The ACT Breathlessness Intervention Service (ABIS) Project

A quality improvement project

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Partnering for better health

Southside Physio

UTS

Centre for Improving Palliative, Aged and Chronic Care through Clinical Research and Translation (IMPACCT)

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Dedication

This report is dedicated to the fond memory of Pam Harris, who drew on her lived experience as a person with breathlessness to partner on co-designing the ACT Breathlessness Intervention Service. Pam died on 15th August 2024 but continues to inspire her partners on the co-design team.

Images in this report have been taken from the ABIS promotional video at
https://youtu.be/EN1CKhyLSLk

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Executive Summary

Introduction

Chronic or persistent breathlessness is a common and debilitating symptom across many chronic and life-limiting conditions, including respiratory disease, heart disease and cancer, affecting around one in 10 Australian adults. As the name suggests, persistent breathlessness continues despite optimised, guideline-concordant pharmacological treatment of underlying medical conditions. Over and above persistent breathlessness on a daily basis, many people experience 'episodes' of acute-on-persistent breathlessness due to physical exertion or environmental factors (e.g. humidity, temperature). These episodes can cause anxiety and panic, and often precipitate Emergency Department (ED) presentations even when these are not clinically indicated, representing low cost-effectiveness for the health system.

The Breathing, Thinking, Functioning (BTF) clinical model emphasises the need to address the 'vicious cycle' that can emerge between breathing patterns, unhelpful thoughts and impacts on everyday living. Management is targeted at all 3 domains and interactions between them using evidence-based non-pharmacological strategies that include exercise, a hand-held fan, breathing techniques, mindfulness-based stress reduction and other relaxation techniques, walking aids and positioning. Over the past 20 years, a model of care called a 'breathlessness intervention service' (BIS) has emerged from the UK that 'coaches' people with breathlessness and family members ('carers') to self-manage the symptom using these non-pharmacological strategies.

Problem

Between 2019 and 2021, a BIS was delivered by specialist palliative care providers at Clare Holland House in the Australian Capital Territory (ACT), but the service was discontinued due to lack of resources. A Needs Assessment by the Capital Health Network (CHN)'s Palliative Care Planning Team identified gaps in home support for people living with persistent breathlessness from progressive chronic disease.

Solution

In 2022, CHN commissioned the University of Technology Sydney (UTS) and a private allied health provider called Southside Physio to co-design, deliver and evaluate a new ACT Breathlessness Intervention Service (ABIS). ABIS was delivered over 22 months until the end of 2024. The co-design team included 2 people with lived experience of breathlessness, 2 carers, 4 physiotherapists (including one from the Clare Holland House BIS), a respiratory nurse with experience of running a BIS in Western Sydney, 2 CHN employees, 2 UTS researchers, and a co-design expert. The project used a quality improvement (QI) approach with plan-do-study-act (PDSA) cycles to inform continuous improvement. Co-design team members shared decision-making throughout the project timeframe on the design, delivery and evaluation of the service. A Medical Steering Committee provided advice, with membership comprised of 2 GPs, a respiratory specialist, a palliative care specialist, a GP Policy Advisor for the ACT, and an international medical expert on breathlessness management.

Referrals to ABIS were initially invited from general practice and then extended to specialist services at Canberra's hospitals. Patients with persistent breathlessness due to chronic disease received an initial home visit by one of 2 physiotherapists and follow-up visits at home or telephone, numbered according to need. Coaching in non-pharmacological strategies was aimed at carers as well as patients.

ABIS was evaluated against 2 specific, measurable, achievable, relevant and timebound (SMART) goals:

1. 100 patients will complete the ABIS program within the first 12 months.
2. At least 75% of patients will experience benefit on one or more patient-reported outcomes, including patient-nominated activities of daily living (ADLs), ‘mastery’ (i.e. confidence) in relation to breathlessness management, and ‘worst’ breathlessness severity.

Qualitative information was drawn from interviews with patients, carers and referrers, as well as minutes from co-design meetings. Integration used the Reach, Effectiveness, Adoption, Implementation, and Maintenance (RE-AIM) framework, summarised as follows.

Findings

Reach

140 patients completed the ABIS program – estimated to be around 4% of the eligible ACT population.

The service reached people with high need, including those who were older, less mobile, unable to access rehabilitation services, and/or approaching end of life.

Effectiveness

All patients reported improvements on at least one outcome: 90% on ADLs, 70% on breathlessness severity, and 68% on mastery.

For many patients, breathlessness severity and mastery became worse as their ADLs improved, with physiotherapists determining the number of follow-ups based on how quickly patients regained mastery at least to pre-service levels in the context of continuing improvement on ADLs.

79% of carers reported improved confidence in supporting breathlessness episodes – a second key factor determining when follow-ups could end.

Adoption

Despite efforts to drive adoption in general practice, both breadth (i.e. number of practices) and depth (i.e. number of GPs within each practice) remained limited.

Referring GPs perceived that limited adoption by their colleagues reflected competing priorities rather than a lack of support for BIS.

Referrers valued ABIS' ease of referral, usually short wait time, home delivery and intensive, holistic support.

Implementation

The number of ABIS home visits varied between patients from one to 6, with a median of 4.

Outcomes were similar between physiotherapists, suggesting delivery was consistent.

The mean per patient cost for home visits was $1,576.86. Additional costs and wait lists were caused by inefficiencies due to irregular referrals and cancellation of home visits.

Cost savings to the health system were implied as follows: 29/136 (21%) patients reported thinking about calling an ambulance for breathlessness on 46 occasions but self-managed instead using strategies they had learned through ABIS; patients and referring physicians alike perceived there to have been other reductions in healthcare use from addressing problems early on before they escalated (i.e. tertiary prevention).

Interviewees from all groups accepted that maintaining ABIS over a longer period might necessitate out-of-pocket fees but felt strongly that these should be means-tested to ensure ongoing access for people on low incomes.

Adaptations introduced for continuous improvement part-way through the service period included the introduction of 3- and 6-month telephone follow-ups and potential for referral to a dietician.

Maintenance

Most patients who received telephone follow-ups at 3 and 6 months maintained or even improved outcomes compared to their final home visit. Knowing that they would be followed up motivated patients to maintain exercise regimens and breathlessness strategies.

The ABIS Project garnered substantial interest among ACT's healthcare providers and momentum for leveraging learnings to provide ongoing support.

Recommendations

Combining evidence from the ABIS Project with previous BIS research, recommendations include the following:

- Support for people with breathlessness should be person-centred, ensuring that goals and strategies are tailored to each patient's preferences, needs and daily living so they have the motivation, opportunity and skills to integrate behaviour change into everyday routines. At least some component of home-based delivery is optimal to inform understanding of each person's daily living. Where available and willing, carers should be considered integral members of the self-management team.
- Tailoring follow-ups to patient need may be more efficient and reduce per patient costs compared to the 6 or more follow-ups offered as standard by most other BIS to date. Resources can be transferred to patients who need more home visits and telephone 'booster' sessions at 3-monthly intervals to maintain behaviour change and benefits.
- While head-to-head comparisons are needed, evidence across studies suggests that BIS approach (self-management framework, coaching, therapeutic alliance) and content (non-pharmacological breathlessness strategies, exercise, diet) are more important than which disciplines deliver the model, except where patients have complex needs that require specialist referral. Patient education resources are available that cover the gamut of self-management strategies and have been designed by discipline-specific experts.
- Further to the above, and considering the prevalence of breathlessness, a BIS approach should be integrated across health services and settings to maximise access. The relative strengths of private (responsiveness/flexibility) versus public (integration with other health services) providers mean that partnership models might be especially strategic. Distributed and networked models offer an alternative to multi-disciplinary BIS for providing patients with ongoing support and might overcome losses in efficiency faced by ABIS. Whilst primary care is a key stakeholder, GPs lack capacity to take a central role in providing support or coordinating care for people living with breathlessness. The ACT's Digital Health Record offers a tool for decentralised integration of support from different public health providers.
- Efforts to build breathlessness-related capacity among the ACT's healthcare providers should leverage innovations prompted by the ABIS Project, including a community of practice, directory of services, and planned responses by the Community Care and Pulmonary Rehabilitation teams, as well as existing expertise among ABIS and other clinicians.
- There is an opportunity to build on a published UK model that trained ACT Ambulance Service paramedics to support patient and carer self-management of breathlessness episodes where these did not require transit to hospital for treatment of an acute medical event.

ABIS evaluation limitations

ABIS' evaluation was limited by the following factors: outcome measures doubled as clinical assessments collected by clinicians; there was no comparison group; and interviews were conducted with only a small number of patients, carers and referrers who engaged with the service, limiting insights into barriers to adoption. The evaluation did not enable a formal cost-effectiveness analysis. Generalisability of findings is limited by Canberra's unique context as Australia's purpose-designed capital.

Conclusion

ABIS was the first BIS model reported worldwide to have been delivered by a private allied health provider and co-designed through a partnership between people with lived experience, carers, clinicians and researchers with equal input to decision-making from each kind of expertise. Learnings highlight new potential for integrating a BIS approach across health services to better support breathlessness self-management by people with chronic disease living in the community.

Abbreviations

ABIS	Australian Capital Territory (ACT) Breathlessness Intervention Service
ACT	Australian Capital Territory
ACTAS	ACT Ambulance Service
ADL	activities of daily living
BIS	Breathlessness Intervention Service
BTF	Breathing, Thinking, Functioning
CBIS	Cambridge Breathlessness Intervention Service
CHN	Capital Health Network
COPD	Chronic Obstructive Pulmonary Disease
CRQ	Chronic Respiratory Questionnaire
ED	emergency department
GCP	Good Clinical Practice
GP	general practitioner
HREC	Human Research Ethics Committee
mMRC	modified Medical Research Council scale
PDSA	plan-do-study-act cycles
PIS	Participant Information Sheet
PSFS	Patient-Specific Functional Scale
QI	quality improvement
SMART	Specific, Measurable, Achievable, Relevant, Time-bound
SPSS	Statistical Package for Social Sciences
UK	United Kingdom
UTS	University of Technology Sydney

Glossary

Activities of daily living (ADL)	The activities that individuals routinely engage in that contribute to physical, mental and social well-being. For many people, ADLs are fundamental for maintaining autonomy and dignity, especially as they age or face declining health.
Breathlessness Intervention Service (BIS)	A specialised healthcare model designed to support people to self-manage persistent breathlessness associated with long-term conditions such as lung disease, heart failure or advanced cancer.
Breathing, Thinking, Functioning (BTF) model	A clinical model designed to help healthcare professionals understand and manage chronic breathlessness. Developed by the Cambridge Breathlessness Intervention Service, the BTF model provides a structured approach to addressing the complex symptom of breathlessness.
Chronic Respiratory Questionnaire (CRQ)	A disease-specific health-related quality of life questionnaire designed to measure the impact of chronic respiratory diseases, such as chronic obstructive pulmonary disease (COPD), on a person's life. The CRQ includes a 4-item 'mastery' of breathlessness scale, which has been used as the primary outcome in evaluations of previous BIS.
modified Medical Research Council (mMRC) scale	A self-assessment tool used to measure the level of breathlessness a person experiences during daily activities. The mMRC scale ranges from 0 ("only breathless with strenuous activity"), to 4 ("too breathless to leave the house or breathless when dressing or undressing"). The mMRC scale is widely used in clinical settings to assess the impact of breathlessness on a patient's daily life and guide management.
Plan-do-study-act (PDSA) cycles	A four-step iterative process used for continuous improvement in various fields, including healthcare, manufacturing, and education.
Patient-Specific Functional Scale	A self-reported outcome measure designed to assess a patient's functional ability to perform specific activities that they find challenging due to a health condition, using an 11-point scale, ranging from 0 ("unable to perform") to 10 ("able to perform at prior level") compared with premorbid levels.
Quality improvement (QI)	A systematic approach aimed at enhancing processes, services, or products within an organisation. It involves efforts to make continuous, incremental improvements over time.
SMART goal	A well-defined objective designed to provide clear direction and improve the likelihood of achieving desired outcomes. SMART stands for specific, measurable, achievable, relevant and timebound.

1. Introduction

1.1. Problem description

Through the Capital Health Network (CHN)'s Needs Assessment, the CHN's Palliative Care Planning Team identified gaps in supporting people at home living with persistent breathlessness from progressive chronic disease in the Australian Capital Territory (ACT).

Chronic or persistent breathlessness is a common and debilitating symptom across many chronic and life-limiting conditions, including respiratory disease (e.g. chronic obstructive pulmonary disease [COPD]), heart disease and cancer, affecting around one in 10 Australian adults.[1, 2] As the name suggests, persistent breathlessness continues despite optimised, guideline-concordant pharmacological treatment of underlying medical conditions.[3] It includes at least 3 dimensions: 'sensory-perceptual' (severity and quality), 'affective' (unpleasantness and distress) and 'impact' (effects on everyday life).[4]

Over and above persistent breathlessness on a daily basis, many people experience 'episodes' of acute-on-persistent breathlessness due to physical exertion or environmental factors (e.g. air pollution, humidity).[5] These episodes or 'crises' are associated with anxiety and panic and often precipitate Emergency Department (ED) presentations even when these are not clinically indicated, representing poor utilisation of healthcare resources.[6, 7]

1.2. Available knowledge

While persistent breathlessness cannot be resolved, it can be managed through supporting a person to modulate their perception of breathlessness and response. The Breathing, Thinking, Functioning (BTF) clinical model emphasises the need to address the 'vicious cycle' that can emerge between breathing patterns, unhelpful thoughts and impacts on everyday life.[8] If unmanaged, this cycle can lead to a 'downward spiral' of activity avoidance, deconditioning and deterioration in physical and mental health. Management is targeted at all 3 BTF domains and interactions between them using evidence-based non-pharmacological strategies that include exercise, a hand-held fan, breathing techniques, mindfulness-based stress reduction and other relaxation techniques, walking aids and positioning.[9]

However, research shows that persistent breathlessness often remains under-identified and under-managed in people's medical care.[10-12] After sitting in a doctor's waiting room, exertional breathlessness from travelling there may have subsided, and breathlessness is often just one problem amongst a cluster caused by multimorbidity or frailty, meaning it may be 'pushed down the list'. Because people tend to avoid activities of daily living (ADLs) for fear of becoming breathless, clinical assessments that focus only on symptom severity may fail to identify the impact of the problem. Moreover, people with chronic illness and physicians alike may lack knowledge of how to manage breathlessness and mistakenly assume that 'nothing can be done' and people simply have to 'put up with it'.

1.3. Rationale

Over the past 20 years, a model of care has emerged from the UK that has been variously termed a 'breathlessness intervention service' (BIS),[13] 'holistic breathlessness service'[14] 'breathlessness support service'[15] or 'multicomponent intervention'.[16] Health professionals form partnerships with people experiencing breathlessness that acknowledge them as experts on their breathlessness and its impact on their lives. Non-pharmacological strategies are implemented within a 'coaching' approach[17, 18] that helps people identify priorities, set goals and build skills for reducing the impact of breathlessness on ADLs and improve emotional coping. As a prerequisite, attention is given to building the person's motivation and confidence to self-manage, variously described in terms of self-efficacy,[19] activation[20] and empowerment.[21] It is also essential to include informal carers and other family/friends as members of the self-management team given their special potential to either support or undermine the person's self-efficacy.[22]

More recently, the BIS model has been adopted by Palliative Care and Respiratory and Sleep Medicine services in a number of countries beyond the UK, including Australia.[15] Clinical trials have found that some but not all BIS can lead to benefits in breathlessness severity, mastery of breathlessness, breathlessness-related distress, anxiety and depression, and quality of life.[14, 16] Differences in effectiveness are likely due to variations in the BIS model across trials with regard to eligibility criteria, setting, range of health professional disciplines involved, and duration and intensity of programs. Qualitative sub-studies suggest that patients and carers attribute benefits not only to the pharmacological strategies they learn through BIS but also the coaching approach and strong therapeutic relationships they form with the personnel, which seem especially important for increasing their motivation and confidence to work on extending ADLs.[23-25] However, no BIS services have been co-designed with people with lived experience of breathlessness and their carers, which limits further insights into ways of optimising benefit.

Between 2019 and 2021 a BIS was delivered by specialist palliative care providers at Clare Holland House in the ACT, but the service was discontinued due to lack of resources. In 2022, CHN's Palliative Care Planning Team allocated funds to the co-design, delivery and evaluation of a short-term home-based BIS to better understand the potential benefits and requirements for support of people in the ACT with persistent breathlessness.

The ACT BIS (ABIS) Project commenced in November 2022 and included an initial service delivery period between March 2023 to March 2024, later extended until the end of 2024.

Following a tender process, a private allied health provider called Southside Physio was contracted to deliver ABIS, and the IMPACCT centre at the University of Technology Sydney (UTS) was contracted to facilitate service co-design and evaluation.

