

Improving the management of chronic

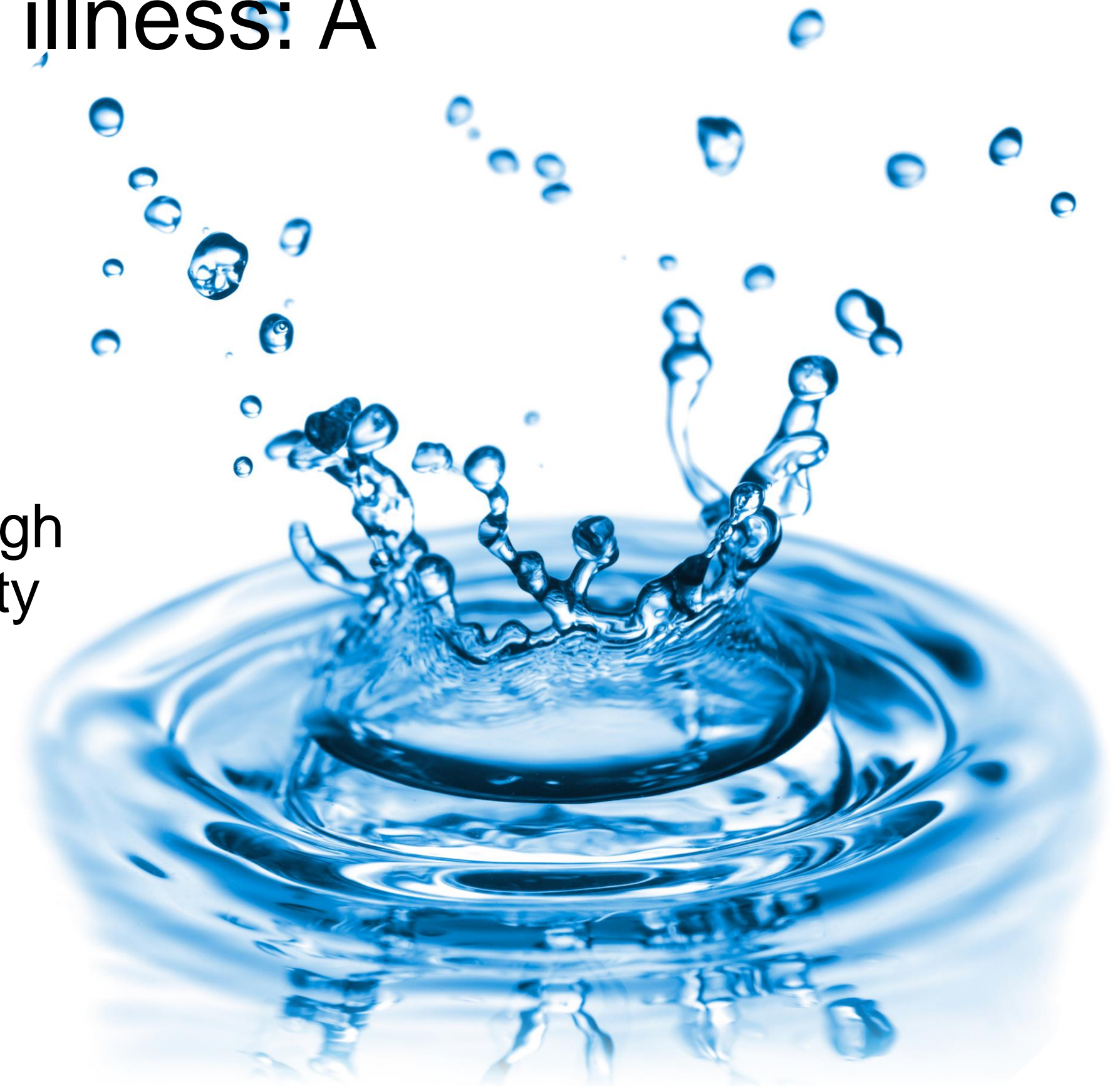
■ breathlessness in people with life-limiting illness: A

Wolfson / IMPACCT collaboration

A/Prof Tim Lockett

IMPACCT (Improving Palliative, Aged and Chronic Care through Clinical Research and Translation, Faculty of Health, University of Technology Sydney (UTS), New South Wales, Australia

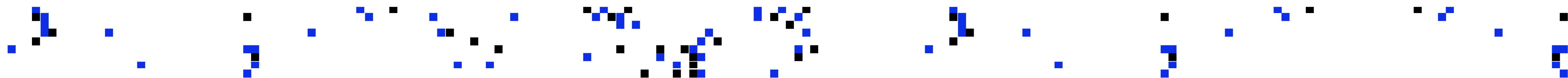
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Creating connections for breathlessness research

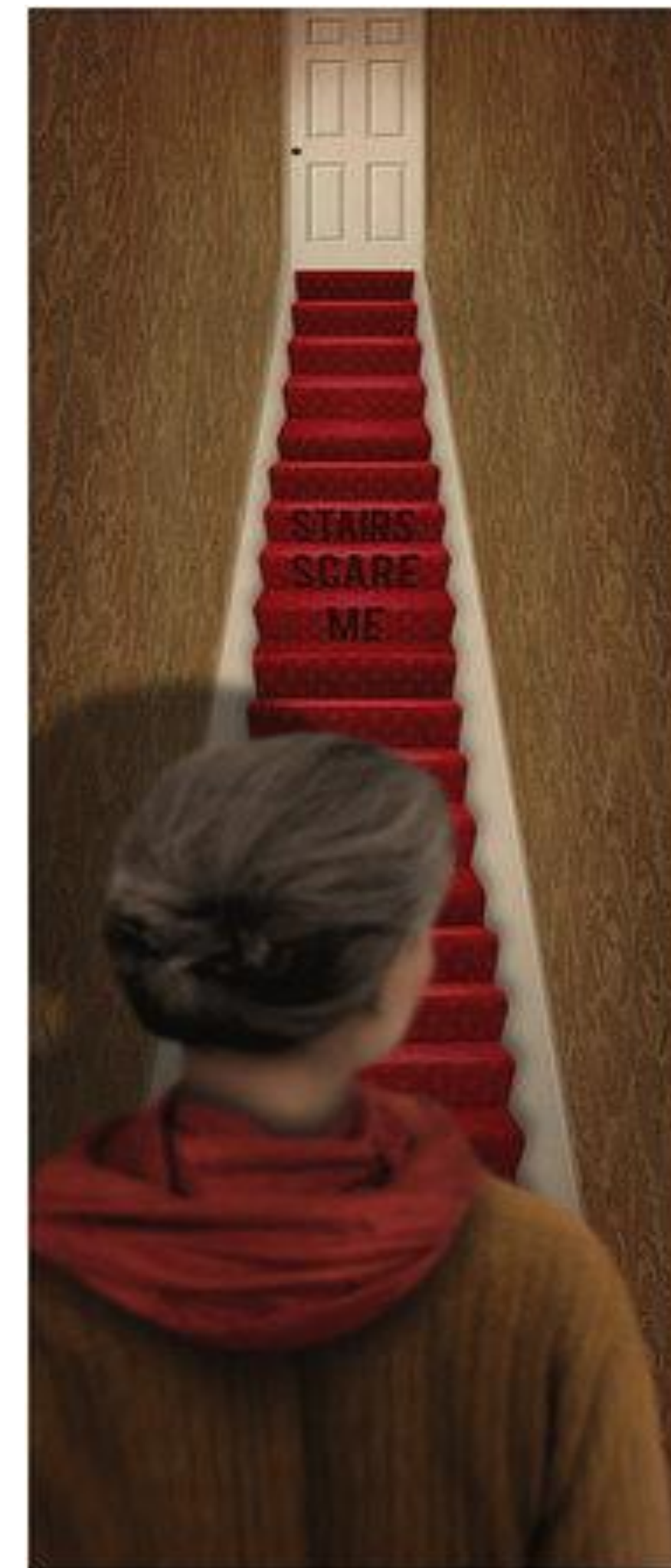
i3 has enabled ...

