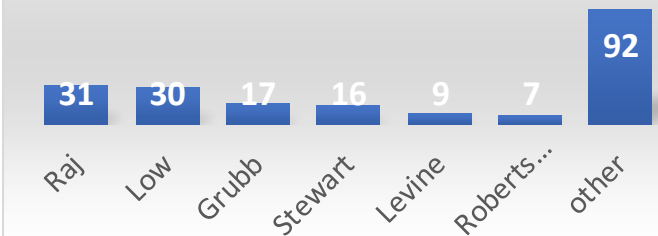
Since 2012 increased diagnostic rate of PoTS
(preceded by increased pubmed publications)

- Small sample size: 27 studies >100 (4 intervention)
- Limited control of variables
- 98 studies measurements over 1 day; 16 studies over 1 week
- Commonly used outcome measure: tilt table n=55
- Subjective measures used in 59 studies
 - Researchers own tool 26 (unvalidated)
 - 15 studies used 2 – 4 tools
 - 11 studies used ≥ 5 tools!!!

Country of Research Team



Author Teams in the Research





Non-pharmacological management research



- 4 fluid studies
- 3 dietary studies
(salt, gluten, effect of food intake)
- 6 Compression studies
- 12 exercise studies
- Dysfunctional breathing intervention
- Body positions & cognitive functioning



Research Needs for PoTS Calls for Action

- Administrative data to track PoTS diagnoses and the impact of the illness
- Improve physician awareness about PoTS
- To better understand the multiple pathophysiology
- Effective treatments for PoTS
- Need for collaborative research
- For more research funding to study PoTS



Exploratory Data Collection Phase 1 SSPoTS Interviews October 2021-September 2022



Diverse sample of 44

- 19 people with PoTS using purposive sampling
3 NHS Participant Identification Sites. Nurse-led

Female (n=17), Caucasian (n=19)

Geographical spread

Northwest (n=6) Northeast (n=8) Southeast (n=5)

- 25 Health Care Professionals (PoTS UK network) using snowball sampling

Consultants (n=6)

Nurses & AHP's (n= 14)

General Practitioners (n=5)

Geographical spread:

England North (n=9) midlands (n=3) Southeast (n=11)

outside England (n=2)

Personal Experience of PoTS (n=4)



Final Thematic Framework

1. A challenging condition

- 1.1 Life Changing
- 1.2 Dismissals
"Brushing me off"
- 1.3 Psychological matters
- 1.4 Our current medical model
"Boxes"
- 1.5 Accessing Healthcare
"distinctly lacking diversity"

2. *"Services by accident not design, few & far between"*

- 2.1 Jumping through
"Diagnostic hoops"
- 2.2 Paying for healthcare
- 2.3 Whose responsibility
"the same fight"
- 2.4 Knowledge and awareness
"opening up those conversations"

3. Validating Experiences

- 3.1 *"Human interactions"*
- 3.2 *"Learning on the job a bit of a mishmash"*
- 3.3 Interconnecting mind & body
"learning that dance"
- 3.4 Movement & rest
"being kind to yourself"

4. Practical self-help *"a hand to get going"*

- 4.1 Go & manage yourself
"thrown in the deep end"
- 4.2 *"Key board warriors - holding each other up"*
- 4.3 Moving forward
"tools, techniques & challenges"
- 4.4 Research
"dipping our toes in the water"



Theme 1

A challenging condition

"Most people with PoTS, their condition is quite challenging, not the person, the condition is quite challenging and for that it presents a big challenge"
(HCP16)

1.1 Life Changing

1.2 Dismissals *"Brushing me off"*

1.3 Psychological matters

1.4 Our current medical model *"Boxes"*

1.5 Accessing Healthcare

"If I call out the elephant in the room on this, what we see with quite a lot of people with PoTS is they can come across to healthcare practitioners as being very complex, very confrontational, very resistant..... what I see is people who've been repeatedly traumatized feeling so desperate, who are feeling so poorly, who have repeatedly been told that, there's nothing wrong with them and they should get back to work or they're letting their family down or something as invalidating as, I expect it's just because you're in your late 30s and you haven't had children"
(HCP4)