1.4. Aims

The ABIS Project aimed to co-design, implement and evaluate a home-based BIS model supporting people in the ACT with persistent breathlessness. .

> Chronic or persistent breathlessness is a common and debilitating symptom across many chronic and life-limiting conditions, affecting around 1 in 10 Australian adults.

2. Methods

2.1. Approach

Co-design and continuous improvement were undertaken within a quality improvement (QI) framework,[26, 27] using Plan-Do-Study-Act (PDSA) cycles.

A co-design team was established, and initial co-design of the ABIS model and evaluation framework occurred through six 2-hour meetings, held fortnightly between 28th November 2022 and 1st March 2023. Referrals to ABIS commenced on 4th March 2023, and co-design team meetings were held at 3-monthly intervals throughout the pilot period to review progress and decide improvements to be implemented in the next cycle (Figure 1).

2.2. Co-design

Co-design involves working in a partnership with people with lived experience and representatives from key stakeholder groups to define a problem and potential solutions. It recognises lived experience as being of equal value to professional expertise. This high-level participatory approach can raise the quality of knowledge translation and relevance of services, research outcomes and interpretation.[28] The ABIS project, co-design partners included not only people with lived experience of breathlessness but also carers, in recognition of their important role and differing perspective (Table X). To expand the number of perspectives involved, carers were independent of the people with breathlessness who contributed. One co-design partner with breathlessness later received the ABIS program as a patient, adding a new dimension to the lived experience perspective she brought to the process. Partners with lived experience and carers were remunerated for their time in accordance with guidance from Health Consumers NSW.

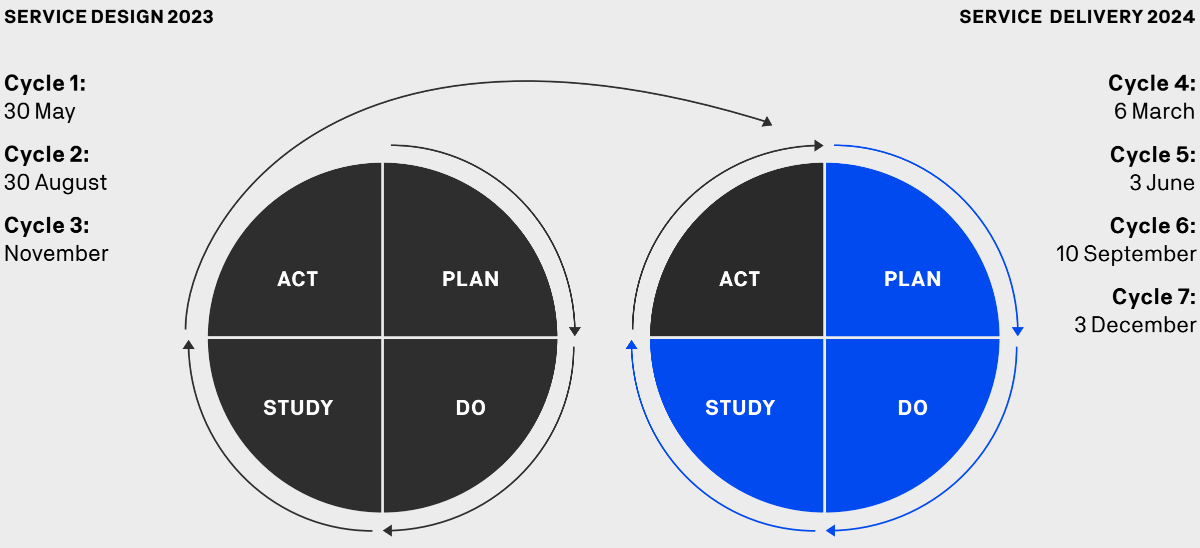


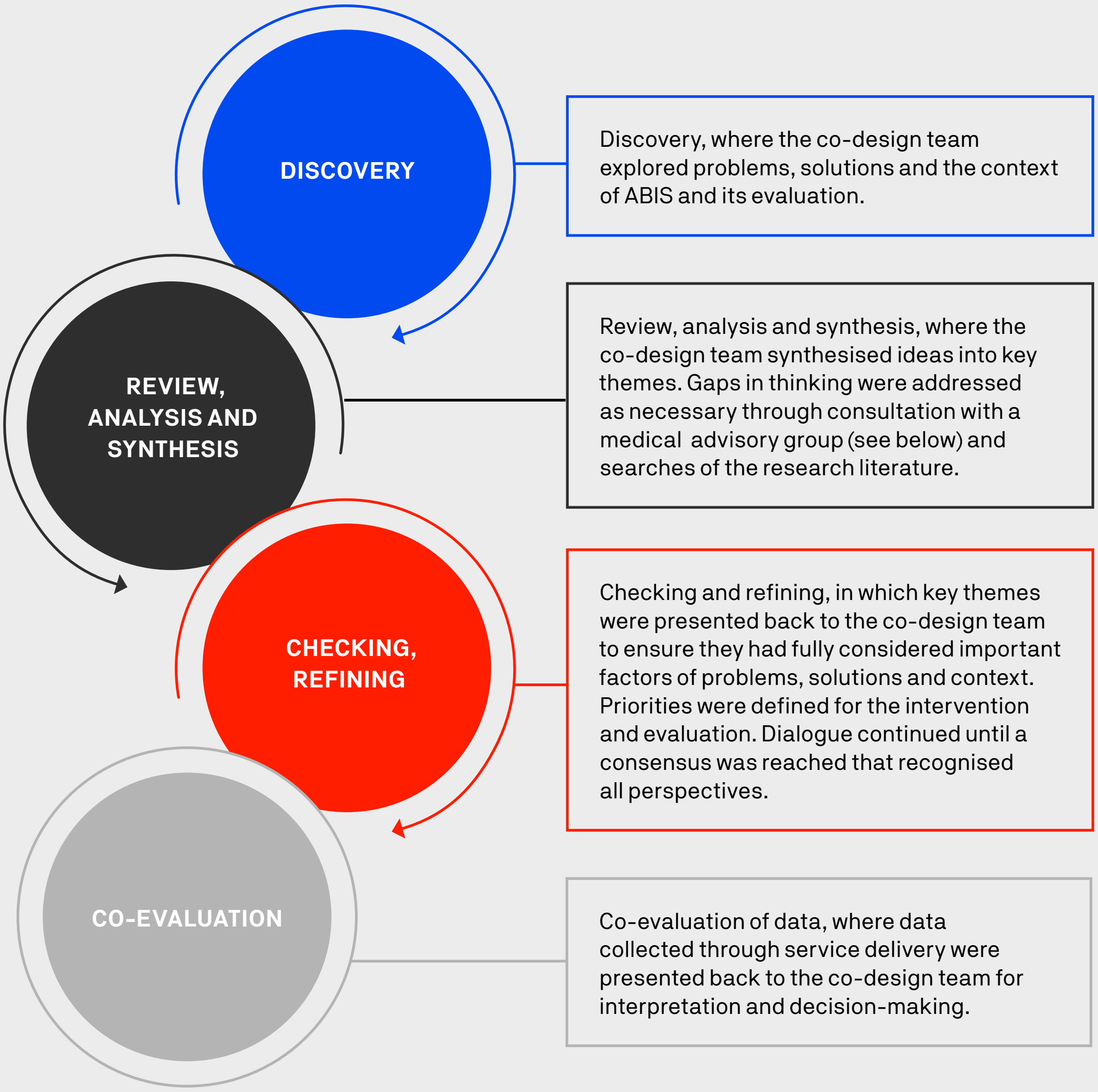
Figure 1. Plan Do Study Act (PDSA) cycles used in the ABIS Project

Table 1. Co-design partners on the ACT Breathlessness Intervention Service (ABIS) Project

Perspective	Number of people contributing each perspective
People with lived experience of breathlessness	2
Carers for people with lived experience of breathlessness	2*
CHN’s Palliative Care Planning Team (the ACT’s primary health network)	2
Southside Physio (ABIS provider)	One Director 2 physiotherapists delivering ABIS**
Clare Holland House BIS	One physiotherapist*
Westmead BIS, Western Sydney Local Health District (WSLHD)	One Clinical Nurse Consultant in Ambulatory Respiratory Care
UTS facilitators and academic experts	3

* One person with lived experience partnered only on development of the ABIS model, not subsequent cycles of improvement;
** partnered on cycles of improvement but not development.

The co-design team engaged in a staged process, facilitated by UTS team members.



Discovery, where the co-design team explored problems, solutions and the context of ABIS and its evaluation.

Review, analysis and synthesis, where the co-design team synthesised ideas into key themes. Gaps in thinking were addressed as necessary through consultation with a medical advisory group (see below) and searches of the research literature.

Checking and refining, in which key themes were presented back to the co-design team to ensure they had fully considered important factors of problems, solutions and context. Priorities were defined for the intervention and evaluation. Dialogue continued until a consensus was reached that recognised all perspectives.

Co-evaluation of data, where data collected through service delivery were presented back to the co-design team for interpretation and decision-making.

Figure 2. The co-design team staged process

To ensure the process adhered to the overriding co-design principle of genuine and equitable partnership in decision making, co-design meetings were:[29]

- **Openly discursive:** Rather than entirely agenda-focused, meetings were semi-structured to encourage open discussion and sharing of perspectives and expertise to garner unexpected insights. This enabled priorities to be co-determined by lived experience and stakeholder partners.
- **Consensus-seeking:** Decision-making aimed for consensus through a process of negotiation that invited, acknowledged and integrated diversities of experience and perspectives.
- **Iterative:** Considerations and decisions were regularly revisited and re-evaluated within the co-design team, with refinements made as needed.
- **Evidence-informed:** Evidence from four sources 30 were integrated into co-design meetings and meetings depending on their availability and relevance (Figure 3). Relevant research evidence was in the form of published evaluations of BIS and validation studies of patient-reported outcome measures. Qualitative research evidence on preferences of people living with breathlessness and their carers was used to supplement the experience and expertise shared by co-design partners. Population-level statistics and information about the configuration of the ACT's healthcare and community services provided additional context alongside the team's Canberra-related knowledge and experience. Relevant local data and information was also incorporated into co-design sessions as relevant. This included professional knowledge available from partners with experience of running BIS at Clare Holland House and in Western Sydney Local Health District, and patient/carer education resources available from these and other BIS.

Co-design team members decided all aspects of the ABIS model and evaluation framework, including:

- referral pathways;
- patient eligibility criteria and screening;
- the number, duration and frequency of home visits, and mode of delivery (i.e. in-home and/or via telephone);
- disciplinary input to service delivery within the constraints available;
- patient and carer educational resources;
- outcomes important for people with breathlessness, carers and the health system that could serve a double purpose both to inform patient care and evaluate the service;
- aspects of service delivery important to measure to inform service improvement and learnings for future BIS;
- interview topics to ask patients, carers and health professionals who agreed to participate.

ABIS model characteristics were designed around outcomes agreed to be important, rather than the other way around.

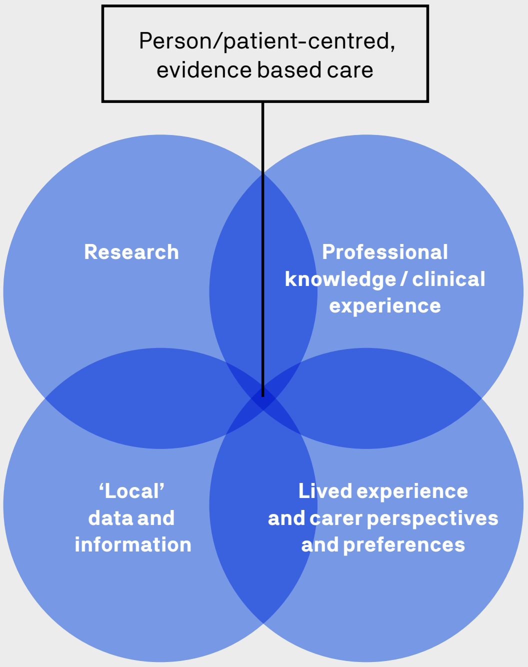


Figure 3. Four sources of evidence for person-centred, evidence-based practice, adapted from Rycroft-Malone et al (2004)[30]

2.3. Medical advisory group

An advisory group of physicians from specialist respiratory care (n=1), palliative care (n=1), and general practice (n=2) was also established. Advisory group members did not make decisions on the ABIS model, but, instead, provided medically-informed advice on key features, which was relayed to the co-design team for consideration alongside relevant research findings and local context. Advisory group members were also asked for their opinions on the feasibility of decisions made by the co-design team, which were reviewed at subsequent co-design meetings as part of the iterative process of checking and refining. A palliative care physician and international expert on breathlessness from the University of Hull UK, Prof Miriam Johnson, was also consulted on 3 occasions.

2.4. Context

A fundamental premise of QI is that evidence-based care should be tailored to local health service and demographic contexts.

Purpose-designed and built as Australia's capital between 1913 and 1927, Canberra represents a unique context for community health services. Travel by road is quick and easy: A 2019 report on traffic congestion identified that, among jurisdictions, Canberra had the highest percentage of free-flow traffic (96.9%) and second highest average speed as a percentage of the speed limit (83.9%).[31] The ACT's population is concentrated in the capital, with most of the rest of the ACT's 2,358 km^2 comprising national parks. Compared with other states/territories at the last census in 2021,[32] the ACT had the second smallest (454,499 people) and youngest (median age 35 years) population. It had the second smallest proportion of Aboriginal and Torres Strait Islander people (2.0%) but was mid-ranking in terms of other cultural and linguistic variables (Australia-born 67.5%; speaks English only at home 71.3%; speaks language other than English at home 24.6%). It had the highest median weekly income ($1,203 per person, $2,872 per family, $2,373 total household), proportion of people with bachelor degree education or above (42.9%) and proportion employed as professionals (31.4%). Compared with the Australian average, it had a slightly lower prevalence of heart disease (3.1% versus 3.9%) and lung conditions (1.3% versus 1.9%) but slightly higher prevalence of asthma (9.0% versus 8.1%). In the period 2021-2023, the ACT had the longest life expectancy among jurisdictions (males 81.7 years; females 85.7 years).[33]

In terms of public health services, the ACT has 2 major hospitals (Canberra Hospital and North Canberra Hospital) offering a comprehensive range of inpatient, outpatient and community services. Pulmonary Rehabilitation is available for people with lung conditions at Canberra Hospital but (unlike in some other jurisdictions) referral must come from a specialist respiratory service rather than a GP. This free-to-patient service comprises an 8-week program of supervised exercise classes and education from a multidisciplinary team on topics that include breathlessness management. The ACT has the second-lowest GP density among jurisdictions (in 2023, approximately 92 FTE GPs per 100,000 people compared to 112 FTE GPs per 100,000 across Australia).[34] The ACT also has the lowest annual GP bulk billing rate in Australia at 53.2% (November 2023 to October 2024) compared to the national average of 77.7%.[35]

2.5. ABIS model of care

The ABIS model of care was co-designed to be delivered as follows. Rationales for each feature of the model and changes made through continuous improvement are summarised in Appendix A. A timeline of adaptations to the service made for continuous improvement is depicted in Figure 4.

2023

March	GP referrals commence
May	Specialist respiratory referrals commence
May	ABIS advertised direct to the community for them to seek referral through GP
June	Referrals with mMRC 1 can receive one education visit and follow-up call
July	GPs can apply for CPD points as an incentive to refer
July	Change in personnel – RN withdraws
August	Change in personnel - new physiotherapist begins
August	ABIS discharge letters routinely sent to patients and referrers
November	Summer heat and air pollution advice included in patient/carer education

2024

February	Referral form integrated into general practice software
March	Re-enrolment allowed for patients whose circumstances have changed
March	3- and 6-month telephone follow-ups commence
April	Referral expanded through HealthPathways, geriatric medicine and nephrology
June	Waitlist prioritised according to mMRC
July	Opportunity becomes available to refer to a dietitian
September	ABIS closes to referrals

Figure 4. Timeline of adaptations made to the ABIS model of care for continuous improvement

2.5.1. Eligibility criteria

ABIS had the most inclusive eligibility criteria of any BIS reported to date, prioritising impact from breathlessness over specific diagnoses or stages of disease.[13-16] No restrictions were placed on whether breathlessness was caused by a single disease or the cumulative effects of multimorbidity.

People were eligible for ABIS if they:

- lived in the ACT;
- were an adult aged 18 or over;
- had reduced ADLs due to breathlessness from chronic disease, which was screened via a two-step process:
  - Grade 2 or higher on the modified Medical Research Council (mMRC) Scale ("*on level ground, I walk slower than people of the same age because of breathlessness, or I have to stop for breath when walking at my own pace on the level*");[36]
  - an open question designed by the team, "*what has breathlessness made you less able to do in everyday life that bothers you?*"
- agreed to receive the ABIS service once potential benefits have been summarised by the referrer.

