

Defining recovery from Complex Regional Pain Syndrome.

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Background

- Complex Regional Pain Syndrome (CRPS) is a persistent pain condition, usually of a single limb¹. Unremitting symptoms are associated with long-term disability, poor psychological health and reduced quality of life (QoL)².
- The trajectory of long-term CRPS is not straightforward. While some initial features may dissipate, meaning patients may no longer meet diagnostic criteria, other symptoms can endure³.
- The longevity and complexity of symptoms leads to problems in defining recovery and evaluating the efficacy of therapeutic interventions.

Aims

- An international consortium was convened, holding 5 workshops to design a 2-Round Delphi-based process to:

Identify patients' definition of recovery, including the qualitative themes they considered most important.

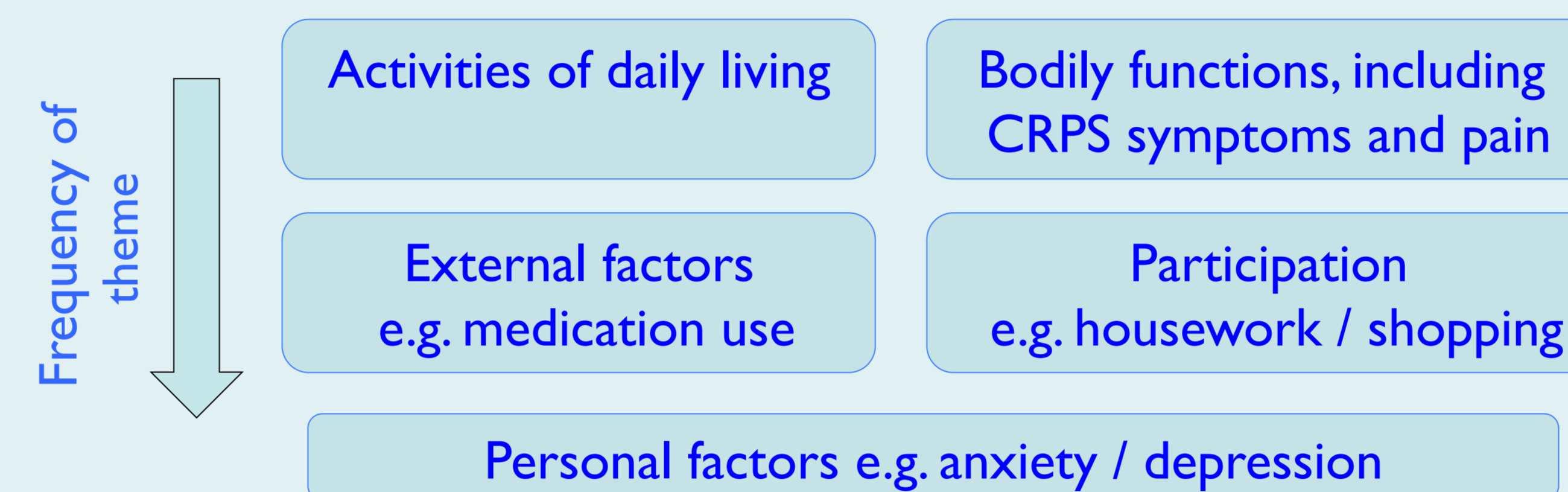
Understand the self-reported symptoms, demographic and bio-psychosocial factors that may impact their definition of recovery.