- new projects building on previous collaborative and separate research:
 - BREATHE Well (completed)
 - BREATHE Action Plan (underway)
 - Hand-held fan program (various)
- PhD co-supervision
- mentoring and support from an international centre of excellence

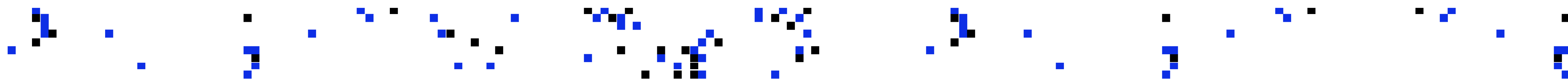


Chronic / persistent breathlessness

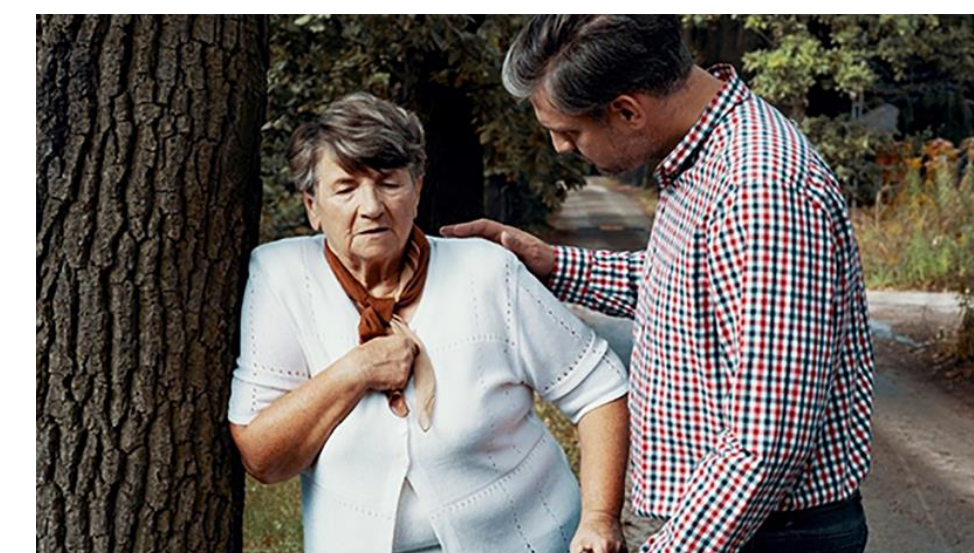
- Breathlessness that persists despite optimal treatment of underlying pathophysiology and that results in disability (Johnson, 2017)
- Common in many life-limiting illnesses, including respiratory diseases like chronic obstructive pulmonary disease (COPD), heart failure and cancer
- Complex symptom with 'sensory-perceptual', 'affective' and 'impact' dimensions (Parshall, 2012)
- Contributes to a 'vicious cycle' of activity avoidance, reduced functioning, deconditioning, social isolation, mental ill health and poor quality of life (Hutchinson, 2018)



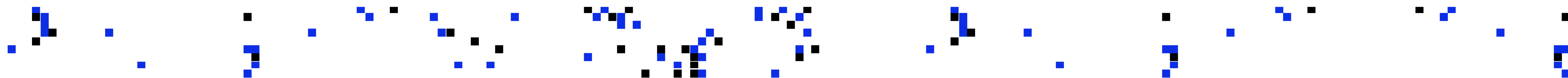
HYMS 'Bringing breathlessness into view' exhibition



Acute-on-chronic episodes (AKA 'breathlessness crises')