People were excluded if they were considered by the referrer to have:

- breathlessness that had persisted for less than 8 weeks, which was caused by an acute event (e.g. infection) or long COVID, or had no established cause;
- a rapidly deteriorating health status or clinical instability;
- a cognitive impairment or limited English proficiency deemed likely to impede patient collaboration in the absence of support from a carer or interpreter.

When a patient was referred who had a heart condition, a letter was sent to the referrer asking them to confirm that this would not present a safety concern if the patient's exercise were to be increased to a similar extent to pulmonary rehabilitation.

2.5.2. Referral pathways

Referral was limited to physicians rather than non-medical clinicians to increase confidence in judgements regarding medical exclusion criteria and other contraindications.

Referring physicians used an electronic referral form on Southside Physio's website which outlined inclusion and exclusion criteria and invited physicians to also upload the patient's health summary and medication list to inform ABIS clinicians of case context Appendix B).

2.5.3. Personnel

Personnel delivering ABIS initially included one registered nurse (RN) and one physiotherapist. The RN withdrew from delivering ABIS after 4 months for personal reasons, and a second physiotherapist was employed from August 2023. The FTE that each clinician devoted to ABIS vis-à-vis Southside Physio's other services varied over time (see costs in the implementation section of this report). In July 2024, physiotherapists had the option of referring to a Southside Physio dietician when required. All personnel had previous experience of delivering community care to older people with chronic health conditions.

2.5.4. Clinician training

On joining ABIS in August 2023, the second physiotherapist was given access to training materials from the workshop and one-to-one training in the role by the physiotherapist who had been in the role since the beginning. Southside Physio personnel were further supported throughout the first year of ABIS delivery by monthly video conferences with the Respiratory CNC from to trouble-shoot clinical issues as these arose.

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2.5.5. Service delivery

Each patient was assigned to a single member of personnel. Patients received an initial visit at their home, with follow-ups either at home or by telephone according to patient preference. Home visits typically lasted 2 hours for initial assessment and one hour thereafter, inclusive of travel. The number of follow-ups and intervals between these were tailored to each patient's needs at the discretion of the ABIS personnel member in consultation with patients and carers.

Like other BIS, ABIS was delivered using a coaching approach,[13] with education on non-pharmacological strategies for managing breathlessness tailored to each patient/carer dyad's needs, including: exercise, a hand-held fan, breathing techniques, mindfulness-based stress reduction and other relaxation techniques, positioning, as well as advice on diet. Written educational materials were provided to most patients and carers as follows. Other education resources were provided on an as-needed basis so as not to overwhelm patients and carers.

- North Western Melbourne Primary Health Network. *Breathe easier... The breathing thinking functioning (BTF) approach*. 2016; nwmphn.org.au/wp-content/uploads/2021/08/1.-Breathe-easier-BTF-approach.pdf
- Southside Physio. *Exercise handbook*. 2023.
- British Lung Foundation education on diet, including *Eating Well for Your Lungs* 2021, and *Nutrition Support in COPD* 2016; www.blf.org.uk/COPD.

Carers were coached in how best to support patients to gain greater independence in ADLs rather than take over tasks for them. No medical care was provided but patients were referred onto other services as necessary.

Patient- and carer-reported measures were completed by Southside Physio at the first visit and each follow-up both to inform individual care and provide data in de-identified form for evaluation (see below). Patients were asked at their first visit to select up to 3 ADLs that had been impacted by breathlessness which they would like to work on and improve.

After the initial assessment, patients were sent a letter summarising the management plan. Patients were sent another letter at the end of the program summarising their progress and self-management strategies (Appendix B).

2.5.6. Service provider and referrer co-management

Building on a template developed by the Westmead BIS, Southside Physiotherapy sent a letter to each patient's GP summarising their involvement in ABIS with the aim of prompting follow-up support for breathlessness by the GP (Appendix B).

2.5.7. Promoting ABIS and building capacity among ACT clinicians

Figure 5 provides a timeline of efforts made to elicit referrals to ABIS and other promotion.

Until May 2023, referral was limited to GPs rather than specialist physicians to enable access to patients who might be receiving less support for breathlessness than those being seen by respiratory or cardiology services. GPs were approached both through general advertisement and engagement with selected practices. Advertisement occurred through CHN's newsletter (received by 109 general practices), website, social media (including a paid campaign) and fora. Practices were selected for targeted approach on the basis of prior engagement with CHN and Southside Physio and higher numbers of GPs and patients, noting the predominance of sole trading among the ACT's practices. CHN reviewed data from the Pen CS Practice Aggregation Tool for the Clinical Audit Tool (PATCAT) to identify practices with large proportions of patients with COPD or heart failure in particular.

Interested practices were visited repeatedly by Southside Physio to support referral by means of processes for routinely identifying patients with breathlessness (e.g. Medicare-funded annual health assessments for patients over 75 years), integrating the referral form into practice software, and training for GPs in screening patients and reviewing progress in partnership with patients.

In light of research showing that breathlessness sometimes goes under-recognised in general practice,[10-12] ABIS was advertised directly to people in the community through the Canberra Lung Life Support Group, public fora, and community stalls on World COPD Day, inviting people to ask their GP for referral. ABIS flyers and posters were made available for practices to display in waiting rooms to encourage patients to self-identify in their consultation. From November 2024, a promotional video was made available on the CHN's website that could be displayed in practice waiting rooms as well as usedat various fora.

Despite the above efforts, challenges with the feasibility of GP-only referral outlined in the findings prompted the co-design team to also invite referrals from specialist physicians at Canberra's hospitals from May 2023 onwards. Initially, this focused on a single respiratory physician but was extended to include other respiratory physicians in August 2023, geriatricians in April 2024, and nephrologists in June 2024.

Two workshops, held in 2023 and 2024, served a double purpose of not only promoting ABIS but also building knowledge and skills among the ACT's clinicians in relation to breathlessness management. These workshops were advertised by CHN and run by co-designer and Respiratory CNC from the Westmead BIS with input from Southside Physio. A webinar on 12th July 2023 was limited to one hour and offered via video conferencing in the evening to enable clinicians working in primary care to attend. Attendance was accredited for Continuous Professional Development (CPD) hours as an incentive. In addition to content on non-pharmacological management of breathlessness, this workshop also covered pharmacological management of lung disease after this was identified as being of special interest to GPs. A workshop on 27th November 2024 was held face-to-face over a full day and was run collaboratively with a local palliative care physician and physiotherapist from Pulmonary Rehabilitation. As well as providing education on breathlessness management, this event featured a panel discussion on ways to build further capacity among the ACT's health providers from 2025 onwards. The panel included the Respiratory CNC and physiotherapist from the ABIS co-design team, the acting manager for Occupational Therapy Community Care, and physiotherapists from Pulmonary Rehabilitation and Specialist Palliative Care.

Finally, presentations on emerging learnings form ABIS were given at the following fora:

- Palliative Care Nurses Australia Biennial Conference, 31 July – 2 August 2024, Melbourne.
- Canberra Health Annual Research Meeting (CHARM), 17-21 June 2024, Canberra.
- Palliative Care NSW Conference, 31 October – 2 November 2024, Tamworth.

2023

7 February	Breathlessness workshop
27 February	General practice engagement
30 March	General practice engagement
30 March	General practice engagement
4 April	General practice engagement
22 May	General practice engagement
11 July	General practice engagement
12 July	Breathlessness workshop
13 July	Community engagement
17 July	General practice engagement
31 July	Promotion
8 August	General practice engagement
10 August	Promotion
August	Specialist engagement
24 September	General practice engagement
2 November	Promotion
15 November	Promotion
21 November	General practice engagement
22 November	General practice engagement

2024

8 January	General practice engagement
15 January	General practice engagement
18 January	General practice engagement
5 February	General practice engagement
7 February	Specialist engagement
20 February	General practice engagement
22 February	General practice engagement
06 March	Promotion
9 April	Specialist engagement
12 April	General practice engagement
17 April	Specialist engagement
18 April	Allied Health engagement
19 April	Specialist engagement
23 April	General practice engagement
23 April	General practice engagement
26 April	Specialist engagement
26 April	Allied Health engagement
14 May	Promotion
15 May	Specialist engagement
21 May	General practice engagement
4 June	Specialist engagement
20 June	Ambulance service engagement
21 June	Community engagement
21 June	Specialist engagement
23 August	General practice engagement
3 September	Promotion
27 November	Breathlessness workshop
November	Promotion

Figure 5. Timeline of efforts to promote ABIS and elicit referrals

General practice engagement included visits to general practices by Southside Physio or CHN, as well as mention of ABIS at GP workshops.

Specialist engagement included visits to Canberra's hospitals by CHN, Southside Physio or promotion of ABIS by the specialist palliative care team.

Promotional activities included newsletters (CHN and Southside Physio), dissemination of flyers at World COPD Day and to local organisations, posting of a video on Youtube and CHN's website, a social media campaign, and discussion with the ACT Health Directorate Palliative Care Government Committee, and reporting in a CHN biannual report to the ACT and federal Health Ministers. Conference presentations on ABIS were given as follows: Palliative Care Nurses Australia Biennial Conference, 31 July – 2 August 2024, Melbourne; Canberra Health Annual Research Meeting (CHARM), 17-21 June 2024, Canberra; Palliative Care NSW Conference, 31 October – 2 November 2024, Tamworth. Further conference presentations will be given in 2025 to report findings.

2.6. Evaluation

2.6.1. Ethical approval and consent

Ethical approval for public reporting of evaluation data was granted by the ACT Human Research Ethics Committee (HREC) (2023/ETH00678). A waiver of consent was approved for the Southside Physio team to transfer de-identified data from patient- and carer-reported measures collected for the purposes of informing clinical care to UTS for analysis via an Excel spreadsheet on a secure server.

Patients, carers and health professionals were provided with a participant information sheet by the Southside Physio team in person or via email or mail, and invited to contact the UTS team if interested in participating in an interview. The UTS team conducted the interviews by telephone at times convenient to participants. Qualitative data were de-identified immediately after collection and were not linked to outcome data.

From 23rd August 2024, an amendment to ethics approval was approved to offer GPs remuneration for time spent on interviews in accordance with the Medicare Benefits Schedule (MBS) item for a Level B-general consultation of at least 6 minutes but less than 20 minutes (MBS item 23 = $42.85).[37]

2.6.2. SMART goals

ABIS was evaluated against 2 specific, measurable, achievable, relevant and timebound (SMART) goals:

1. 100 patients will complete the ABIS program within the first 12 months.
2. At least 75% of patients will experience benefit on one or more patient-reported outcomes, including ADLs, mastery of breathlessness and ‘worst’ breathlessness severity.

2.6.3. Design

A mixed method approach[38] was used in which both qualitative and quantitative data were collected and integrated from sources summarised in Figure 6.

2.6.4. Quantitative data

2.6.4.1. Patient characteristics

Patient demographic and clinical characteristics collected by Southside Physio at time of referral included: sex, age group (in 10-year categories) and disease group (lung disease, heart disease, cancer, other).

QUANTITATIVE

- Service process measures (e.g. referrals, patient characteristics, number of home visits)
- Patient-reported outcomes: Activities of daily living (ADLs), mastery of breathlessness, ‘worst’ breathlessness severity
- Carer-reported confidence
- Patient-reported healthcare use

QUALITATIVE

- Minutes from co-design meetings
- Interviews with patients, carers and referrers

Figure 6. Data sources informing the ABIS Project

2.6.4.2. Outcome data

All clinical assessments/outcomes were patient- or carer-reported. Because they served the double purpose of informing clinical care, quantitative measures were administered at the beginning of each home visit by Southside Physio personnel. Patients were not reminded of their ratings on measures at previous timepoints until after they had rated the current recall period. At initial assessment, patients were asked to report each outcome over a recall period of the past 2 weeks. At subsequent home visits, patients were asked to recall the period since they were last seen by Southside Physio. See Appendix C for the standardised scripts. A 'minimally important difference' (i.e. the smallest change deemed clinically relevant) was defined for each measure based on previous research or the co-design team's appraisal.

Activities of daily living: The ABIS co-design team, including lived experience and carer representatives, identified independence in ADLs to be especially important as a focus for determining improvement (i.e. the primary outcome). The Patient-Specific Functional Scale (PSFS) was chosen as a measure that enables patients to self-select between one to three activities on which to focus improvement efforts.[39] For each activity, patients were asked to rate their ability to perform each activity on a 0-10 numerical rating scale (NRS), where 0 meant "*you're unable to perform the activity at all*" and 10 meant "*you're able to perform it at the same level as before you had breathlessness.*" For each activity, they were asked to rate it twice – once for how well they could perform it on a 'good day' and then again for a 'bad day'. Based on previous research, a change over time of 2 points or more was considered to be 'minimally important', either for improvement (increase) or deterioration (decrease).[40]

Breathlessness mastery: The Chronic Respiratory Questionnaire (CRQ) 'Mastery' subscale was used, which comprises the following four questions:[41]

1. *"How often did you have a feeling of fear or panic when you had difficulty getting your breath?"*
2. *"How much of the time did you feel very confident and sure that you could deal with your illness?"*
3. *"How often have you had complete control of your breathing problems?"*
4. *"How often did you feel upset or scared when you difficulty getting your breath?"*

Patients were asked to rate on a 1-7 NRS as follows: 1) "*none of the time*"; 2) "*a little of the time*"; 3) "*some of the time*"; 4) "*a good bit of the time*"; 5) "*most of the time*"; 6) "*almost all of the time*"; 7) "*all of the time*". After reverse scoring for items one and 4, a minimally important change was defined as a mean across the four items of 0.64 points based on previous estimates.[42]

'Worst' breathlessness severity: Patients were asked "*how severe has your breathlessness been at its worst over the last 2 weeks?*" rated on a 0-10 NRS, where 0 meant "*the best you can imagine*" and 10 meant "*the worst you can imagine*". A minimally important change was defined as a 2 point reduction (improvement) or increase (deterioration) on the NRS as a conservative estimate based on previous research.[43] The co-design team considered breathlessness severity to be a more equivocal outcome than ADLs or mastery given that improvement may reflect a reduction in activity due to fear of breathlessness and thus have negative implications for wellbeing. For this reason, severity was measured to provide context for other outcomes more than as an outcome in its own right.

Healthcare use: Patients were asked "*what if any healthcare have you needed to help with your breathlessness?*" Tick box options included: "*none*", "*ED*", "*hospital admission*", "*change in medication*"; "*GP visit*"; "*specialist visit*", or "*other*". Patients were also asked "*was there any time since your last session with Southside Physiotherapy that you thought about calling an ambulance for breathlessness, but instead managed to control it using the strategies you've learned through ABIS?*" with "*yes*" or "*no*" response options.

Carer confidence: Carers were family members or friends who patients identified as providing substantial support to help with their breathlessness. Carers were asked "*how would you rate your confidence in supporting (patient name) when his/her breathlessness gets suddenly worse?*" Response options were on a 3-point verbal rating scale: "*very confident*"; "*somewhat confident*" or "*not confident*". In the absence of previous research, a minimally important change was defined as one point.

2.6.4.3. Quantitative data analysis

As is conventional for QI projects, graphic representations of data trends over time were used to summarise quantitative data for interpretation at each co-design meeting. For SMART Goal 1, column charts were generated in MS Excel showing the proportion of patients discharged each month who reported a minimally important improvement on each and any outcome compared to their initial assessment. To provide more detail on each outcome, stacked column charts were used to plot within-patient changes at each home visit, using traffic light colour coding (green for minimally important improvement, amber for no change, and red for deterioration). The unchanged category was divided into darker and lighter amber colouring denoting whether there was room for improvement since the previous timepoint or not, according to the minimally important difference for each measure (i.e. a 'ceiling effect'). A matrix was also generated to compare improvement/no change/deterioration on ADLs against the same categories for breathlessness severity and mastery.

Stacked column charts were also used to represent the numbers of patients referred each month from each general practice and specialty at Canberra's hospitals.

Descriptive statistics were used to summarise characteristics of patients and carers accessing ABIS, as well as numbers of and times between home visits. Statistical analyses also examined the effects of sociodemographic and clinical factors on changes in ADLs and CRQ mastery. Given that each patient could select up to 3 ADLs, a Generalized Estimating Equation (GEE) approach was employed to account for the potential correlation between repeated measurements within individuals. Independent variables included activity type, age group (Under 70, 70–79, 80 years and older), gender, presence of a lung condition and mMRC score (2, 3, 4). The change in ADL scores was modelled as a normally distributed outcome. An exchangeable correlation structure was assumed in the GEE model to account for within-subject correlations across repeated measurements. The statistical significance of the regression coefficients was assessed using Wald tests. A logistic regression was used to examine correlations between MID improvement on the CRQ mastery scale and the same independent variables listed above, including only those found to correlate with mastery in initial bivariate analyses.

