Most patients are diagnosed only when admitted to hospital,[7] resulting in higher economic costs[8] and much worse outcomes.[9]

Developing a core outcome set for patient-reported symptom monitoring to reduce hospital admissions for patients with heart failure in primary care.

Claire Lawson, Carolyn Lam, Tiny Jaarsma, Umesh Kadam, Anna Stromberg, Mohammad Ali, Wan Ting Tay, Louise Clayton, Kamlesh Khunti, Iain Squire.

Background

- In heart failure (HF), hospitalisation rates are increasing, particularly for non-HF causes and over half may be avoidable.(1)
- Self-monitoring of symptoms and health related quality of life (HRQoL) play a key part in early identification of deterioration.
- Patient reported outcome measures (PROMs) are validated measures that are sensitive to changes in physiological and clinical status(2) and predictive of hospitalisation.(3, 4)
- ICHOMs has recommended inclusion of 6-monthly monitoring of HF and mental health symptoms alongside HRQoL, to facilitate research and quality of care assessment at an organisational level.(5) However, there is no current consensus on which symptom should be used for PROMs in routine patient self-monitoring to help prevent unplanned admission for people with HF.
- Our objective was to develop expert consensus for a core outcome set (COS) of symptoms to be monitored by patients, using validated single-item patient reported outcome measures (PROMs), focussing on the key priority of reducing admissions in HF.

Methods

- A rigorous COS development process incorporating systematic review, modified e-Delphi and nominal group technique (NGT) methods. Participants included HF patients, carers and clinicians in England. In 3 Delphi and NGT rounds participants rated potential outcomes on their importance before a HF or a non-HF admission and ease of detection, using a 5-point Likert scale. Opinion change between rounds was assessed and a two-thirds threshold was used for outcome selection.

Results:

From 315 unique studies including 10 literature reviews of PROMs in HF patients (**Figure 1**), we extracted 100 single-item visual analogue (VAS) or numerical rating scales (NRS) covering 24 symptoms, which were relevant to admission in patients with HF, to be included in the Delphi questionnaire (**Table 1**).

- 24 patients (mean age 59 [SD 12.]) years, 43% female, 79% White), 4 carers, 29 nurses and 6 doctors took part in the Delphi survey.
- In round 1, change in taste, constipation, forgetfulness, depression and nausea were eliminated. Following free text comments from participants, the symptom of weight gain was added.
- In round 2, eight symptoms (shortness of breath; at any time/at rest/at night, arm or leg swelling, abdomen bloating, palpitations, weight gain and chest pain) met both criteria for at least one admission type, for inclusion in the COS.
- In round 3, only anxiety, met the two thirds threshold and was stable between rounds and was added to the COS. Fatigue, drowsy, numbness/tingling and urination problems were unstable and taken forward to the NGT. Overall health was eliminated at round 2, but was also taken forward given the strong supporting evidence of its association with outcomes in HF.
- In the NGT meeting, the group agreed that fatigue was often ‘constant’, ‘chronic’, ‘temporary’ and so ‘may not be sensitive to change’. They did agree that overall health could be related to symptom change and the feeling that that ‘something is going wrong’ and should be added. A final COS comprising 8 symptoms and signs was agreed (**Figure 2**).