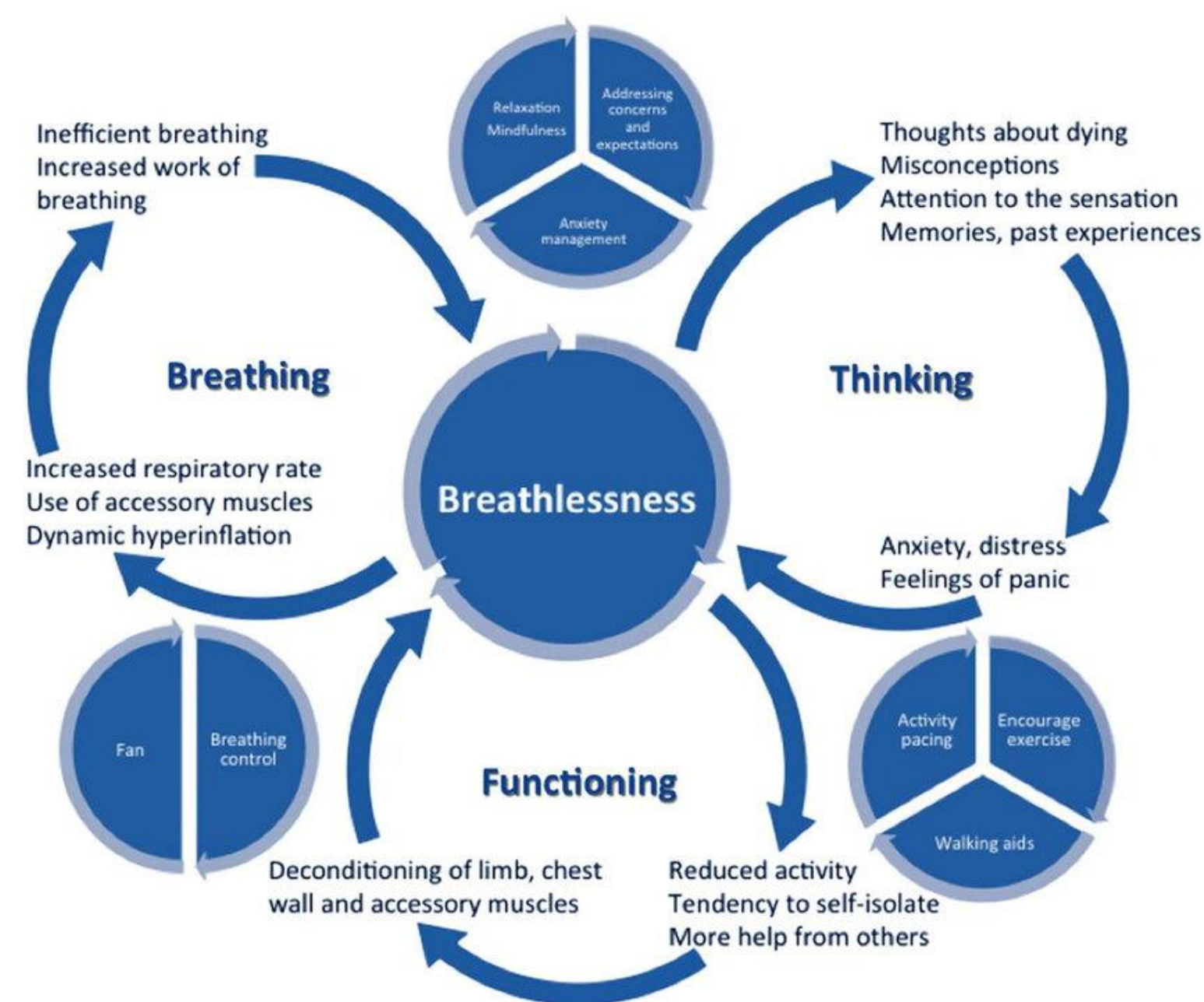


- Worsening of breathlessness on top of everyday 'background' levels
- Sometimes but not always a symptom of acute pathology (e.g. COPD exacerbation)
- At other times, due to over-exertion, airborne pollutants, humidity or other reasons that are difficult to understand or predict
- Can make the person feel as if they are “*gasping for breath*”, “*suffocating*” and “*about to die*” (Hutchinson, 2020; Lockett, 2017)
- May result in sense of disempowerment, loss of control and panic both for person with breathlessness and family (Lockett, 2017)
- May prompt at least 5% of all ED presentations - and 20% of ambulance-to-ED presentations - despite not always being in the person's best interests (Hutchinson, 2017)



Management of chronic breathlessness

- Aims to address ‘breathing’, ‘thinking’ and ‘functioning’ dimensions (Spathis, 2017)
- Evidence-based non-pharmacological strategies include: breathing techniques, pacing, positioning, relaxation and a hand-held fan (Booth and Johnson, 2019)
- As for all chronic health problems, patient education occurs within a ‘self-management’ framework



Mooren (2022)

Self-management of chronic conditions – a complex construct

Journal of
Nursing and Healthcare of Chronic Illness An International Journal

ORIGINAL ARTICLE

doi: 10.1111/j.1752-9824.2011.01085.x

Self-management in chronic illness: concept and dimensional analysis

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Original Article

Self-Management of Multiple Chronic Conditions by Community-Dwelling Older Adults: A Concept Analysis

Anna Garnett, MSc, RN^{1,2}, Jenny Ploeg, PhD, RN^{1,2},
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Patricia H. Strachan, PhD, RN²

SAGE Open Nursing
Volume 4: 1–16
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DOI: 10.1177/2377960817752471
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Nursing Outlook

Volume 63, Issue 2, March–April 2015, Pages 154-161



Article

Research

Chronic disease self-management: A hybrid concept analysis

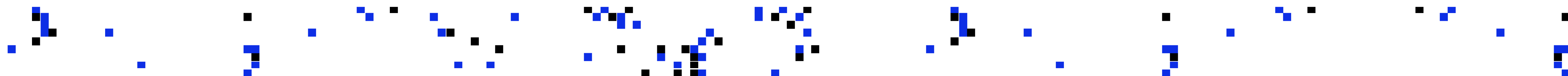
Wendy R. Miller PhD, RN, CCRN^a  , Sue Lasiter PhD, RN^a, Rebecca Bartlett Ellis PhD, RN^a,
Janice M. Buelow PhD, RN, FAAN^b

Open access

Research

BMJ Open Delineating the concept of self-management in chronic conditions: a concept analysis

Dominique Van de Velde,^{1,2} Freya De Zutter,¹ Ton Satink,³ Ursula Costa,⁴
Sara Janquart,¹ Daniela Senn,⁵ Patricia De Vriendt^{1,2,6}

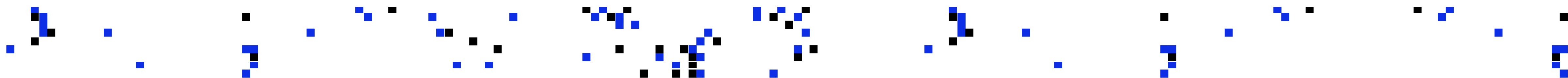


Self-management as autonomous agency

*“**Active participation** by people in their own health care” (Australian National Chronic Disease Strategy, 2006)*

*“A process through which individuals **actively cope** with their chronic disease in the context of their daily lives” (O’Connell et al, 2018)*

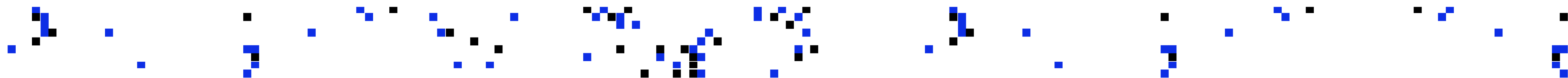
*“Knowing that you can **take control** and change your life if you really need to, **instead of feeling helpless**” (man with COPD)*



Self-management 'skills' (Lorig and Holman, 2003)