2.6.5. Qualitative data

2.6.5.1. Qualitative data collection

Semi-structured interviews were conducted with patients and carers as soon as possible after they completed the ABIS to minimise recall bias, while interviews with referring health professionals were conducted at any time during their involvement with ABIS to fit in around workload.

Interviews were conducted by the UTS team via telephone/videoconference according to each participant's preference. Interviews asked participants about their experience of ABIS and perspectives on what worked well, and what might be improved. Questions were initially asked in general terms to elicit participant priorities with minimal bias from the researcher, before focusing more specifically on perceived benefits and problems, referral, delivery and follow-up (see topic guides in Appendix D).

Patient demographic data included gender and age group (in 10-year categories), and clinical data included diagnostic group (lung disease, heart disease, cancer, other) likely to cause breathlessness. Carer demographic data included relationship to the patient (spouse, sibling, child, friend, other). Health professional data items were limited to specialty only.

2.6.5.2. Qualitative data analysis

Interview data were transcribed and imported to NVivo V14 software for management and coding. Data were thematically analysed using an integrative method specifically designed for informing the development of health interventions.[44] This method uses both inductive and deductive approaches to build on previous findings while remaining open to new insights. The initial coding structure was defined by themes identified by previous qualitative research on BIS, including interviews assessing the Westmead BIS by members of the current team.[23-25, 45] Further codes were added as needed to capture perspectives on ABIS not previously documented in the literature. Initial coding was conducted by one member of the team, with review and development by others at co-design meetings.

2.6.6. Data integration

Because both qualitative and quantitative data were de-identified immediately after collection, data were integrated at the aggregate rather than individual patient level. Dimensions from the RE-AIM framework [46] – Reach, Effectiveness, Adoption, Implementation and Maintenance - were used to organise findings. See Table 2 for questions asked within each dimension and contributions to answering them made by quantitative and qualitative data.

Table 2. Insights used from quantitative and qualitative data to answer RE-AIM questions

RE-AIM questions	Quantitative insights	Qualitative insights
Reach		
· Did the service reach the population it was aimed at? · What were the facilitators and barriers to reach?	· Referral rates per month · Completion rates per month · Patient clinical/demographic characteristics	· Service characteristics aimed at promoting reach · Referrer perspectives on eligibility criteria and patient acceptance of referral · Patient and carer perspectives on desirable and undesirable service characteristics · Co-design meeting minutes on barriers and facilitators to patient engagement
Effectiveness		
· What benefits were there from the service? · Which groups of patients benefited more or less?	· Change in patient and carer outcomes across home visits · Variation in outcomes between patients grouped by socio-demographic and clinical characteristics	· Patient, carer and referrer perspectives on benefit in each domain of the BTF model · Co-design meeting minutes on patient and carer factors impacting patient benefit
Adoption		
· What adoption was there among general practice and specialist services? · What adoption was there among individual physicians?	· Referral rates over time per general practice and specialty · Proportion of practices approached that referred · Characteristics of referring general practices · Proportion of GPs at each referring practice who referred	· Referrer perspectives on: efforts to promote adoption; desirable and undesirable service characteristics · Co-design meeting minutes on activities and response in relation to engaging general practices and specialist services · Patient and carer perspectives on referrers' level of engagement

RE-AIM questions	Quantitative insights	Qualitative insights
Implementation		
▪ How was the service delivered? ▪ Was the service implemented as intended (fidelity)? ▪ How much did the service cost? ▪ What if any savings to the health system might there have been from the service? ▪ What adaptations were made to service delivery? ▪ What adaptations were made to service delivery?	▪ Wait times, numbers of home visits, duration of program ▪ Comparisons of number of home visits and patient outcomes between ABIS clinicians ▪ Per patient and total costs ▪ Proportions of patients indicating they thought of calling an ambulance for breathlessness but self-managed instead using strategies learned through ABIS ▪ Health care use (compared to population estimates)	▪ Patient and carer perspectives on whether numbers of home visits were necessary and sufficient ▪ Co-design meeting minutes on reasons for variability in number of home visits ▪ Co-design meeting minutes on reasons for any variation between clinicians ▪ Patient and carer perspectives on program approach and content (compared to those published) ▪ Patient, carer and referrer perspectives on willingness to pay and impact on healthcare use ▪ Co-design meeting minutes on reasons for adaptations
Maintenance		
▪ Were benefits maintained for patients? ▪ How can support for people living with breathlessness in the ACT be maintained beyond the ABIS Project?	▪ Patient outcomes at longer-term follow-up compared with last home visit	▪ Patient and carer perspectives on whether and how benefit was maintained ▪ Co-design meeting minutes on the value-add of longer-term follow-up ▪ Co-design meeting minutes on discussions with ACT healthcare providers.

In the ABIS project, co-design partners included not only people with lived experience of breathlessness but also carers in recognition of their important role and differing perspective.

3. Findings

Findings are discussed under each of the RE-AIM dimensions, comparing with previous research where relevant. To limit report length, this section focuses on findings that add to rather than simply duplicate results from clinical trials of other BIS[14,16] and related qualitative research,[23-25,45] with which findings from the ABIS Project were largely consistent.

3.1. Interview participants

Interviews were conducted with 24 patients, 4 carers and 6 referrers (n=4 general practice; n=2 respiratory medicine). See Table 3 for a summary of patient characteristics, which roughly mirrored those of patients receiving the service with regard to proportions (see next section).

Table 3. Characteristics of 24 patients who agreed to be interviewed

Characteristic	N	%
Men/women	12/12	50/50
Age		
50-59	2	8
60-69	4	17
70-79	10	42
80-89	7	29
90+	1	4
Condition		
Lung	18	75
Heart	5	21
Both	1	4

3.2. Reach

3.2.1. SMART Goal 1: 100 patients completing ABIS within the first 12 months

Referrals to ABIS commenced on 4th March 2023 and ended on 2nd October 2024 to allow sufficient time for patients to complete the program by the project end date of 31st December.

In the first 12 months, only 64 patients completed the program, falling 36% short of the goal. The goal of 100 patients was not met until 31st August 2024, nearly 18 months after referrals commenced. The main barrier to ABIS reaching the first SMART Goal was limited adoption by general practice, described further below.

In total, 140 patients completed the ABIS program. Based on Australian estimates that around 10% of the adult population have breathlessness ≥2 mMRC,[1, 2] this equated to approximately 4% of the eligible ACT population (n=3,570).[32]

ABIS received 168 referrals but 4 people were found to be ineligible (mMRC 1 and unlikely to benefit from ABIS based on initial telephone assessment) and 15 people did not commence the service for the following reasons: 7 were non-contactable, 4 declined when contacted, 3 died before receiving their first consult, and one was admitted to hospital and did not restabilise during the project period. People were not obliged to give a reason for declining the service, leaving open the possibility that some initially accepted either from a misunderstanding of what ABIS offered or a desire to maintain relations with their referring doctor despite not planning to follow through. Data were not collected on the numbers of people who declined at point of referral, but only one physician who was interviewed reported a patient having done so.

> *One patient [declined], because of time.* (GP 1)
>
> *I do choose the appropriate patients, but no, nobody's refused. Everyone's been interested in it ... I think I've had good take up.* (GP 2)

3.2.2. Patient characteristics

Socio-demographic and clinical characteristics of the final ABIS patient cohort are summarised in Table 4 and remained consistent throughout the project period.

Table 4. Clinical and demographic characteristics of 140 patients who completed the ABIS program

Age	N	%
18-29	0	0%
30-39	2	1%
40-49	4	3%
50-59	6	4%
60-69	25	18%
70-79	63	45%
80-89	36	26%
90+	4	3%
Gender		
Male	68	49%
Female	72	51%
mMRC Grade*		
2	38	27%
3	74	53%
4	28	20%
Primary disease		
Lung	113	81%
Heart	19	14%
Other	7	5%

*mMRC (modified Medical Research Council) grades: 2 = On level ground I walk slower than people of same age due to breathlessness, or I have to stop for breath when walking at my own pace; 3 = I stop for breath after walking 100 yards or after a few minutes; 4 = I am too breathless to leave the house, or I am breathless when dressing.

Positive signs that ABIS reached people with high levels of need included nearly three-quarters having mMRC Grade breathlessness >2 (73%) and/or being aged ≥70 years (74%). Several patients deteriorated in health status whilst completing the program and died shortly afterwards, demonstrating reach to people with symptom burden towards the end of life.

Compared with a recent Australia-wide population-based estimate of the prevalence of breathlessness mMRC ≥2 across disease groups,[2] the ABIS patient cohort included a higher proportion with lung versus heart disease (81% versus 14%, compared with 29% versus 17%). However, the Australia-wide estimate differed from the ABIS dataset in counting people with multimorbidity separately, a group that made up 53% of people with mMRC ≥2.

Few patients who were interviewed reported having received support for breathlessness prior to ABIS, even those who had received care from specialist respiratory or cardiology teams.

> *The intervention service was a surprise, given that I'd probably had some breathlessness problems for nearly nine years.* (P08_50-59 year-old woman with lung disease)

3.2.3. Facilitators of reach

Patient interviews highlighted ABIS' home-based delivery as a major drawcard, enabling it to reach people who would have struggled to attend a similar program in the outpatient setting.

> *I was thrilled to see that it was a home-based service… I suppose more for access. Yes, I can drive, but when I'm out, I need to use a portable mobility scooter. So going out is always, it's an issue to know where you're going to park and how far to get where you need to go... So yeah. Yes, it's about convenience, but it's about for all of those issues really.* (P08_50-59 year-old woman with lung disease)

Both patients and referrers highlighted ABIS' value in providing support to people who were ineligible for hospital rehabilitation services or faced a long wait list.

> *Sometimes, these people, we found it difficult to get them into pulmonary rehab or cardiac rehab, so by doing this, we'll bypass all this bureaucratic work, just straight and the people are happy because [ABIS provider] goes to them at home.* (GP 1)

> *I'm now 14- or 15-weeks post heart attack and I still haven't got into cardio rehab at the hospital. They have a waiting list…Imagine if someone had a hip replacement and they say, "oh, you've got to wait six months for your rehab after the surgery," so the hospital is overrun.* (P11_70-79 year-old woman with lung disease)

As in previous qualitative studies of BIS, patients praised the person-centred coaching approach taken by ABIS clinicians and the importance of their personal (e.g. "*caring*" [C2_ Carer, son]) as well as professional qualities in building a therapeutic relationship.[23-25] In the early co-design meetings, partners with lived experience of breathlessness and carers emphasised the importance of patients being in control of setting their own ADL goals not only to ensure these matched their priorities and were contextualised within their daily lives but also so the process itself was empowering, re-affirming self-identity and building self-respect. The value of this approach was supported by interview data in which patients emphasised the psychological and social meaning of goals they had chosen.

> *Until I had this illness, I was reasonably fit and rode a pushbike and did a lot of walking and things like that. So we focused on the fact that I hadn't been doing that because of the illness. And I would go back to doing that … [and] little things around the house, like mowing the lawn and that, which I had been finding difficult, you know, again, because of the breathlessness and the build-up of the fluid. Yes, so our goal was for me to be doing those things and, yes, I'm back doing them.* (P02_60-69 year-old man with heart disease)

Patients appreciated the practical, "common sense" approach to education on pacing, positioning and breathing techniques which was embedded as problem-solving within their everyday contexts and helped them to learn new ways of maintaining or recommencing routine tasks with greater efficiency and sustainability.

> *There was nothing mind blowing to it. I mean, she said, "I can't cure you, but I can give you techniques that will help you." And I do put that into practice. I do have to remember that, to do it. So that helps me get to the clothesline now and have a walk around. And I've been to the shopping centre a lot more than I was prior to her giving me those hints so to speak.* (P22_80-89 year-old woman with lung disease

> *A lot of it was common sense kind stuff…that you didn't really think about…it was important to us that we just got some basic ideas that we could work on every day. And I think that was the strength of the program. So we would say that perhaps something that we focused on is those basic, you know, points you can hit and build on that.* (C01_Carer, daughter)

> *I have a series of practical hints, which [ABIS provider] gave me, which I have been able to follow up to a certain point. I'm not doing nearly enough of the sort of exercise that she recommended, but I'm doing enough of it, I think, to have my breathlessness under control.* (P03_80-89-year-old man with heart disease)

> *The tips and tricks she had for making sure that I was consistent in my breathing approach was really good. I was immobile because every time I moved, I was breathless, and it was seriously impacting my quality of life. So, after I saw [ABIS provider], she had a few tricks for ensuring that I breathe consistently using triggers to breathe in and breathe out. So, when you stand up, you breathe out. When you take your first step, you breathe in. She gave me a little fan so that when I got really breathless, I blew it on my face, and it tricked me into breathing properly. So that changed the quality of my life. As I say, I went from being practically immobile to [ABIS provider] running me up and down the street. (*P23_60-69 year-old woman with lung disease)

Patients were especially impressed with the team's efforts to integrate ABIS' exercise component into everyday activities so it was meaningful and motivating.

> *One of the things that [ABIS provider] was very good at was to try incorporate the exercise in your normal day of doing things. If I've got to reach up into a cupboard and do it a certain way that instead of just reaching up and get what you want, you can do it raising your arm a bit different. And so, you get more benefit out of what you would normally do in the course of a day to turn it into an exercise… she cleverly incorporated them by just doing these in your normal course of action… By the time you have a shower and you dry yourself off, it was getting quite exhausting. And she said, "look, turn that around the other way and treat it as an exercise." And I thought, you tend to think differently when you're doing an exercise. You push yourself and you're happy to do that. And I've been doing that and it's just made a difference.* (P21_70-79 year-old man with lung disease)

Educational patient resources (adopted from previous sources) were praised for their relevance, imbuing patients with a sense that other people had shared their experience in the past.

> *The program has just been, like with [ABIS clinician] has been wonderful in the materials that I'm reading and then I go back and reread. It really speaks to me about what my situation is; it seems grounded … whoever put that together should get a gold star because it described the commonness of my situation as opposed to making me feel like no one has an answer. The materials in the program described and [ABIS clinician]'s guidance and interpreting everything told me that this is common. A whole bunch of her patients or clients are suffering one version or another of the same thing. So, you're not alone, you're not isolated, you're not unique.* (P04_60-69-year-old man with heart disease)

3.2.4. Barriers to reach

While GPs generally perceived screening and eligibility criteria to be acceptable and easy to operationalise, the manager and nurse at one practice argued that eligibility criteria should be widened to include mMRC 1 where patients were motivated to undertake the program.

> *I do think widening the scope of patients that it is accessible to is a good thing because … you've got people actively looking to improve their health or do something to improve their health and they were knocked back.* (Practice Manager 1)

Co-design partners discussed this request and agreed a compromise whereby motivated patients with mMRC 1 could receive a single home visit for education purposes but mMRC ≥2 would remain the standard criterion to ensure resources were reserved for patients most impacted (co-design meeting 7).

Through co-design meetings, it became apparent that referral and completion rates over-estimated reach in some instances because patients only partly engaged with the program. Some patients appraised their ADLs more favourably than clinical observation suggested, limiting the team's ability to leverage improvement as a motivator (co-design meeting 12). Other patients seemed reluctant to change their routines even if this promised to extend ADLs or improve efficiency. This finding is consistent with analysis of UK BIS trial data showing that benefit was associated with the personality trait of 'openness'.[47] Eligibility criteria on the referral form asked physicians to assess whether the patient "*wants to receive ABIS after hearing potential benefits*". However, at least one patient admitted to accepting referral only to please his GP.

In one case of limited patient engagement, attention from the ABIS team could be redirected productively toward carer support. However, other cases posed a dilemma in regard to whether the team should persevere with trying to motivate the patient or reallocate time to others who might benefit more readily (see implementation section below).

Not all carers were willing to engage with the program either. In some cases, this stemmed from unconducive dynamics in the patient-carer relationship or a lack of self-identification with the role of carer, as found by other research.[48] Alternatively, some carers may have believed they were already providing support to the limit of their capacity and effectiveness, reducing motivation to engage with ABIS. These interpretations remain speculative given that carers who did not engage could not be interviewed to share their perspectives.

3.2.5. Summary of findings on Reach

- ABIS is estimated to have reached around 4% of adults in the ACT with breathlessness ≥2 mMRC.
- Patient characteristics suggest the service reached population sub-groups with high need, including people who were older, less mobile, unable to access rehabilitation services, or approaching end of life.
- Patient motivation is a central focus of the coaching approach taken by BIS, but ABIS clinicians sometimes faced challenges in predicting likely return on investment from further home visits vis-à-vis opportunity costs to reaching other patients.
- Insights into barriers to reach are limited by the fact that only patients and carers who completed the program volunteered to be interviewed.
- Reach was impeded by limited adoption from general practice, as described below.