Figure 1: PRISMA flow chart

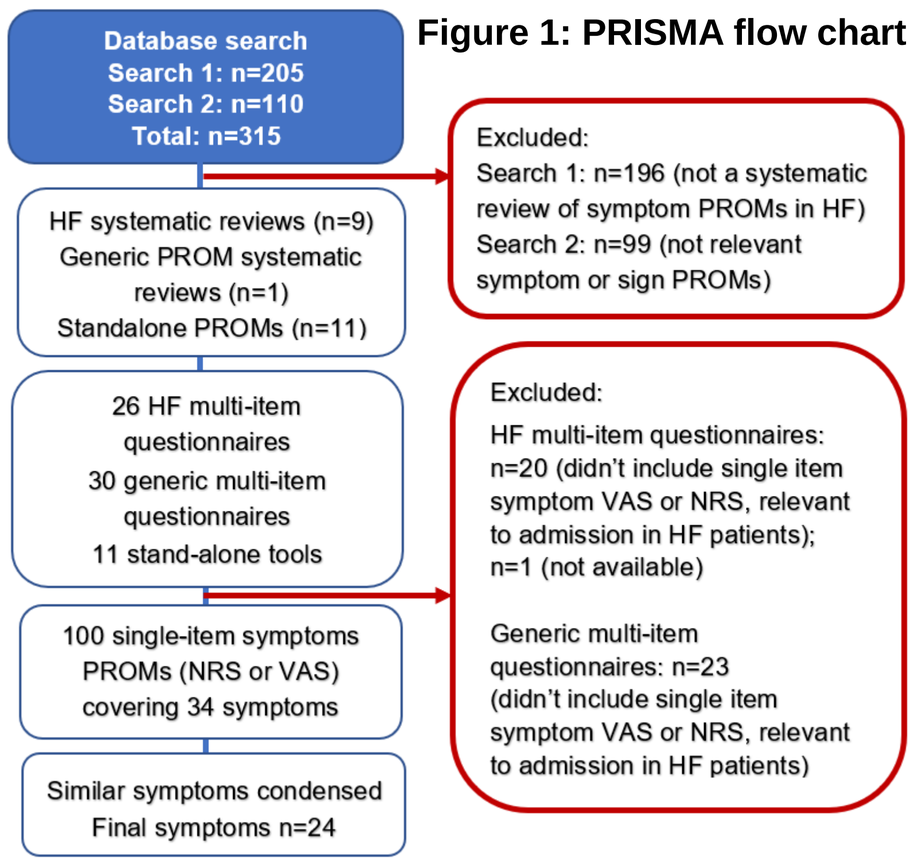
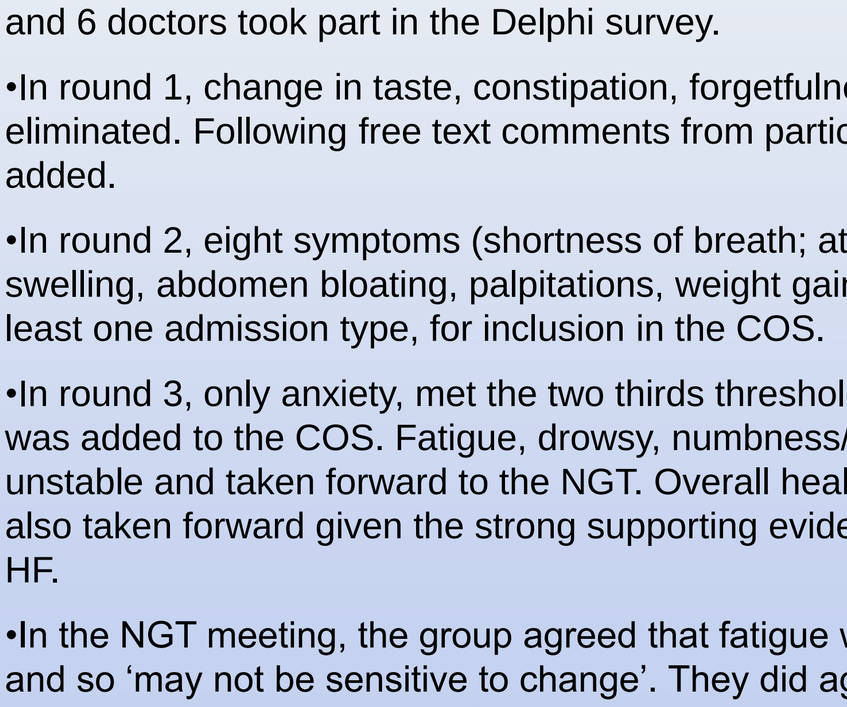


Table 1: Symptoms included in Delphi survey

Shortness of breath at anytime	Chest pain
Shortness of breath at night	Numbness or tingling
Cough at anytime	Nausea
Cough at night	Vomiting
Tiredness/fatigue	Diarrhoea
Change in taste	Constipation
Drowsiness	Anxiety
Abdomen bloating	Sad or depressed
Feet swelling	Overall health
Arm swelling	Disturbed sleep
Palpitations	Urination problems
General pain	Forgetfulness

Figure 2: Final Core Outcome Set



Conclusion:

Recognition of a range of HF specific and general symptoms, alongside comorbidities, is an important consideration for admission prevention. Further work is needed to validate and integrate the COS in routine care with the aim of facilitating earlier identification of clinical deterioration.

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