1. Problem solving (e.g. *how do I still do the things I enjoy when I can hardly get to the toilet and back?*)
2. Decision-making (e.g. *should I call the ambulance because I feel like I'm dying from lack of air and risk being made to sit there for hours and feel like a fool?*)
3. Resource utilisation (e.g. *how do I make optimal use of my social network?*)
4. Building patient/health care provider partnerships (e.g. *which professional helps me with what?*)
5. Taking action (e.g. *what are the steps I should follow when my breathlessness gets suddenly worse?*)

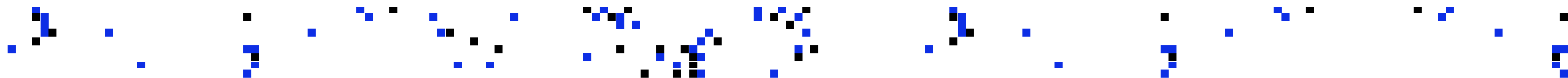
“One cannot not manage. If one decides not to engage in a healthful behaviour or not to be active in managing a disease, this decision reflects a management style”



But self-management requires support

*“The ability of the individual, **in conjunction with family, community, and healthcare professionals**, to manage symptoms, treatments, lifestyle changes, and psychosocial, cultural, and spiritual consequences of health conditions” (Richard & Shea, 2011)*

*“The intrinsically controlled ability of an active, responsible, informed and autonomous individual to live with the medical, role and emotional consequences of his chronic condition(s) **in partnership with his social network and the healthcare provider(s)**” (Van de Velde, 2019)*



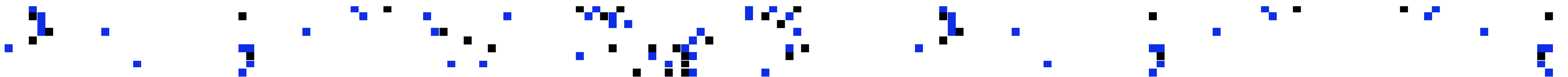
BREATHE Well Project

Using realist review to develop theory and working with stakeholders to co-design an implementation strategy for breathlessness self-management

Ann Hutchinson, Flavia Swan, Sarah Greenley, Tim Lockett, Kath Sartain, Miriam Johnson and Mark Pearson



Funding: National Institute for Health and Care Research (NIHR), Research for Patient Benefit (RfPB) Programme (Grant Reference Number NIHR204312). The views expressed are those of the author(s) and not necessarily those of the NIHR or the Department of Health and Social Care



BREATHE Well

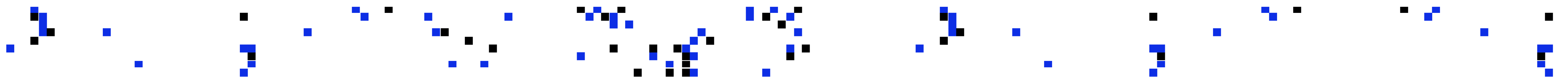


Aims

1. Review evidence on the use of self-management interventions across long-term conditions and breathlessness more specifically
2. Bring together review evidence with the experiences of patients, support persons and clinicians to co-design an implementation strategy for chronic breathlessness

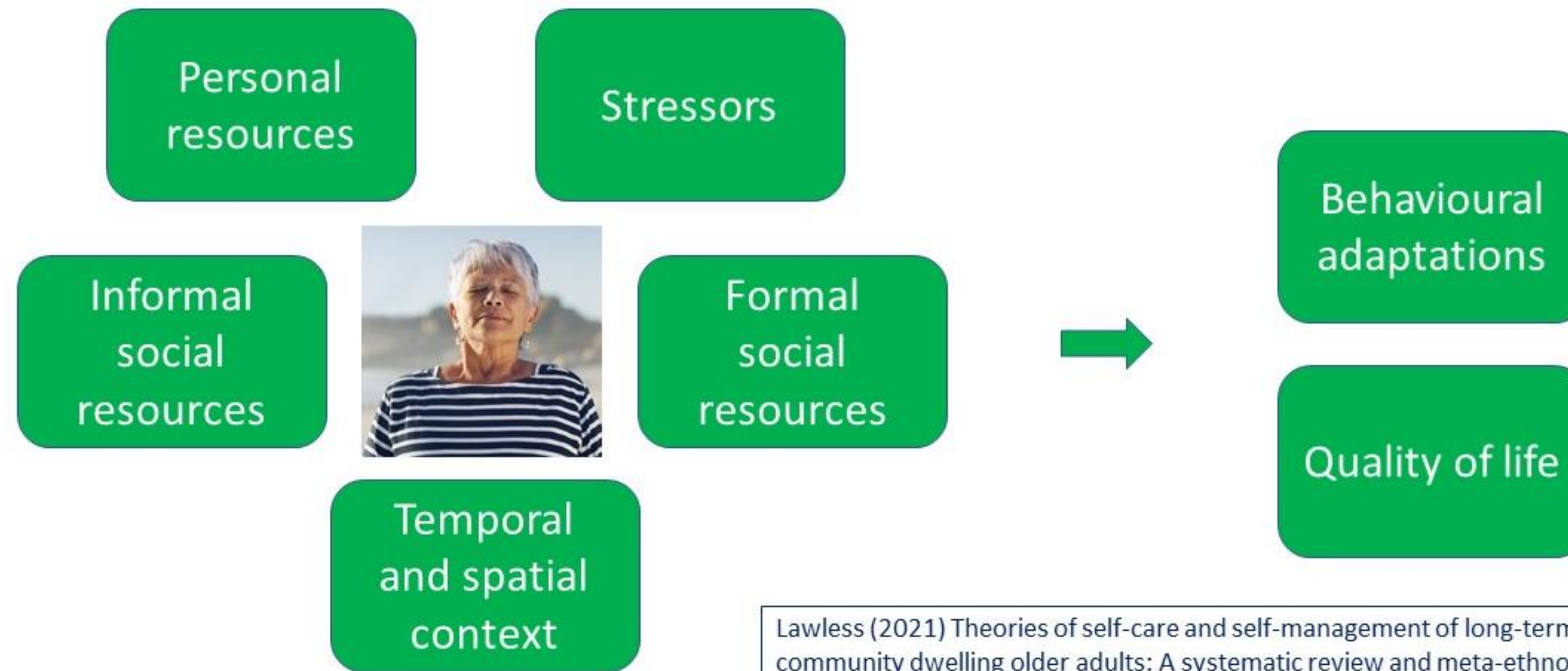
Methods

- Realist Review to develop and test theory
- ‘If ... then ... because’ explanatory statements developed for domains in Lawless et al’s (2021) framework for self-management of long-term conditions
- Three stakeholder workshops to discuss and refine the explanatory statements and co-design practical components to support implementation