3.3. Effectiveness

This section reports outcome data for the 136 patients who provided at least 2 data points for comparative analysis, excluding four who required only one visit from the ABIS team.

3.3.1. SMART Goal 2: At least 75% of patients experiencing benefit on one or more outcomes

All 136 patients with 2 data points reported minimally important improvements on at least one outcome: 91% on ADLs on a 'bad day', 88% on ADLs on a 'good day', 68% on breathlessness mastery, and 70% on 'worst' breathlessness severity (Figure 7).

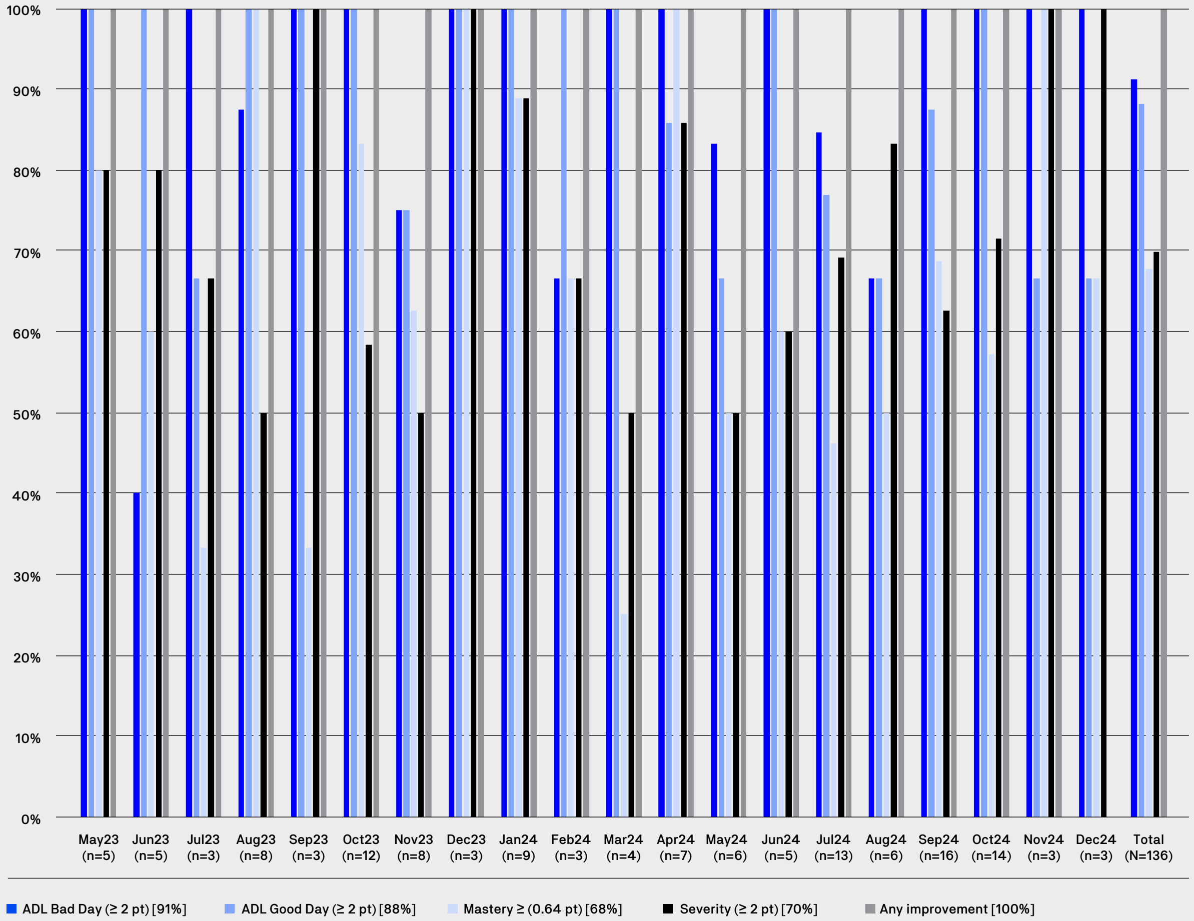


Figure 7. Proportion of patients completing ABIS in each month who reported an improvement on each measure (n=136)

Minimally important differences are shown for each outcome as points on the relevant scale; in addition to the percentages who improved, 6 (4%) patients were at 'ceiling' (i.e. could not improve) from first to final time-point for ADLs good day, and 20 (15%) for mastery.

Table 5 summarises results from analyses of pre/post changes in patient-reported outcomes from initial assessment to final home visit. Changes were statistically significant for all outcomes.

Table 5. Changes in outcomes for patients from pre to post the ABIS program (n=136)

Outcome	Initial		Final home visit		Change		p-value
	Mean	SD	Mean	SD	Mean	SD	
ADLs ‘good day’	5.17	2.11	8.19	1.57	3.02	2.15	<0.001
ADLs ‘bad day’	2.27	1.77	5.87	1.95	3.60	2.36	<0.001
Mastery	4.49	1.72	6.22	0.71	1.73	1.63	<0.001
‘Worst’ breathlessness	7.29	1.81	4.48	2.28	2.82	2.56	<0.001

SD = standard deviation

> Patients appreciated the practical, “common sense” approach to education on pacing, positioning and breathing techniques.

3.3.2. Benefits to breathing, thinking and functioning

Findings relevant to each domain of the Breathing Thinking Functioning (BTF) model [8] are separated into sections below. Stacked column charts are used to represent within-patient changes across adjacent home visits. Declining numbers at each timepoint denote the number of episodes varied according to patient need. Findings from qualitative analyses are summarised in the text.

3.3.2.1. Breathing

Figure 8 indicates the proportions of patients improving, worsening and not changing on the 'worst' breathlessness scale remained fairly stable across home visits. At their final visit, all patients reported their 'worst' breathlessness had either improved or remained unchanged since their previous visit. Worsening breathlessness reflects interactions with ADLs discussed below under 'functioning'.

When interviewed, patients most commonly described benefits as changes to their breathing patterns that helped them to recover more quickly from exercise-induced breathlessness.

> *She gave me some breathing techniques that were - before I'd be getting quite exhausted. I'll still get exhausted, but it's how to affect a recovery... that's frequently quicker.* (P21_70-79-year-old man with lung disease)

> *I learned things about breathing that I didn't know, which was quite enlightening to me on how to breathe.* (P02_60-69-year-old man with heart disease)

> *She showed me how to do it… it's basically using your diaphragm all the time, but really emptying my lungs out. She explained to me why I was becoming breathless and the mechanics of how that occurred and how this breathing technique would lessen my breathlessness.* (P10_70-79-year-old woman with lung disease)

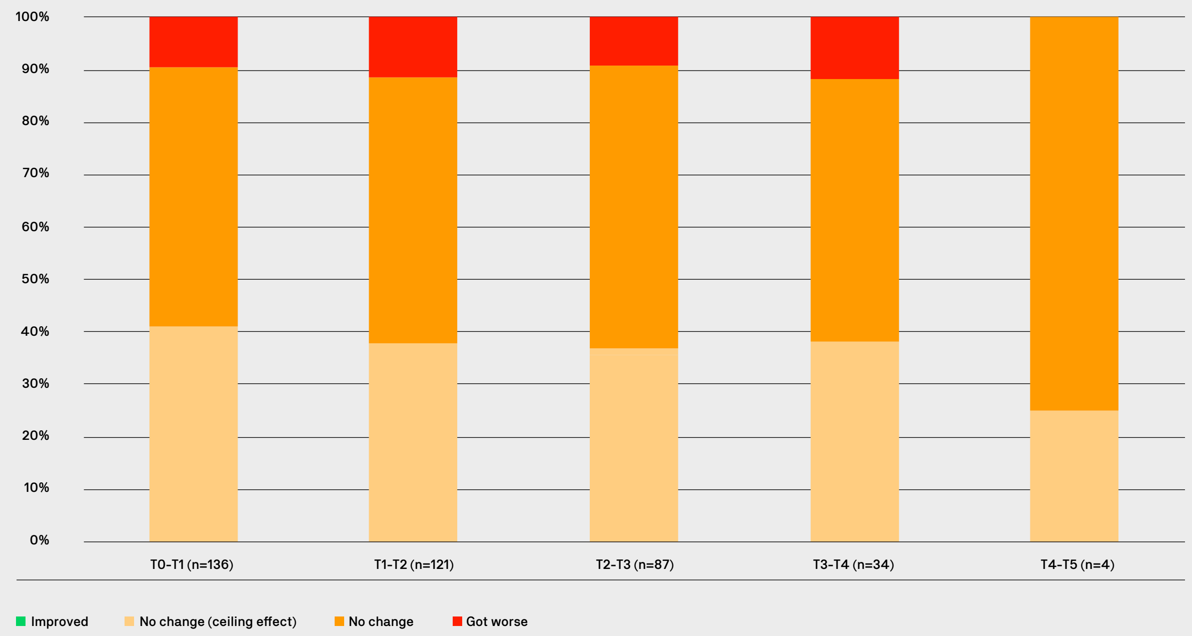


Figure 8. Change in scores on 'worst' breathlessness severity for all patients who completed at least 2 home visits (n=136)

*T0 denotes initial assessment and T1, T2, T3, T4 and T5 follow-up visits. Changes were measured against a minimally important difference ±2 points, with a higher score indicating *worse* breathlessness; 'ceiling effect' indicates that scores at the previous session were too low to enable improvement to the extent of a minimally important difference; 'no change' indicates that a minimally important difference was possible but did not occur.

3.3.2.2. Thinking

Figure 9 shows the proportions of patients improving or reaching ceiling on breathlessness mastery increased across home visits. A sustained improvement in mastery was considered by the ABIS personnel to be a key requirement for discharge (codesign meeting 12).

Several patients were at a ceiling for mastery at initial assessment or increased quickly over the first home visits and plateaued. Clinicians found that generalised (as opposed to breathlessness-specific) anxiety posed the greatest challenge to increasing mastery (codesign meeting 12). Reasons mastery reduced included its inverse relationship with ADLs (see interactions below) and acute medical events, especially those that led to hospitalisation and further deconditioning.

Consistent with previous BIS research,[23] patient interviews and ABIS clinicians identified the most important service component for reducing breathlessness-related fear to be education targeting misconceptions that breathlessness is dangerous in and of itself (acknowledging the caveat that underlying acute medical events should be ruled out [e.g. lung infection or pulmonary embolism]).

> *She [ABIS clinician] told me that you can't die from breathlessness. So, it made me feel a bit better.* (P09_70-79 year-old woman with lung disease)

Patient interviews confirmed that reducing their fear of episodic breathless and the associated avoidance of ADLs was a key benefit from the service.

> *I've been able through the program to manage the deeply inset anxiety that was created by some really difficult breathing situations in the home environment…* (P04_60-69-year-old man with heart disease)

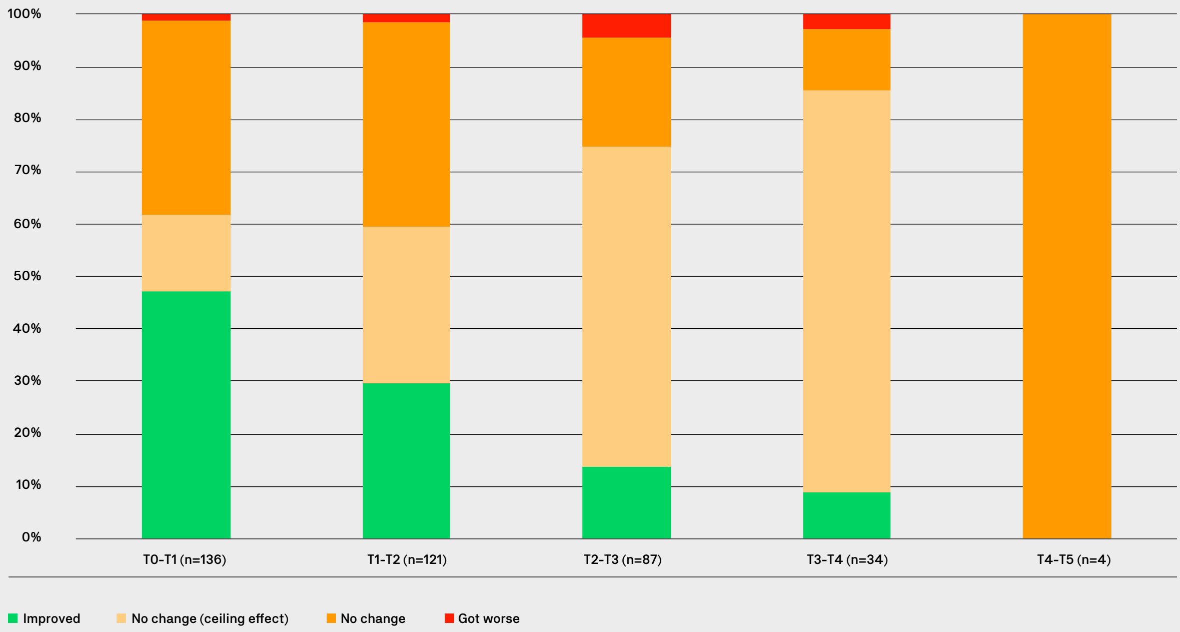


Figure 9. Change in breathlessness 'mastery' scores for all patients who completed at least 2 home visits (n=136)

*Minimally important difference ± 0.64 points; 'ceiling effect' indicates that scores at the previous session were too high to enable improvement to the extent of a minimally important difference; 'no change' indicates that a minimally important difference was possible but did not occur.

3.3.2.3. Functioning

Independence in ADLs was chosen by the co-design team as the most important (‘primary’) outcome and improved for 91% and 88% of patients on a ‘bad day’ and ‘good day’ respectively.

Figure 10 shows the proportions and numbers of patients choosing various kinds of ADL to work on. Instrumental ADLs includes all categories other than self-care (i.e. washing, dressing, eating).

All patients improved at least one ADL on either a ‘good day’ or ‘bad day’. Unsurprisingly, ADLs on a ‘good day’ tended to reach a ceiling effect earlier in the program than on a ‘bad day’ (Figures 11 and 12).

In interviews, patients reported increases in functional capacity, enabling them to walk distances and restart ADLs they had resigned themselves to giving up prior to ABIS.

> *I live in a complex of about 50 units and our letterbox is right up at the top, at the entrance. And I used to go up on my scooter, but now I found out I'm walking up and I'm walking around the block to get home.* (P09_-70-79 year-old woman with lung disease)

> *Walking around the mall without having to stop and take breathers; and I'm finding that's a revelation. I got back to the car with my husband the other day, and even he noticed, he said, “oh, you didn't have to stop and take a breather, babe.”* (P11_ 70-79 year-old woman with heart disease)

> *She actually got me up walking, and she even took me outside, which I haven't been out there for about a year.* (P05_80-89 year-old woman with lung disease)

> *With [ABIS provider]’s help, I've achieved something that I didn't think I'd be able to [going to the shopping centre].* (P09_70-79 year-old woman with lung disease)

Interviewees attributed improvements to the in-situ assessment and person-centred management plans enabled by home visits.