Method

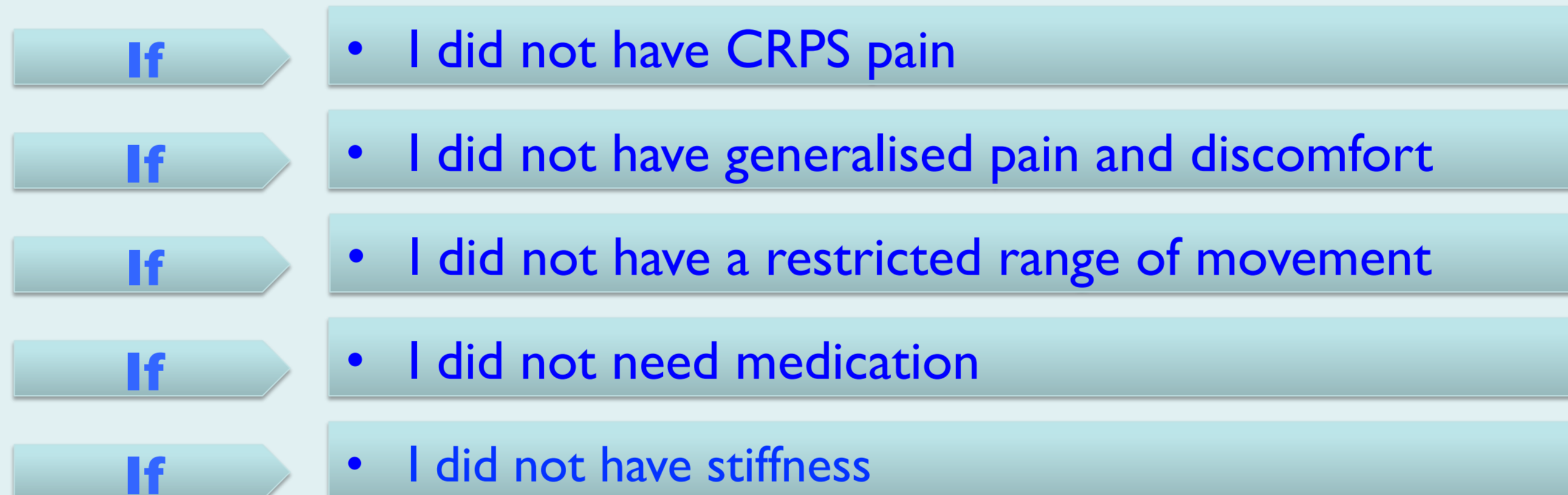
- Participants ≥ 18 years, who met CRPS type I Budapest diagnostic criteria, were identified from databases and clinics in 8 countries: UK, Netherlands, Germany, Denmark, Switzerland, Poland, Canada, USA.
- Round 1: participants completed the statement "I **would** consider myself recovered if..." or "I **do** consider myself recovered because ..."
- Data were thematically analysed and ordered under the WHO ICF classification, providing **62 statements representing the most frequently mentioned themes**.
- Round 2: the same participants identified and **ranked the 10 statements they considered most important** to their perception of recovery. Cumulative weighted percentages identified the top statements overall.
- Other measures: demographic and symptom questionnaires; standardized measures for pain (MPQ), quality of life (QoL) (EQ-5D), psychological flexibility (AAQ-II), function (RSQ for upper-limb CRPS / WAQ for lower-limb).

Results

- Round 1: Dominant themes** for patient defined recovery (N=347, 80% female, 91% non-recovered, 53% disease duration ≥ 3 years) were:



- Round 2: Top 5 ranked recovery statements** (n=252, 77% female, 90% non-recovered) were:



- The top three statements of most subgroups (e.g. by gender, recovered/non-recovered, disease duration, upper and lower limb CRPS) were all within the overall top five.
- Self-reported recovery (n=310) was associated with:**
 - number of symptoms ($\chi^2 = 124.94, df = 15, p < .001$)
 - knowing disease type (CRPS Type I or II) ($\chi^2 = 6.11, df = 1, p < .05$)
 - having caring responsibilities ($\chi^2 = 4.57, df = 1, p < .05$)
- Self-reported recovery was **not** associated with: demographics, disease duration or limb affected.
- Non-recovery was associated with:** lower psychological flexibility, higher pain, lower QoL, and poorer mental and physical health.
- Non-recovered participants with lower limb CRPS (n=85) had poorer outcomes (symptoms, pain, QoL) than non-recovered participants with upper limb CRPS (n=166).

Conclusions

- A very small number of themes are of highest importance to people with CRPS, and these vary little with demographics.
- People want their CRPS-related pain, generalised pain, movement difficulties, and medication reliance to be addressed, above all other factors, for them to consider themselves recovered.
- Non-recovery is associated with on-going symptoms and bio-psychosocial factors.
- Unresolved CRPS has negative consequences for mental and physical well-being.
- People with lower-limb CRPS have poorer health outcomes than those with upper-limb CRPS.
- The themes and bio-psychosocial factors identified as important in patients' definition of recovery support the role of pain management and multidisciplinary rehabilitation services in CRPS, and are consistent with current UK treatment guidance.

References

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