Self-management concepts in the Lawless et al (2021) framework

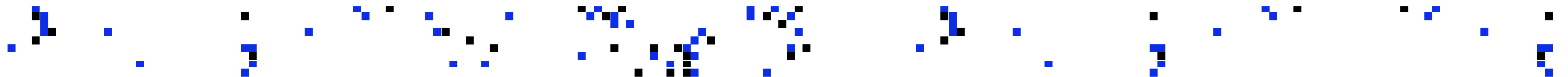
“A dynamic process of behavioural adaptation, enabled by personal resources and informal and formal social resources, aimed at alleviating the impacts of stressors and maintaining quality of life”



BREATHE Well - Results



- Review included 32 literature sources on self-management in long-term conditions and 31 sources on breathlessness self-management
- 53 explanatory statements were developed and refined
- 34 stakeholders took part in workshops to co-design the implementation strategy:
 - 10 people living with breathlessness or supporting people with breathlessness
 - 20 clinicians
 - 4 health service managers



BREATHE Well - Results



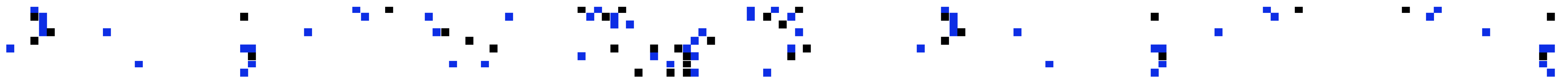
Examples of explanatory statements:

If a person is fearful of breathlessness or fearful that exercise may make other comorbidities worse, then they may not attend a self-management programme.

(Stressors)

If a person's clinician puts the responsibility for their ability or motivation to self-manage onto the individual and fails to understand the impact of other factors on their ability or motivation to self-manage (such as health literacy and contextual factors constraining the person), then the person may not self-manage effectively, because they are not given the support they need and they feel blamed and demotivated.

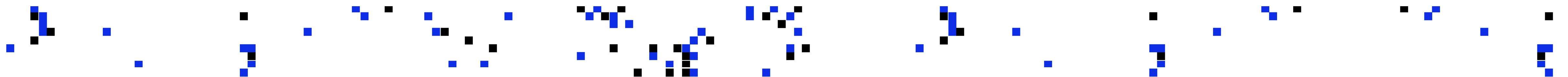
(Formal social resources)



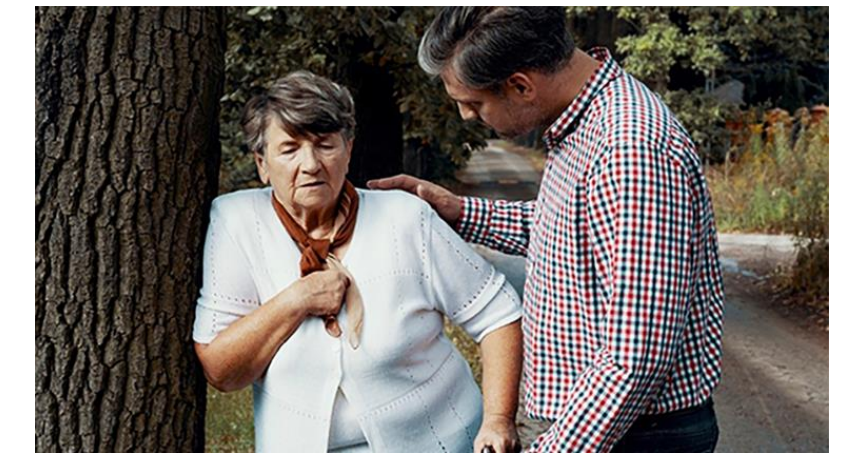
BREATHE Well - Results

A self-management implementation strategy should ...

- enable all clinicians who are seeing people with breathlessness to explain the benefits of, and what is entailed in, a self-management programme, addressing any concerns that they may have. (Stressors)
- enable clinicians who are closely involved in encouraging breathlessness self-management to enable access for patients and carers to online support and/or videocalls with others who can support them. (Informal social resources)
- enable all clinicians who are seeing people with breathlessness to understand that a person's self-management behaviour is influenced by their physical and social environment, rather than it solely being their individual responsibility to self-manage. (Formal social resources)
- encourage healthcare organisations to allocate funding so that their staff have the time and resources to offer self-management interventions and support in a way that is integrated into routine practice. (Temporal and spatial context)



BREATHE Action Plan Project



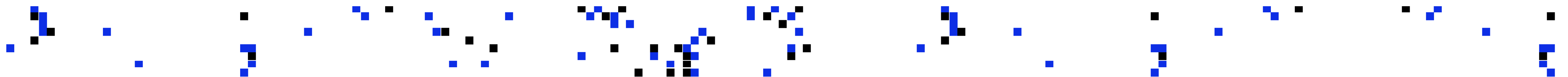
Co-designing and feasibility testing a breathlessness action plan for people with chronic obstructive pulmonary disease (COPD) and their support persons

Investigators: Tim Luckett, Mary Roberts, Don Dennett, Lennette Ruttle, Jo River, Tracy Smith, Ann Hutchinson, Flavia Swan, Mark Pearson, Miriam Johnson, Michael Crooks, Anna Keedwell, Marie Williams, Kylie Johnston, Slavica Kochovska, Joel Rhee, Eila Erfani, Ester Klimkeit, David Currow, Gerben Keijzers, Meera Agar

Additional project team: Muneeba Chaudhry, John Hancock, Marina Siemionow, Kate Smith

Partner organisation: Lung Foundation Australia

Funding: Australian Medical Research Future Fund (MRFF) Emerging Priorities and Consumer-Driven Research initiative (ID 2023248)



BREATHE Action Plan Project – Scoping review and survey

Background

Breathlessness action plans (BAPs) are easy-to-follow guides that summarise non-pharmacological strategies for managing worsening breathlessness.

Aims

With a focus on people living with chronic obstructive pulmonary disease (COPD) and their support persons, this study aimed to:

1 Identify evidence of effectiveness for Breathlessness Action Plans

2 Describe content & quality of available Breathlessness Action Plans

3 Describe current use of Breathlessness Action Plans

Methods

Oct 2023 **Scoping Review**

Systematic searches (academic databases, internet) identified primary studies reporting effectiveness of BAPs and English-language plans for adults in general or people with COPD and their support persons.