> *They go to the house and help them to better understand the functional day-to-day activities and help them to also personalise their care.* (Respiratory Physician 2)

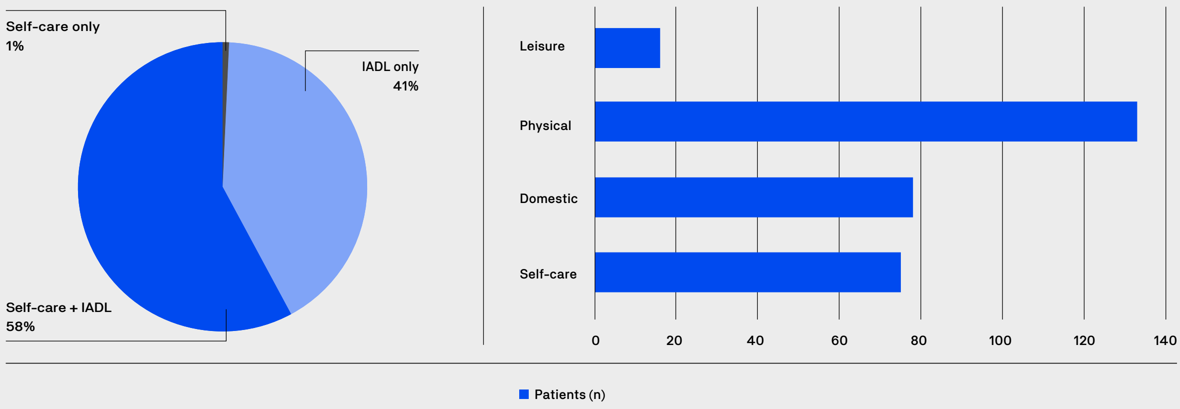


Figure 10. Proportions and numbers of patients choosing various kinds of ADL to work on (n=136)

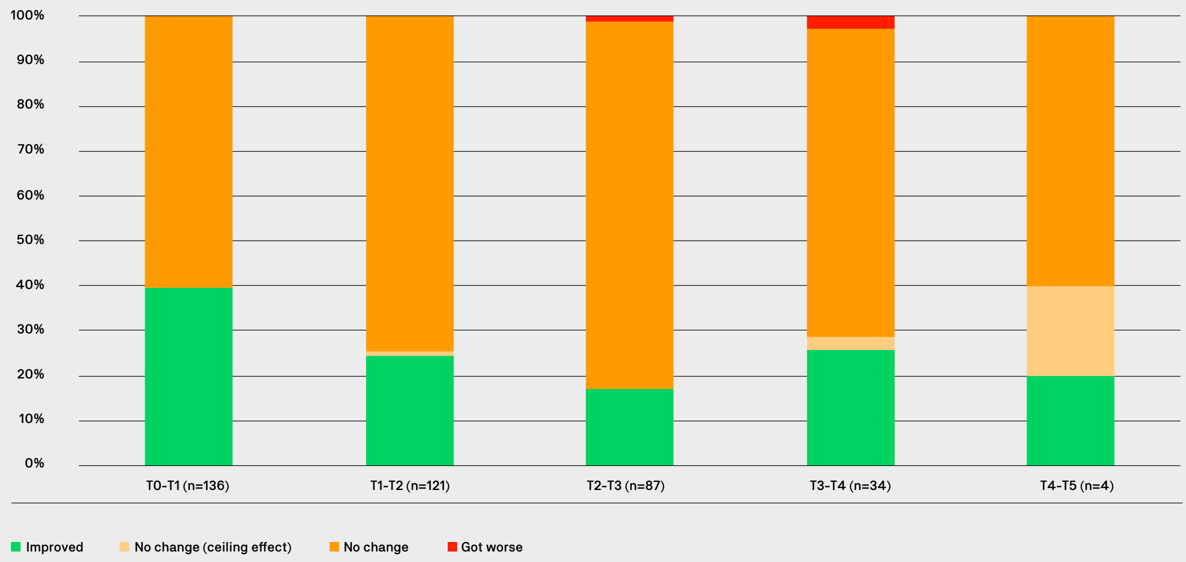


Figure 11. Change in average ADL scores on a 'bad day' for patients who had at least 2 home visits (n=136)

*Minimally important difference ± 2 points; 'ceiling effect' indicates that scores at the previous session were too high to enable improvement to the extent of a minimally important difference; 'no change' indicates that a minimally important difference was possible but did not occur. All patients had three ADLs, except one patient who had two ADLs.

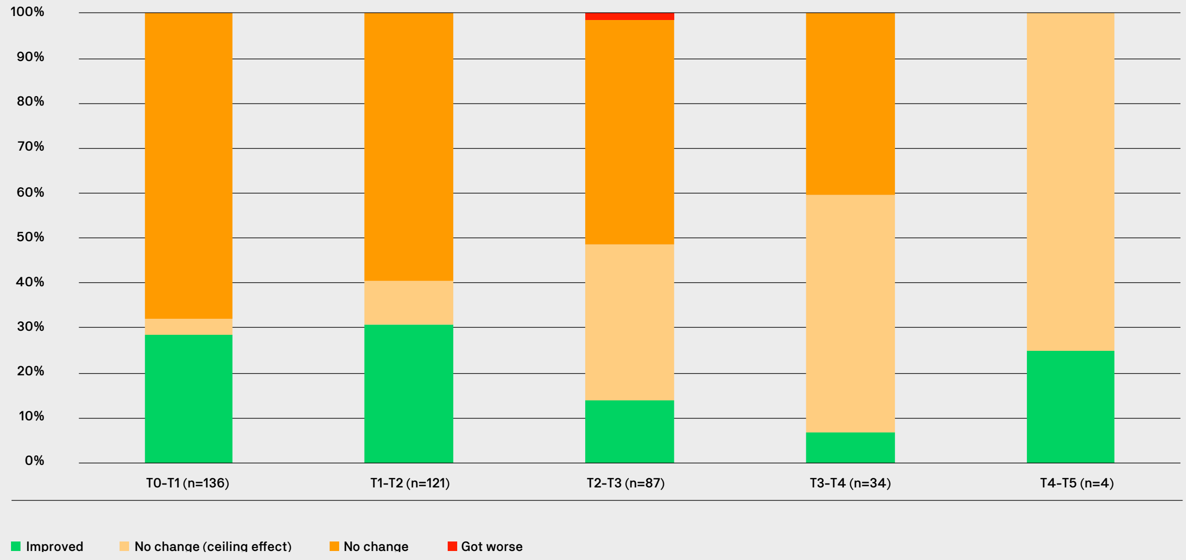


Figure 12. Change in average ADL scores on a 'good day' for patients who had at least 2 home visits (n=136)

*Minimally important difference ± 2 points; 'ceiling effect' indicates that scores at the previous session were too high to enable improvement to the extent of a minimally important difference; 'no change' indicates that a minimally important difference was possible but did not occur. All patients had three ADLs, except one patient who had two ADLs.

3.3.2.4. Interactions between breathing, thinking and functioning

Outcome data from the ABIS project identified interactions between BTF domains that have not been considered in reports of previous BIS trials (Figure 13).

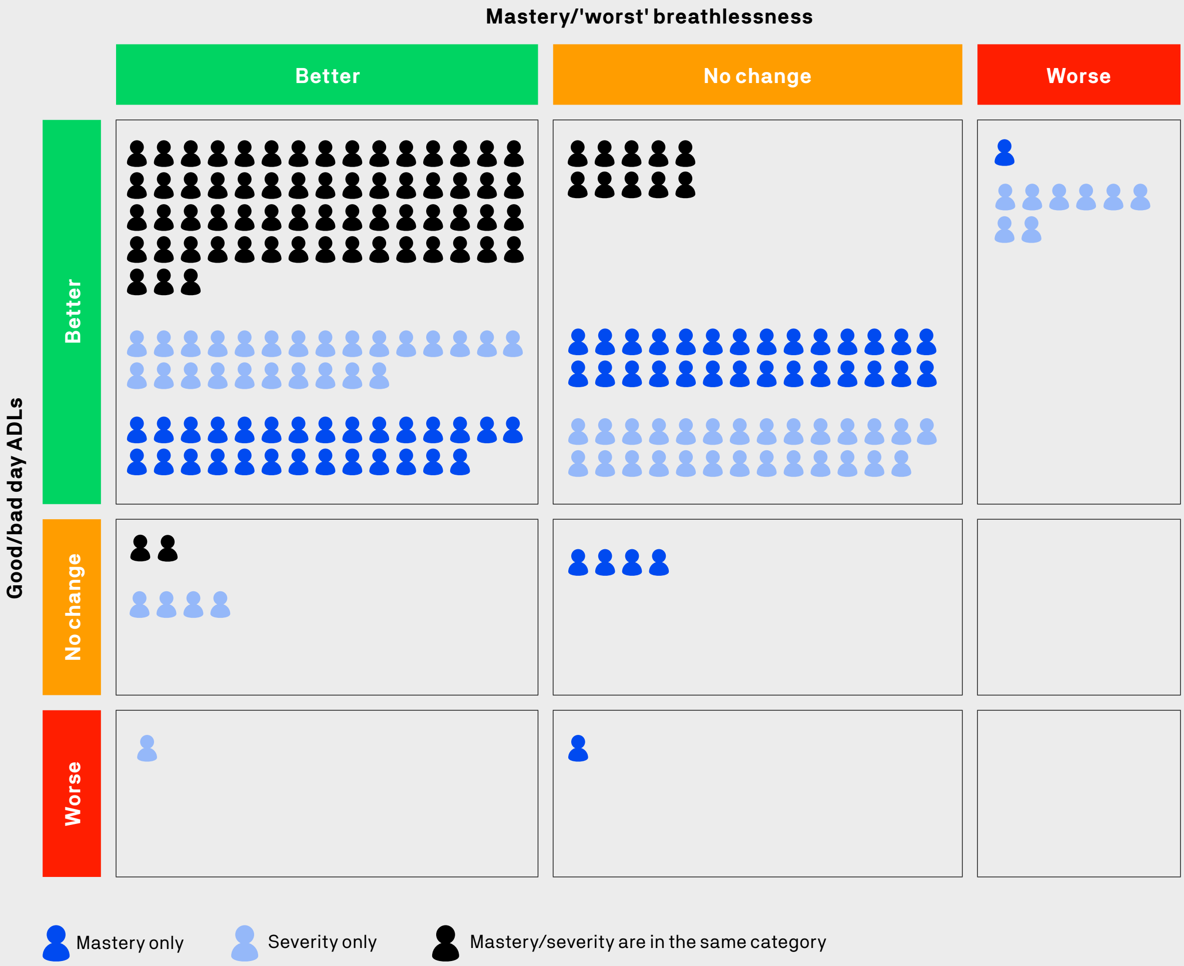


Figure 13. Interactions between changes in ADL scores versus breathlessness mastery and 'worst' breathlessness severity and for patients discharged from ABIS (n=136)

Improvements in ADLs were usually associated with a temporary worsening of breathlessness severity and reduction in mastery. During co-design meetings, ABIS clinicians confirmed coaching patients towards their ADL goals tended to increase breathlessness until their cardiorespiratory fitness developed over time to improve aerobic efficiency (codesign meeting 12). This sometimes also led to "*wobbles*" in patient mastery in the short-term followed by longer-term gains in satisfaction with having reached their goals. ABIS clinicians found it important to warn patients this pattern might occur in order to ensure they were better prepared and able to "*push themselves*" without giving up.

A number of 'virtuous cycles' between BTF domains were identified through interviews with patients and referrers, the most important being that reducing fear of breathlessness episodes enabled patients to restart ADLs they had previously given up to avoid breathlessness.

> *I wouldn't have had the confidence to do it because of the fear of getting uncontrolled breathlessness… It is indispensable for everyone that's some version of me, and there must be an awful lot of people who are lost as I would've been if I didn't have this program… I wish I had this a lot earlier, and I wouldn't have had the problems I have now.* (P04_ 60–69 year-old man with heart disease)

> *My lack of confidence meant that I wasn't going out because I was afraid that I was going to get ill while I was out and not be able to breathe. But given that little swag bag of tips and tricks gave me the confidence that I needed to get out and do things. It also encouraged exercise, which meant that as I got physically stronger, I was more confident in my legs and my arms. So, once I was able to breathe properly, all these other things were sort of consequential and made me better.* (P23_60-69 year-old woman with pulmonary hypertension)

> *I've had several [patients] and they've really found it useful, found that it's made a real difference, I think particularly psychologically, in their ability to have confidence to handle their breathing. I've sent several patients who were really in a phase where they were getting distressed by it, and restricting movement, and trying to not go out, and things like that because they were frightened of their breathlessness. And in that sense, it's made a huge difference for those patients.* (GP 2)

Learning new breathing patterns also helped patients reduce the impact of exertion on breathlessness, allowing them to extend activities such as walking.

> *She taught me the proper way to breathe. I have COPD and I find, when I'm walking, I'm not as breathless anymore because I'm conscious of how I'm breathing while I'm walking.* (P09_70-79 year-old woman with lung disease)

Finally, one of the co-design partners with lived experience of breathlessness reported his own experience that managing feelings of frustration through pacing and mindfulness prevented breathlessness episodes (co-design meeting 13), consistent with evidence that these can be caused by emotional exertion as well as physical.[5]

3.3.3. Which patients responded best to the ABIS program?

3.3.3.1. Outcomes sub-group analyses

The Generalized Estimating Equation (GEE) analysis found patients with a lung condition to report significantly less improvement in 'bad day' ADLs compared to those with other conditions (p=0.023). However, this finding should be interpreted with caution because of the imbalance in numbers/percentages of patients in lung versus non-lung groups (n=113/19, 81/19%). Improvement on ADLs was not related to activity type, patient gender, age group or mMRC score.

Similar to a previous BIS analysis,[49] we found no differences in Chronic Respiratory Questionnaire (CRQ) mastery improvement between patients grouped according to sociodemographic or clinical characteristics.

3.3.3.2. Reasons some patients did not improve outcomes

In co-design meetings, ABIS clinicians were invited to discuss specific cases where improvement had been limited on certain outcomes. In most cases, patients who showed less improvement on breathlessness severity and ADLs were deteriorating in health status towards the end of life. Importantly, even these cases were able to maintain functioning and mastery until shortly before death (co-design meetings 9 and 12).

Acute medical events such as lung infections posed a widespread setback to progress across all outcomes. More indirectly, a worsening of comorbidities that affected mobility or eyesight could have flow-on effects to ADLs that were independent of gains made in self-managing breathlessness. In one case, a patient's mastery also reduced after her carer husband became less available due to his own health problems.

ABIS clinicians also found mental health played a significant role in whether patients derived benefit from the service. Some patients presented with generalised anxiety or depression that required treatment beyond the scope of support available from ABIS clinicians. The team referred to mental health services where possible, but wait times were found to be between 6 months and a year (codesign meeting 13). Where needed, personnel also helped patients access funding for services and liaised with these regarding handover (codesign meeting 10).

> *It's a real challenge to take yourself to that level of where you basically have to be really confident... there's a natural tendency to quit early, a natural tendency to not go as far, and therefore there's a natural default tendency to short-change yourself with progress.* (P04_60-69-year-old man with heart disease)

3.3.4. Dyadic coping between patient and carer

Previous research emphasises the importance of supporting 'dyadic' coping between patient and carer, i.e. how the 2 people can work together as a team, , especially in relation to episodic breathlessness where carers can play a key role in remaining calm and deciding when to seek emergency medical care.[50, 51]

3.3.4.1. Improvements in carer confidence

123/140 (88%) patients identified a carer who could be involved in supporting breathlessness self-management. Carers held a range of relationships with the person experiencing breathlessness (Figure 14).

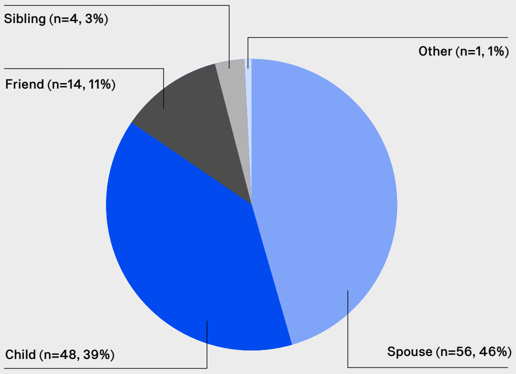


Figure 14. Carer relationships identified by persons with breathlessness completing the ABIS program (n=123)

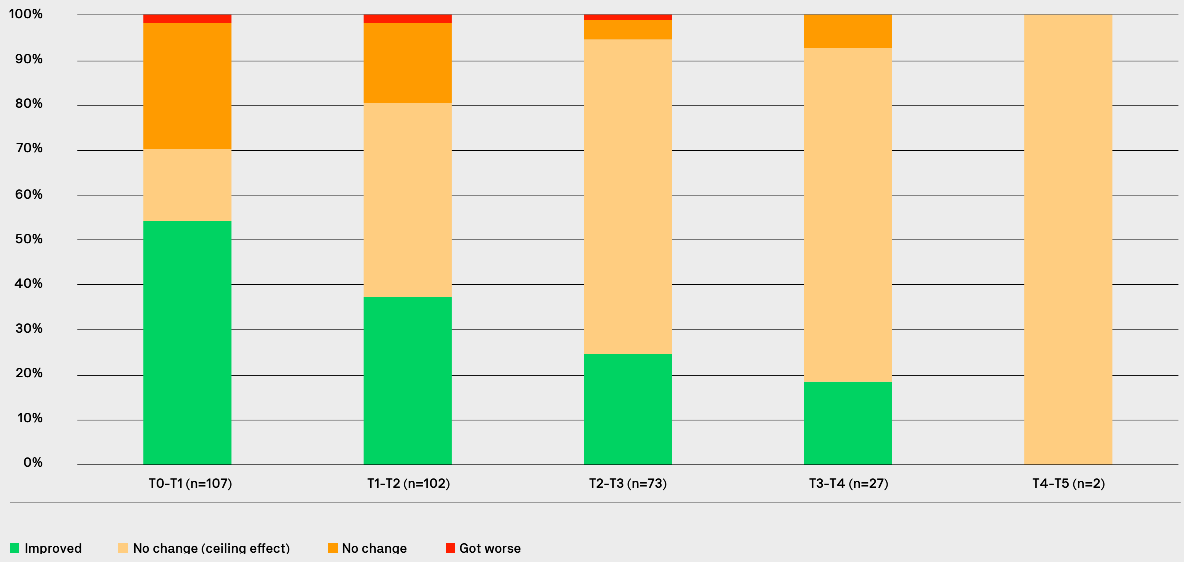


Figure 15. Change in confidence supporting breathlessness episodes reported by carers who participated in 2 or more home visits (n=119)

Notes: Minimally important difference ± 1 points. Confidence is rated on a 3-point scale – 'not', 'somewhat', 'very'.