*"Do I think PoTS patients are any more anxious than the general population?
No, but does anxiety sound like PoTS, it certainly can do. Lots of patients are labelled as anxious...there's a lot of anxiety associated with it, it's not the cause"* (HCP15)

"This patriarchal bloody society nonsense that goes on in medicine. They're always 'right women being hysterical'. If you can't treat it with a vibrator, well, we'll just lock them up. This attitude is still passed down again and again. God forbid you're a woman and a person of colour... the odds are stacked against you...whatever you do your damned. That's gotta go all the way back to medical schools and medical training and how we view women as a society in the medical world, we're always going to be up against it, unfortunately. No soapboxing." (P12)

Theme 2



"Services by accident not design, few & far between"

2.1 Jumping through
"Diagnostic hoops"

2.2 Paying for healthcare

2.3 Whose responsibility

"the same fight"

2.4 Knowledge and awareness
"opening up those conversations"

"It's also a question of whether you find somebody who again has an interest, who then has somebody who can support that interest and develop it....it's by accident rather than by design... therefore it develops into something but it's random. It's not by design."
(HCP15)

"I think people are exploited and I think people pay a lot of money for a lot of tests that don't move them any further forward...always they don't see one person, they end up seeing at least two or probably three people ... told what treatment they need, which is often treatments that I might not choose to use. So that sets up a real problem in the relationship between the clinician and the patientthey've got their money, their patients gone, they've got no continuing duty of care or responsibility. They've written a nice letter, got their money, and sent them back."
(HCP17)

"I was telling them till I was blue in the face that this was not a PoTS collapse ...I don't use this word lightly, but the doctor mansplained POTS to me....(another health care practitioner) laughed at me and it was sort of quite humiliating, especially because I was right..... it was all the myasthenia, and as soon as I went on the medication for the myasthenia, all these new symptoms stopped and I just think, what if I hadn't pushed, what if I hadn't kept going back and what would I have had to get to before they would take it seriously and stop saying it's POTS" (P10)

Theme 3 Validating Experiences

3.1 "Human interactions"

3.2 "Learning on the job -
a bit of a mishmash"

3.3 Interconnecting mind & body -
"learning that dance"

3.4 Movement & rest
"Being kind to yourself"

"Me and my mum burst into tears..she was literally in floods of tears. She had watched me suffer my entire life with being told I was mentally ill, but I was feeling poorly, faint, weak, shaky...to know that it wasn't in my head. I was bordering on ecstatic to be honest, and I wanted to hug them, and yeah, I cried. It was life changing" (P8)

"I'm comfortable in my knowledge... in my limitations, if we don't speak openly about what we know and what we don't know we're not going to get anywhere... I use a lot of clinical reasoning. I have to read around the houses, apply what I read to what I see....make my own theories and a test them which is what I say to patients as well" (HCP10)

"I prefer to accept that they (patients) know things that I don't know and then I could learn from them and maybe modify things a little bit to put them into better perspective (par.32).I was actually helped much by a few early patients who came to me with printed literature. And said please you read this, and I did, and I said I understand better" (HCP12)



Theme 4 Practical self-help - *"A hand to get going"*

4.1 Go & manage yourself
"thrown in the deep end"

4.2 *"Key board warriors –
holding each other up"*

4.3 Moving forward
"tools, techniques & challenges"

4.4 Research
"dipping our toes in the water"

"Most people, and even those highly activated people in the first instance, actually need a hand to kind of get going with it. You know need to know, is this good information or is this bad information... if people have enough knowledge to know how to manage their condition when the symptoms are worse... giving people the tools and the techniques that they need... it's self-efficacy" (HCP11)

"If you say to somebody who's struggled to get GPs to believe them, you've got this condition and what you're gonna do is you're gonna manage it yourself. They'll generally think you're fobbing them off and that's the balance. So, you do want to say there's lots of things you can do for yourself, but it is real... You have to be very careful" (HCP13)

"You don't get a lot of support from doctors because it's not very well known and also a lot of the treatments for PoTS is like anecdotal. So, you just see other people who are like similar to you struggle and it's like easy to identify with them. They know the struggle you've been through and being fobbed of and things like that. It's just easy to relate to." (P15)

Conceptual model of the experience of PoTS