Nov 2023 **Online Survey**

Eligible respondents had experience of BAPs (person with COPD, support person or health professional). Recruitment included international peak bodies and respiratory and palliative care services in Australia and New Zealand.

Dec 2023

Research evidence was synthesised using a **narrative approach**. **Content analysis** was used to summarise strategies recommended by plans.

Quality of content was analysed using the **'Patient Education Materials Assessment Tool (PEMAT)'**

Reading grade was assessed using the **'Flesch-Kincaid Formula'**

Managing breathlessness

When feeling breathless

- 1 **STOP** Stop what you are doing
- 2 Find a resting position
- 3 Use your fan or the breeze
- 4 Choose your preferred breathing technique, & continue for 2-3 minutes

After 2-3 minutes evaluate your breathlessness

Are you feeling less breathless and more in control?
Yes: Continue with your activity
OR
No: Take your prescribed reliever inhaler medication through a spacer, then resume breathing technique for another 2-3 minutes

! If you remain breathless, refer to your written Action Plan on the front (turn over).

Common activities that can cause breathlessness when you live with COPD

Breathlessness is a common symptom in COPD. It can often seem to come on for no apparent reason or with very little exertion. This can cause people to feel frightened, out of control and anxious.

- Preparing and eating meals
- Hanging out washing
- Bending down to tie shoes
- Walking
- Vacuuming
- Showering and dressing

Self-management

Self-managing your condition helps to give you control. To learn more about these tools and how they can assist you in self-managing your condition, visit the Lung Foundation Australia website.

Self-management tool

Inhaler techniques
 Correct inhaler technique helps you get the most benefit from your inhaled medications. Ask your doctor, nurse or pharmacist to check your technique.

Relaxed breathing and control
 Bending over or leaning forward while resting your arms on a stable surface can assist with getting control of your breathing.

Chest clearance
 Airway clearance techniques are breathing exercises that can help you cough up phlegm. Ask a physiotherapist skilled in airway clearance techniques for instructions on how to start.

Hand-held fans
 A cool draft of air from a hand-held fan can help you feel less breathless and more in control.

COPD medications chart
 It is important you understand your medicines, their role, how they work, and when and how to take them.

Pulmonary rehabilitation (PR)
 PR is an exercise and education program that helps you to exercise safely and manage your breathlessness.

Vaccination
 Vaccinations for influenza, pneumococcal pneumonia and COVID-19 can reduce the risk of a flare up. Ask your doctor to check if your vaccinations are up to date.



Access information and support today
 lungfoundation.com.au
 enquiries@lungfoundation.com.au
 1800 654 301

Access the My COPD Checklist and discuss with your doctor or nurse

Lung Foundation Australia's BAP (second page of COPD Action Plan)

BREATHE Action Plan – scoping review and survey


Results

Scoping Review

Identified only one evaluative study (single site, pre-post, positive support) (Qian et al, 2016).

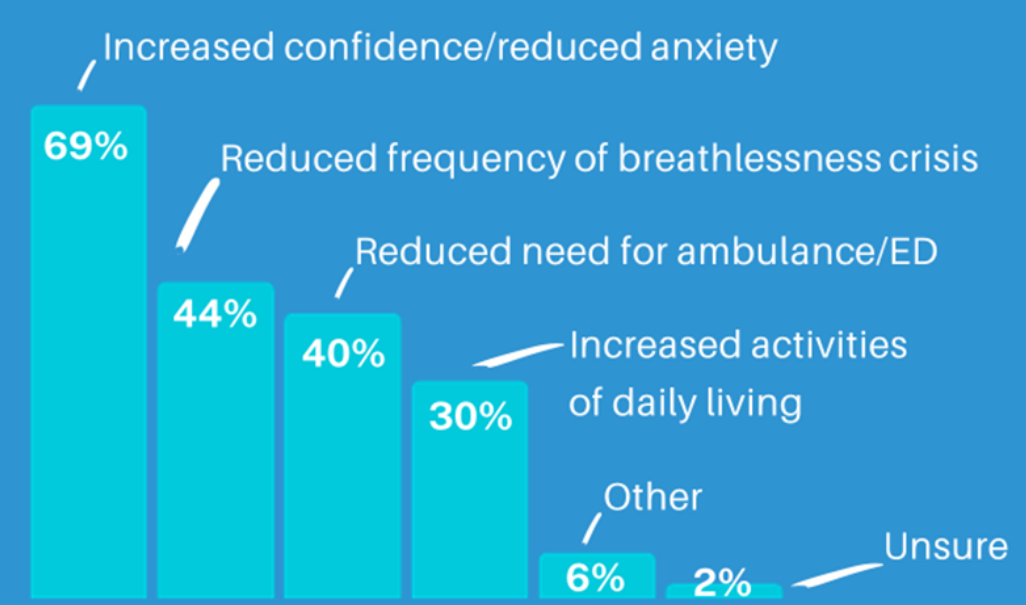
Survey Responses


44 people with COPD


2 support persons

Most users reported an increase in breathlessness in the past year that became suddenly worse in a way that was frightening.

55% of people reported BAPs prevented the need to call an ambulance or go to emergency ALWAYS or USUALLY



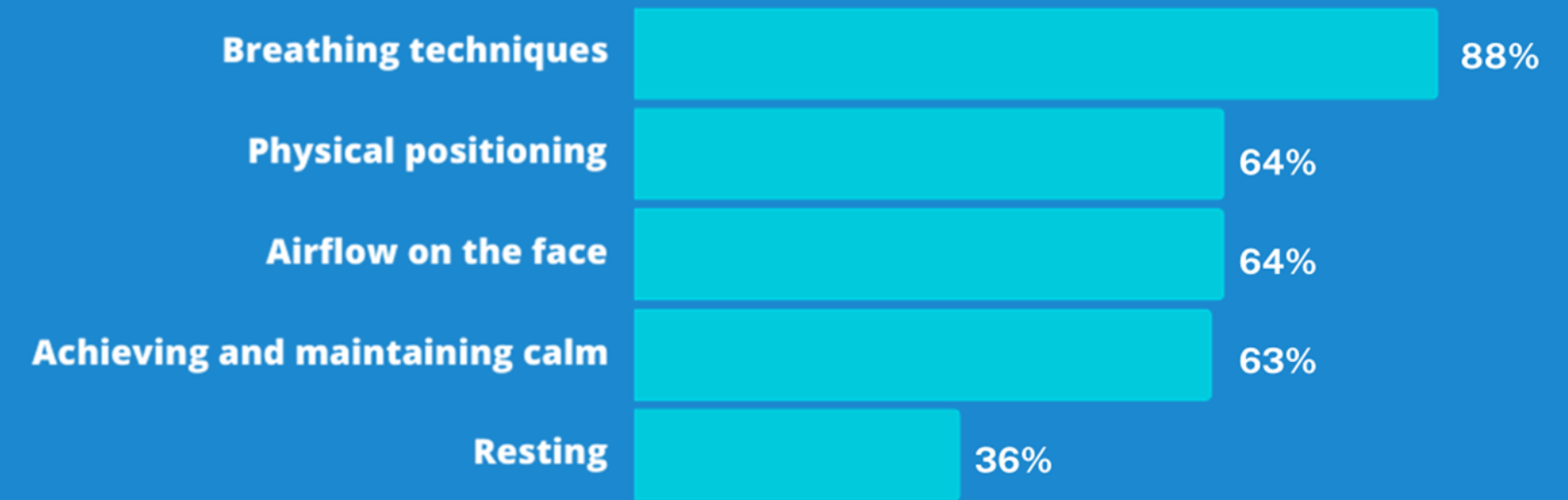
Health professional reported benefits of using a breathlessness action plan