94/119 (79%) of carers who provided at least 2 data points reported at least a 1-point improvement in the 3-point scale of: "*not confident*", "*somewhat confident*" or "*very confident*" in response to the question "*how would you rate your confidence in supporting (patient name) when his/her breathlessness gets suddenly worse?*" 19/119 (16%) of carers answered "*very confident*" at initial assessment and so were subject to a ceiling effect on the scale. However, 2 of these reduced from "*very*" to "*somewhat*" confident at subsequent visits, only one of whom regained their initial level. According to the ABIS clinician involved, this resulted from an increasing awareness of the carer role through the program (co-design meeting 13). A further 5/119 (4%) carers made no improvement in carer confidence.

The 4 carers who agreed to participate in an interview provided more detail about the ways in which ABIS had boosted their confidence in providing breathlessness-related support. They reported a deepened understanding of how best to provide support – including the need to support patients to do more rather than doing things for them - and more generalised improvements to their relationships and daily lives.

> *I'll say to him, I haven't seen you do your exercise.* (C03_Carer, wife)

> *I really felt supported… I was encouraged to be part of it. It helped me build it into our routine… being able to build it together and work on it together with dad meant that he would get the best outcome of it… It helped dad recover quicker and feel more confident. And that helped me because I felt more confident and able to encourage him as well. So, it just makes things easier for the both of us.* (C01_Carer, daughter)

During co-design workshops, ABIS clinicians highlighted the availability and receptiveness of carers as a key factor in determining how many home visits were required (co-design meeting 10). Education and support for carers was focused on enabling them to take over the coaching role once the ABIS program finished, and was considered important for maintaining longer-term improvements in patient outcomes.

3.3.4.2. Carer perspectives on other ABIS benefits

Even carers who were already confident in supporting breathlessness self-management welcomed the reinforcement provided by ABIS clinicians, who they perceived to bring an authoritative voice that the person with breathlessness was more likely to listen and respond to.

> *To be honest with you, I think just having somebody who I guess is a professional advising, my mum, my mum's more receptive to that than she will listen if I give her some advice or whatever, but she'll take it more seriously, I guess, if it's coming from someone who's qualified to give that advice.* (C02_Carer, son)

> *He's more willing to hear, he accepts the feedback, 'no, you need to do this.'* (C03_Carer, wife)

Carers also reported improvements in their own physical and mental health through becoming more active and able to pursue recreational activities, as well as a heightened awareness of the importance of looking after themselves so they could better maintain the carer role.

> *It's got me more active, obviously…it's got us out of the house more … Dad goes twice a week to the Men's Shed, and I just feel more confident about leaving him there. You know, I'm not worried so much that I'm going to get a phone call to come pick him up earlier or anything like that.* (C01_Carer, daughter)

3.3.5. Summary of findings on Effectiveness

Consistent with some but not all trials of other BIS, ABIS was effective in improving patient outcomes across all 3 domains of the BTF framework, as well as confidence in most carers.

For the first time, the ABIS Project identified interactions between BTF domains in quantitative as well as qualitative findings, highlighting the need to:

- forewarn patients that breathlessness severity and mastery may be negatively affected in the short term as ADLs improve; and
- determine the optimal number of episodes of care according to the outcome trajectory of each patient.

Even carers who were already confident in supporting breathlessness self-management welcomed the reinforcement provided by ABIS clinicians.

3.4. Adoption

3.4.1. Referral rates and sources over time

For the 140 patients who completed the program, Figure 16 shows the numbers referred from each general practice and specialist service over time. Despite concerted attempts by CHN and Southside Physio outlined in the methods section, adoption among general practices was slow, prompting a decision by the co-design team to commence and then increase referrals from specialist services at Canberra's hospitals.

3.4.2. Adoption by general practice

Of the 140 patients who completed ABIS, 74 (53%) were referred from general practice. 19 (83%) practices referred out of 23 approached on the basis of pre-existing relationships with the CHN and/or Southside Physio. No practices volunteered to refer or referred based on patient request after hearing about the service through other means. Although attended by 5 GPs, the 1-hour video-conference workshop on 12th July 2023 did not elicit any new referrals.

Table 6 summarises characteristics of the 19 referring practices. The practices were evenly distributed across the ACT. However, the proportion of referring practices that offered bulk billing was lower than the 53.2% for the ACT in general.[35] More details have not been presented to avoid re-identification.

Table 6. Characteristics of 19 general practices referring to ABIS

Characteristic	N (% or median, range)
Number of practices with ≥10 GPs	11 (58%)
Number of GPs (in total and per practice)	192 (median 10, range 2 – 29)
Number of referring GPs in total and per practice)	28 (median 1, range 1-6)
Bulk-billing	
All patients	2 (10%)
Mixed	6 (32%)
None	11 (58%)
Region of the ACT	
North	7 (37%)
Central	5 (26%)
South	7 (37%)

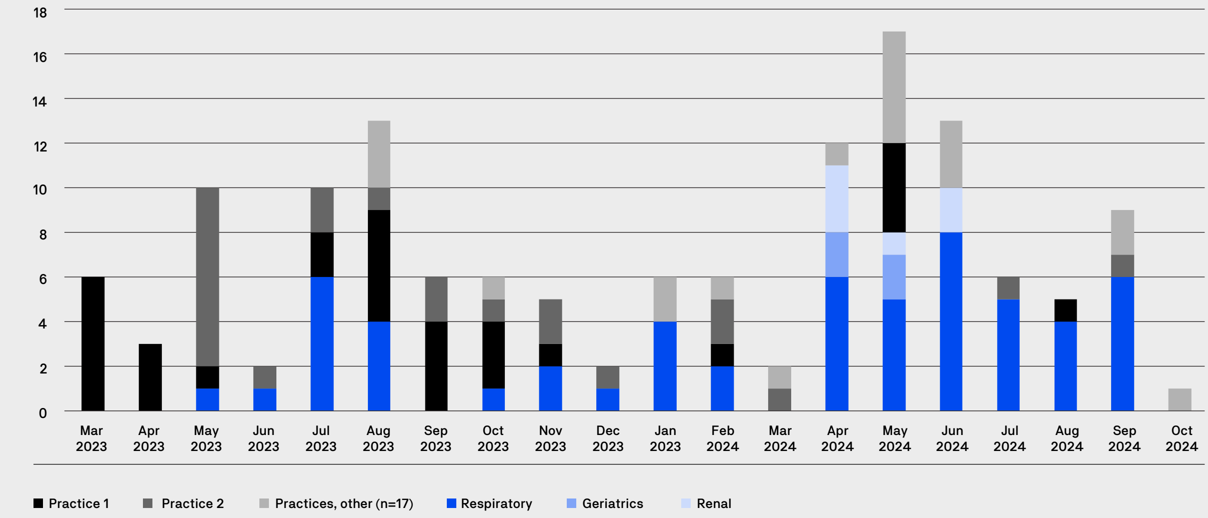


Figure 16. Referral rates per month for the 140 patients who completed the ABIS program

3.4.2.1. Factors limiting adoption by general practice

Despite efforts to introduce routine screening of medical records and advertise ABIS to patients in waiting rooms, referral at most practices remained at the discretion of individual GPs. Flyers were often buried by other health promoting materials, and no practices chose to display the ABIS video in their waiting rooms.

> *I think I'm the only one regularly using it [ABIS] at my practice.* (GP 2)

GPs typically used less formal means of identifying patients before screening against eligibility criteria, making it likely that patients who would have benefited from referral were missed.[10-12]

> *I don't take new patients, and I'm very familiar with them. Even sometimes, I've visioned the patient are breathless even without looking at their file. When they walk to the corridor, you know, when they walk to my room in the corridor, I noticed that they are breathless.* (GP 1)

Limited adoption by general practice was non-concordant with recent qualitative research suggesting that Australian GPs would like to see primary care play a greater role in managing chronic breathlessness facilitated by enhanced access to allied health and BIS.[52] GPs who did refer to ABIS perceived limited adoption by colleagues was likely due to competing priorities rather than a lack of in-principle support for BIS.

> *I think it [limited adoption] is just a function of the fact that we're all under so much pressure. GPs at the moment, time pressure, logistical pressure, exhaustion, pressure… I don't think it reflects a lack of enthusiasm or engagement as much as a lack of time and a lack of ability to prioritise… There are so many competing priorities and expectations and the patient has to present to give you time to make that referral.* (GP 3)

> *We did hear about it [ABIS] at a talk [by Southside Physio at the practice]… but maybe not everyone was there and then it's fallen away… the [difficulty with] integration of knowing about it and keeping it on the forefront of everybody's minds who might have appropriate patients for it, I guess, is the downside.* (GP 2)

Interviewees from different practices varied as to whether they considered ongoing support and reminders to be helpful in eliciting referrals amidst competing pressures. The manager and nurse from one practice in particular perceived repeated approaches to be unnecessary and burdensome.

> *A medical practice does a lot of things. We wouldn't join the program or we wouldn't come on board to do with if we didn't feel that we had the capacity to do it. But just I think that understanding that we are doing our best, we will do these referrals. It might not be as quickly as you want, but you are on our list. It was a program that we were incorporating into something else, it was going to be done. But the weekly phone calls were just maybe a bit much. (*Practice Manager 1)

Referring GPs attributed their motivation either to a pre-existing interest in chronic care or contextual factors that raised their awareness of breathlessness more specifically.

> *I think we're slow adopters of things sometimes, GPs, and maybe it's even coming down to things like luck that I had a few appropriate patients in mind even when I heard the talk [from Southside Physio at the practice].* (GP 2)
>
> *[The presentation by CHN was] hugely engaging. I think it was only 45 minutes, but with graphs and things that was just so convincing to me that all my patients that I thought of that popped into my mind when I saw that I referred straight away. And so that real evidence base for something that feels a bit hopeless, to be honest as a GP, when you've got someone who's breathless and miserable, what can I do for them? I can't fix the underlying disease. Having something like ABIS is lovely.* (GP 3)

However, feedback from GPs, patients and carers alike suggested GP adoption was largely limited to referral rather than deeper engagement involving partnering with patients to support breathlessness self-management when they returned to the practice after completing the ABIS program. This appeared to be because both parties relied on the other initiating this aspect of care.

> *I think we may have gone over it [ABIS]… but I don't think we really had an in-depth discussion about it.* (C01_Carer, daughter)
>
> *I think she completed, I don't even know that she completed… I sort of rely on the patient to tell me what's going on.* (GP 3)

3.4.2.2. Factors facilitating general practice adoption

Two GPs perceived there to be a trade-off between ABIS' singular focus on breathlessness versus a broader focus on chronic care. Both acknowledged that the latter might address a wider range of problems but felt this was outweighed by advantages of specialisation.

> *We [GPs] are good at the diabetes, we're good at cardiovascular disease risk prevention. We don't need a team to support us with that the same way as breathlessness. Those behavioural strategies are not something that would ever get to the top of our list in a general practice 20-minute consult because we'd be busy prescribing the drugs, writing the referrals, doing a weight height, blood pressure, talking about carer fatigue, talking about mental wellbeing … So I think those really high impact things like breathlessness are a better use of the multidisciplinary teams who can really subspecialise. (*GP 3)

GPs also perceived there to be a trade-off between the relative benefits and disadvantages of a private versus public provider which they described in terms of shorter wait time from referral to first home visit versus reduced integration with other services.

> *Service integration is such a problem and it becomes so much of our role… We don't match patients properly to what's out there. But, having said that, this service is so useful and I wouldn't want it to get lost if it was then integrated into a bigger program… Often, I will send off referrals to even very specific things at the hospital, and it takes so long, and you know that you're up for a year wait or more, and patients have forgotten about it, or it's become less appropriate by the time that kicks around. Well, this private service, it enables it to be so responsive, and we get patients on board straight away once I've made the referral, and I think that's been really good.* (GP 2)

Responsiveness to referral was especially welcomed because of the ACT's requirement that patients could only access pulmonary rehabilitation through specialist referral.

> *We found it difficult to get them into pulmonary rehab so, by doing this, we'll bypass all this bureaucratic work.* (GP 1)

GPs welcomed integration of the online referral portal with practice software where this could be achieved.

> *All automated, really. There's no issues.* (GP 1)

> *It's fairly straightforward [ABIS referral process]… it's something we already had on our system… I just import the document in [ABIS referral form] and then add those fields into it, and it automatically pulls in for the referrals.* (Practice Nurse 1)

CPD hours were recommended as an incentive for GPs to attend education offered by Southside Physio on screening for breathlessness and referring to ABIS, but this had little effect on referrals when actioned.

> *It sounds like this is an education process and measuring outcomes, and something that the Royal College will acknowledge for CPD points…This is what drives the doctors now, because the whole thing about CPD has meant they [the government] make it more and more difficult for GPs. (*GP 1)

The medical advisory group suggested reimbursement for case conferencing by means of relevant MBS items might promote deeper adoption of a partnership model. However, this was not actioned because a minimum of 3 clinicians are needed and recent media attention to purported MBS 'rorts' [53] were perceived to make GPs wary of using MBS items of this kind (co-design meeting 4).

Referrers shared the opinion that broader-scale adoption of ABIS would take time and be subject to perceptions regarding its effectiveness through feedback either from patients or colleagues.

> *Then I heard how successful it was [from patients who'd completed it] and have therefore kept using it.* (GP 2)

However, a GP who was interviewed in the middle of 2024 when referrals were stretching the ABIS team's capacity highlighted that lengthening wait times might disincentivise further referrals.

> *If something is good, like I found ABIS to be, there's a supply and demand problem that just kick in really quickly, and then it's always overwhelmed and then it's not worth referring … [I would start to think] well I won't bother any more.* (GP 3)

This GP's observation was consistent with pattern of referral in Figure 16 above, which shows a decline in referral numbers after the peak commensurate with the possibility that referrers perceived wait times to be unacceptable.

3.4.3. Adoption by specialists at Canberra's hospitals

Of the 140 patients completing ABIS, 66 (47%) were referred by specialist services at Canberra Hospital (n=65) and North Canberra Hospital (n=1), including 56 (40%) from Respiratory & Sleep Medicine, 6 (4%) from Nephrology and 4 (3%) from Geriatrics. To prioritise referrals from general practice who might receive less support for breathlessness, hospital referrals did not commence until May 2023 and were subject to periodic and intentional reductions in flow by the ABIS team if GP referrals increased. 7 respiratory physicians, 2 nephrologists and 2 geriatricians provided referrals. Of these, 2 respiratory physicians were interviewed. They reported positive feedback from patients returning to their service.

> *The ones [patients] who have come back so far have all been very impressed, both on the professionalism of the service, on the individuals involved, but also on the benefits that they've received. So I haven't, so far, asked anyone who's told me that they didn't find it helpful.* (Respiratory Physician 1)

Both respiratory physicians felt patient safety had been satisfactorily dealt with by the eligibility criteria and requirement for medical review prior to referral.