138 health professionals

43 + **30** = **73**

Identified from Scoping Review Reported in Survey of Current Practice Total Breathlessness Action Plans analysed

Non-Pharmacological Strategies Recommended



Quality of breathlessness action plans was variable, and some plans exceeded reading grade 8, reducing accessibility.

BREATHE Action Plan – next phases

Conclusions



Breathlessness Action Plans have proliferated, with limited evidence to guide choice.



In the absence of high-quality research evidence, a consensus approach is needed to inform practice

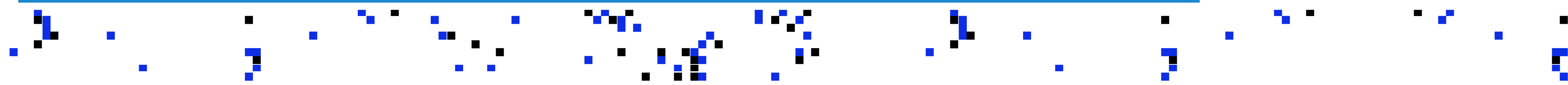
Findings form a foundation for the project's next phase of co-designing an optimal breathlessness action plan



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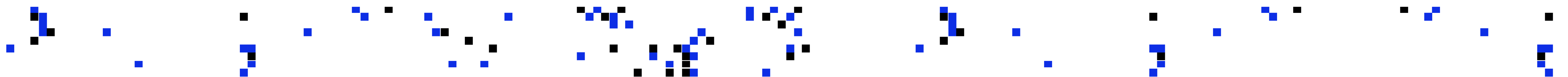
Hand-held fan program



- Hand-held fans are readily available, cheap and portable, with few adverse effects
- Benefits include faster recovery from breathlessness (including in a crisis) and increased physical activity and activities of daily living (e.g. Barnes Harris, 2019; Johnson, 2016; Luckett, 2017; Burrell, 2023; Swan, 2017)
- For some people, may also reduce inhaler and oxygen use (Luckett, 2017)
- Mechanisms include facial cooling (Brew, 2023; Burrell, 2023)
- Still not widely implemented in clinical practice

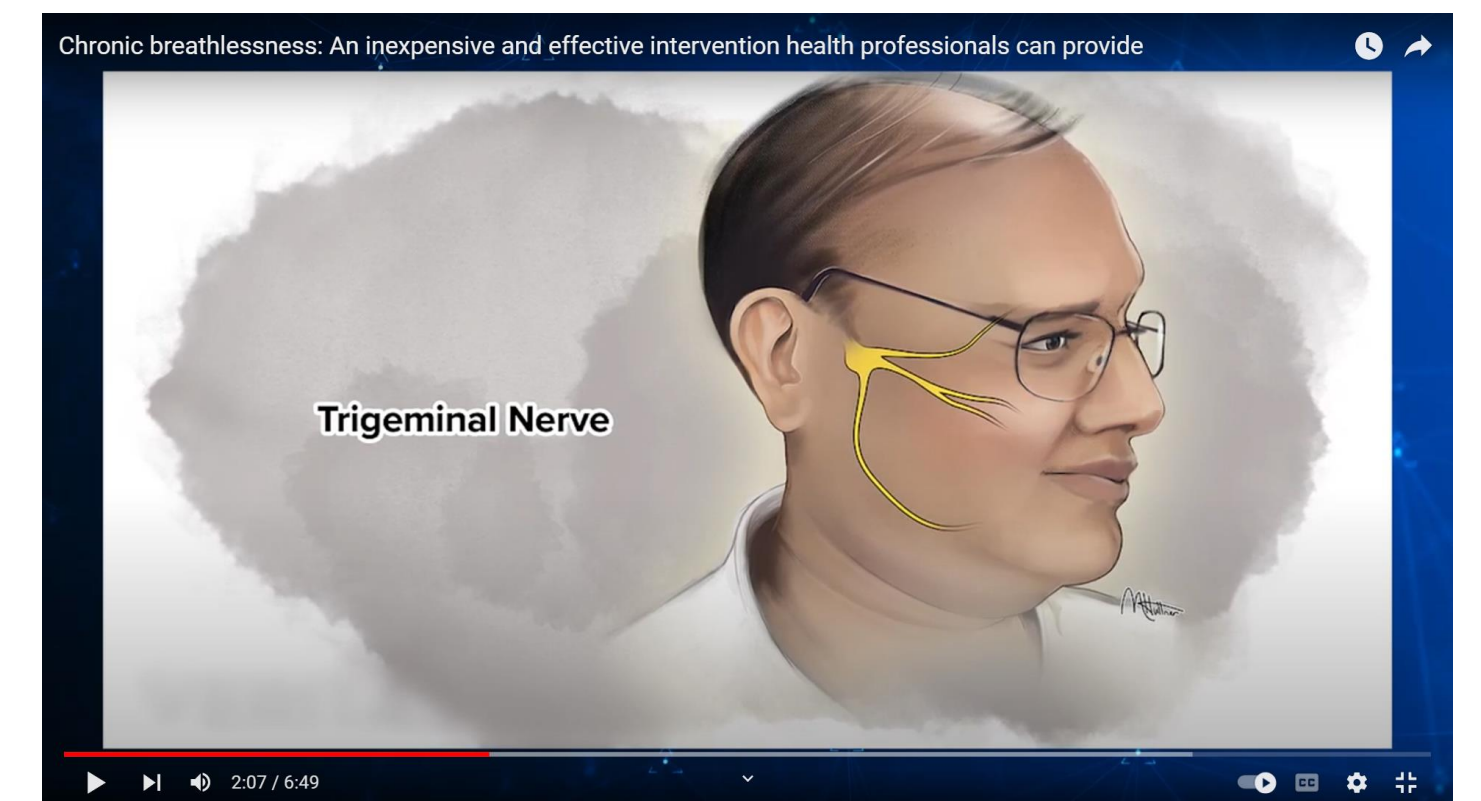
There's a big difference of thinking 'well this is normal - nobody gives a shit, they just give me a prescription - this must be it' ... That's what I've been like for 8 years until I met you, and now I find that you've introduced me to a fan that's 4 quid [pound sterling] from Marks & Spencers [British chain store] (laughs), and it's helped me, and I appreciate the help!" (man with COPD)

The CHAFF Study, led by Dr Flavia Swan (University of Hull, UK)

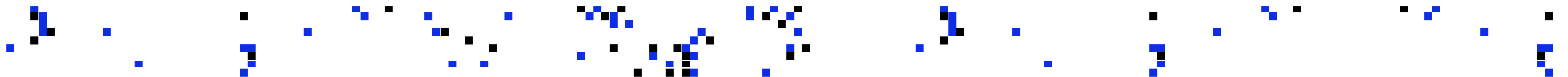


Fan implementation studies

- Parallel studies in the UK and Australia to identify clinician-reported barriers to the fan's implementation in clinical practice (Brown, 2023; Lockett, 2022)
- Clinician survey and interviews (UK) and focus groups (Australia)
- Participants were respiratory (UK/Australia) and palliative care (UK) clinicians from various disciplines
- Barriers identified across both countries:
 - Slack of understanding regarding mechanisms for efficacy
 - Lack of funding in hospitals to provide fans to patients
- Barriers more salient in UK data:
 - Concern about spreading COVID-19
- Barriers more salient in Australian data:
 - Reserved as a 'last resort' for patients nearing end of life
 - Lack of clarity about which discipline's scope of practice fans fall within



Clinician education video arising from the project



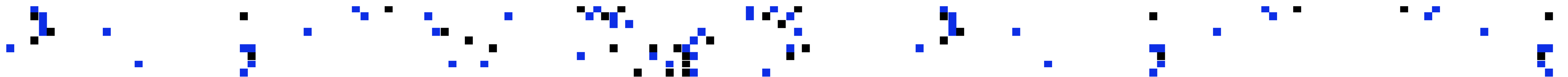
FanFIRST

Feasibility randomised controlled trial (RCT) of a hand-held fan centred intervention versus usual care for people living with COPD and high short-acting beta agonist (SABA) intake

Investigators: Michael Crooks, Miriam Johnson, Flavia Swan, Ann Hutchinson, Judith Cohen, Chao Huang, Mark Pearson, Alexander Wilkinson

Collaborator: Tim Luckett

Funding: National Institute for Health and Care Research (NIHR), Research for Patient Benefit (RfPB) Programme. The views expressed are those of the author(s) and not necessarily those of the NIHR or the Department of Health and Social Care



FanFIRST

Aims

1. Assess the feasibility and optimal design for a phase-3 RCT comparing fan-based breathlessness management (FanFirst intervention*) with usual care in people with COPD and high SABA use
2. Explore barriers and facilitators to NHS-wide implementation of the FanFIRST intervention

Design: Multicentre, parallel-group, open-label, randomised controlled, hybrid Type-I effectiveness-implementation feasibility study, with process evaluation

Intervention: Provision and verbal/written instruction in the hand-held fan alongside breathing techniques, positioning and anxiety management

Outcomes: Feasibility (recruitment/retention, data quality/integrity, outcome acceptability*, and intervention acceptability/feasibility)

Process evaluation: Qualitative approach using semi-structured interviews and theoretical framework of acceptability (Sekhon, 2017)

* change in mean daily SABA use, symptoms, quality of life, healthcare-resource-utilisation, carbon impact and safety

Wolfson collaborators



Prof Miriam Johnson



Dr Ann Hutchinson



Dr Mark Pearson



Dr Flavia Swan



Prof Mike Crooks
(HYMS Academic Respiratory Group)

IMPACCT collaborators



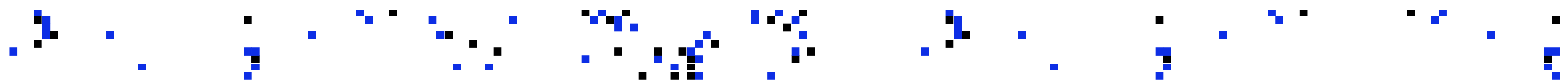
Mary Roberts and Dr Tracy Smith
(Western Sydney Local Health District)



Muneeba Chaudhry

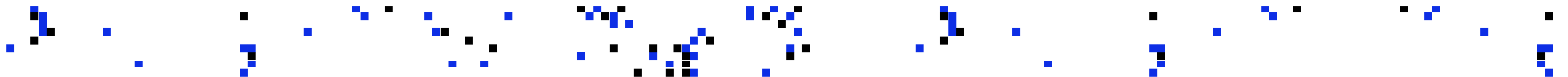


A/Prof Tim Luckett



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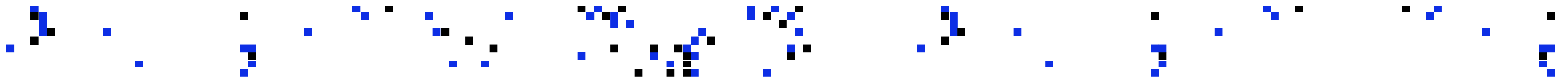
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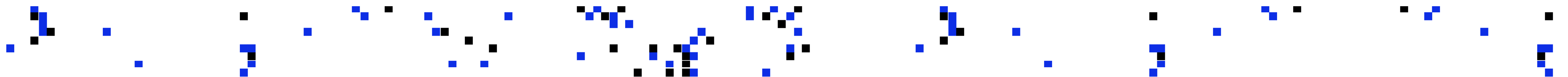
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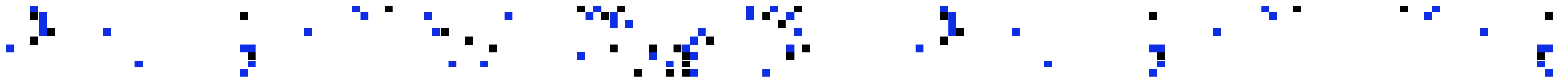


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■ Thank you

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