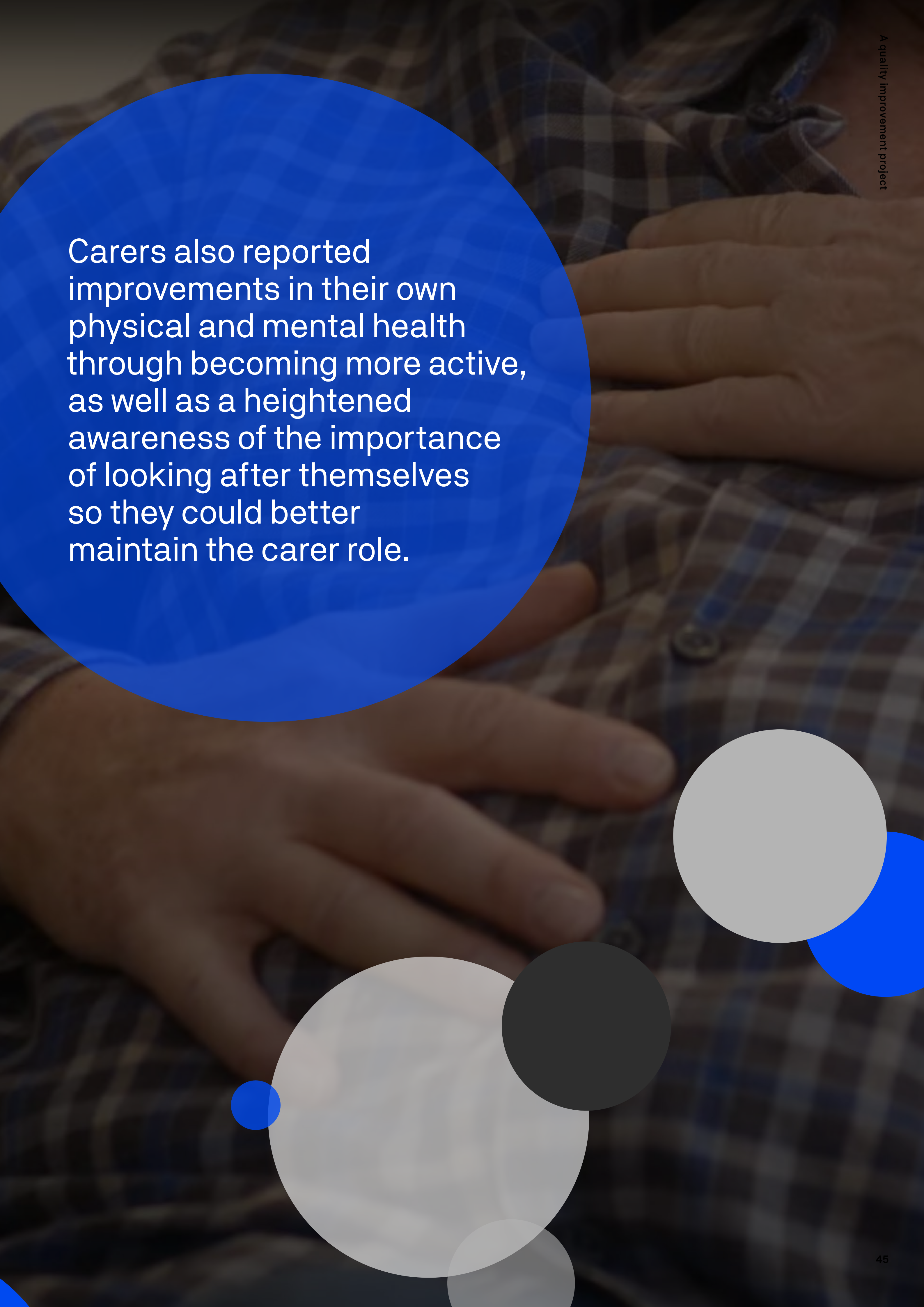
> *I agree medical input is necessary to ensure that anything reversible or anything that can be optimised is optimised medically. But I think that it's fairly low risk to refer the patients for the [behavioural] interventions that is employing even for patients who have some medical comorbidity.* (Respiratory Physician 2)

Despite ABIS' narrow focus on breathlessness, one interviewee perceived assessment to be holistic enough to identify problems and refer on in a way that complemented specialist medical assessment.

> *And some patients have chronic pain, some patients might benefit from other specific therapies too…and sometimes that's not necessarily picked up in the doctor's assessment.* (Respiratory Physician 2)

3.4.4. Summary of findings on adoption

- Despite efforts to drive adoption of ABIS in general practice, both breadth (across practices) and depth (number of GPs within each practice and willingness to partner with patients on self-management) remained limited.
- Referring GPs perceived limited adoption by their colleagues likely reflected competing priorities rather than support for BIS.
- Referrers valued ABIS' ease of referral, short wait time and resource-intensive, holistic support through home visits.
- Insights into barriers to adoption from the ABIS Project were limited by the fact that only more engaged referrers volunteered to be interviewed, despite being offered remuneration for time.



Carers also reported improvements in their own physical and mental health through becoming more active, as well as a heightened awareness of the importance of looking after themselves so they could better maintain the carer role.

3.5. Implementation

3.5.1. Wait times, number of home visits, and program duration

Table 7 and Figure 17 summarise wait times, duration of the program and number of episodes for the 140 patients who completed the ABIS program. The inter-quartile range for program duration fell within the parameters for other BIS published in the literature, which have always been standardised across patients, with a range from 2 to 12 weeks.[13, 15] The small number of patients who received ABIS for longer than 12 weeks did so because of interruption from an acute medical event or personal reasons. Between-patient variation in program duration and number of home visits was driven not only by patient need but also the engagement of a carer to maintain the coaching role (co-design meeting 10). The program's first 2 home visits typically focused on assessment, goal setting and education, with subsequent visits focused on integrating self-management strategies and exercise regimens within daily life, solving problems and referring for additional support when needed.

Table 7. Service delivery characteristics for 140 patients who completed the ABIS program.

Service measure	Median	Interquartile range	Range
Wait time from referral to first home visit	18 days	27 days (10–37 days)	1 – 166 days
Time between first and last home visit	42 days	45 days (22–66 days)	0 – 319 days
Number of home visits per patient	4 visits	2 visits (3 – 5 visits)	1 – 6 visits

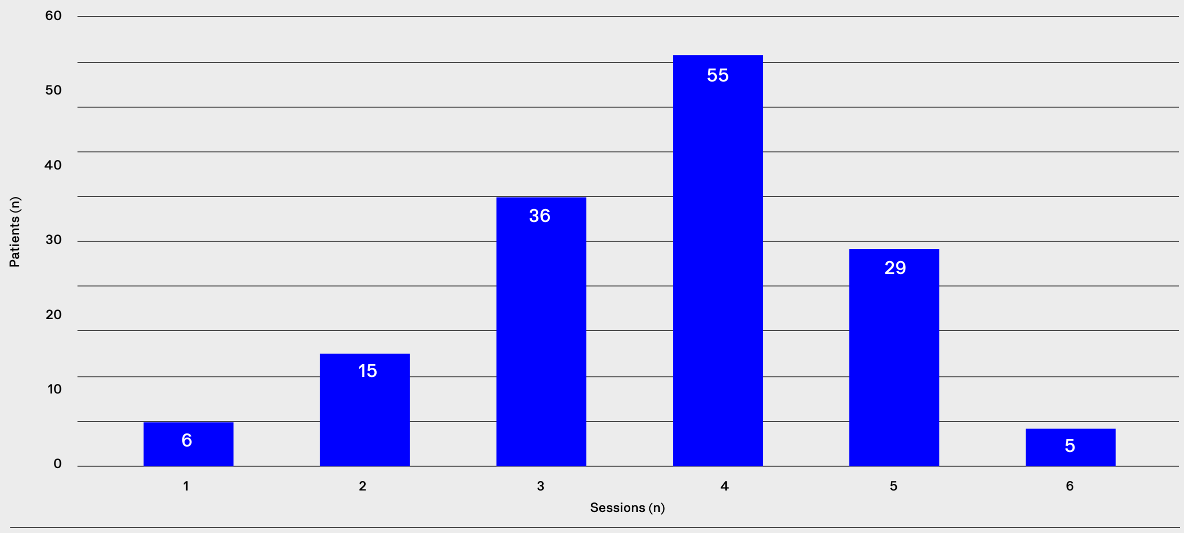


Figure 17. Numbers of patients receiving various numbers of home visits (n=140)

Nearly all patients and carers who were interviewed expressed satisfaction with the number of home visits, regardless of how many they had received.

- Received 2 home visits - *I think for me it was right. Yes. I kept wanting to uphill myself.* (P08_ 50-59 year-old woman with lung disease)
- Received 3 home visits - *we got enough time and opportunity to talk with [clinician] about what was involved. We got the information and we got time to work on it and to internalise it.* (C01_Carer, daughter)
- Received 4 home visits - *By the time we had her last visit, I was fine and felt what she was doing, you know, I had got all the information…she said, "look, this will be the last time I come and see you. I don't think I need to come again." And yes, I agree with that.* (P02_60-69-year-old man with heart disease)

While some patients would have liked more home visits, all except one admitted this was more for social support than improving self-management, and accepted that a free-to-patient service was necessarily time-limited to enable access for other patients.

> *Yeah, that [4 visits] was enough. I mean, I'd like to talk to [clinician] about other things, but as far as the breathlessness was concerned, I felt we had covered the ground.* (P03_80-89-year-old man with heart disease)

> *I was highly motivated, so yeah, I think 4 was probably enough. I would've liked more, but I think four got me on the path that I needed to be on to get better.* (P23_60-69 year-old woman with lung disease)

> *Oh, well, more is better, but 3 [home visits] was good.* (P17_70-79-year-old man with lung disease)

Only one patient expressed a view that his self-management would have improved with further home visits, and even here the clinician perceived that loneliness was a motivating factor.

> *I would have liked probably 2 more, I think … It would be good if the visits could be a little longer and some of the exercises could be explored, maybe one or 2 explored physically each time. But I thought generally it was an excellent way of introducing people to the whole concept of helping to manage breathlessness.* (P16_70-79-year-old man with lung disease)

In contrast to research on the Westmead BIS which offers a standardised 8-week program following initial assessment,[23] no patients felt they had received more home visits than were needed.

3.5.2. Fidelity – was the intervention implemented as intended?

As noted elsewhere in this report, efforts to ensure ABIS was delivered in accordance with evidence-based practice for BIS included: clinician training and resources from the multi-disciplinary Westmead BIS team and monthly clinical troubleshooting meetings with the team's respiratory CNC; standardised scripts for administering clinical/outcome measures; and 3-monthly co-design meetings in which cases, outcome data and interview data were interpreted to inform continuous improvement. Focal discussions included consistency in outcomes data across patients seen by each of the 2 ABIS clinicians, with the only differences identified being that: a) clinician A delivered 6 home visits for 4 patients, whereas clinician B delivered a maximum of 5; and b) on average, clinician B's patients reported better outcomes at initial assessment and showed slightly less improvement at subsequent visits (Figure 18 and 19). Potential explanations for these differences put forward by the clinicians themselves included clinician A being allocated more complex patients who required longer follow-up, and patients being more or less likely to appraise their outcomes positively before building the therapeutic relationship. Accounting for ceiling effects, within-clinician patterns in outcomes were otherwise fairly similar over time, consistent with fidelity of implementation.

Figure 18. Comparison of average change in ADL scores on a 'bad day' and 'good day' for patients who had at least 2 home visits between Clinician A (n=66) and Clinician B (n=66)

**Minimally important difference ± 2 points.*

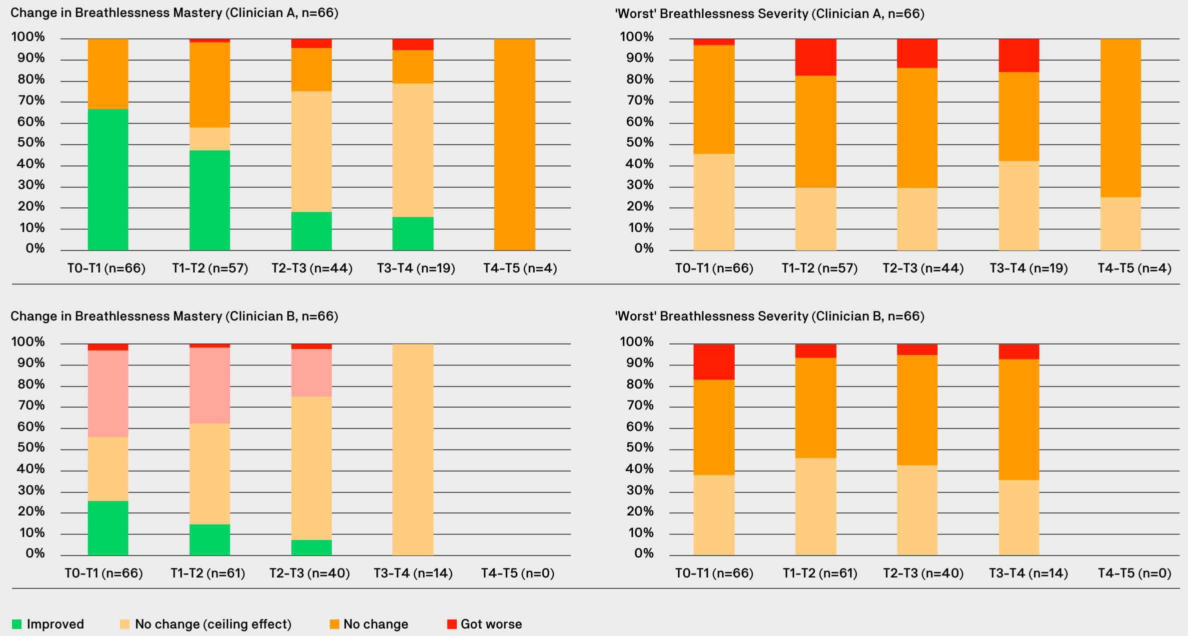


Figure 19. Comparison of change in scores for 'Worst' breathlessness severity and Mastery for patients who had at least two home visits between Clinician A (n=66) and Clinician B (n=66)

**Minimally important difference ± 2 points. A higher score indicates worse breathlessness*
**Minimally important difference for change in breathlessness mastery, ± 0.64 points.*

3.5.3. Cost of implementation

Operational costs for delivering ABIS are provided below, and do not include team members' time spent on co-designing, promoting and evaluating the service.

3.5.3.1. Per patient costs

Direct clinical costs per patient were charged at the National Disability Insurance (NDIS) rate for physiotherapy of $193.99/hour, including travel time (item number 15_055_0128_1_3).[54] Summary statistics for home visit costs in Table 8 are based on 2 hours for initial assessment and one hour per home visit thereafter, giving an overall total of $154,416.04 for 140 patients. The median cost per patient was $1,163.94 for 4 home visits, with the mean cost per patient being $1,102.97 (standard deviation $373.18).

Because 3- and 6-month telephone follow-ups and dietetic referral were introduced later in the project period, costings have not been included in the table. Telephone follow-ups were costed at 30 minutes physiotherapist time per follow-up, which would have amounted to an additional $193.99 per patient and a total of $27,158.60 if all 140 patients had received both. After dietetic referral became available in July 2024, 9/18 (50%) patients received a combined total of 17 episodes of care. If extrapolated pro rata to all 140 patients, an estimated 70 patients might have received 132 episodes, giving a total of $25,606.68 when costed at $193.99/hour. In addition, discharge letters sent to referrers took 30 minutes per patient to write, resulting in a per patient cost of $97.00 and a total for 140 patients of $13,579.30 (although this task could usually be completed during unplanned idle time when patients cancelled home visits [see below]).

All the above items combined results in a total cost of $220,760.62 with a mean per patient cost of $1,576.86.

The only other BIS for which service delivery costs have been published recently is the Munich BIS in Germany, which had a mean per patient cost of 357 euros ($585).[55] The Munich BIS provided multi-disciplinary input, including medical, but only 2 outpatient episodes and 1 home visit.[56]

Table 8. Summary of home visit costs for 140 patients who completed the ABIS program

Number of home visits per patient	Cost per patient	Number of patients	Total cost
1	$387.98	4	$1,551.92
2	$775.96	15	$11,639.40
3	$969.95	35	$33,948.25
4	$1,163.94	53	$61,688.82
5	$1,357.93	29	$39,379.97
6	$1,551.92	4	$6,207.68

Because NDIS rates have not been increased for several years, many of the ACT's private providers now charge more than $193.99/hour, likely leading to an increase in costs were ABIS to be continued privately.

3.5.3.2. Other costs

The above per patient costs do not include indirect costs for clinician idle time when patients cancelled home visits at short notice and time could not be reallocated to Southside Physio's other services, which occurred in about 25% of cases. Across the service period, home visits and telephone follow-ups were cancelled that amounted to a total of 83 hours, including 36 initial assessment visits of 2 hours. The most common reason for cancellations was the patient being too unwell, with 51% of cancellations being for patients who cancelled on more than one occasion. Assuming an hourly rate of $193.99 that had to be charged to the ABIS Project for 25% of these visits, costs from idle time are estimated to have amounted to $ $4,018.26. Cancellations may be an unavoidable consequence of reaching patients who are in poor health and therefore likely to benefit most from BIS. However, some private providers may be less able than Southside Physio to reallocate clinician idle time from BIS to other services.

Equipment costs were $2,201.77 (GST exclusive), primarily in relation to hand-held fans, pedometers, and shower chairs.

3.5.4. Patients' willingness to pay

Interviews with patients, carers and GPs explored perspectives regarding patients' likely willingness to pay for ABIS were it to be offered as a private service. Interviewees from all groups reluctantly accepted that maintaining ABIS over a longer period might necessitate out-of-pocket fees but felt strongly that these should be means-tested to ensure ongoing access for people unable to pay.

> *And if a person can afford to, I suppose, I think that's okay, but I don't think that they should ask patients to contribute if, well – basically, depending on their financial circumstances.* (C02_Carer, son)

> *I've got patients of quite low income, pensioners, etc. That was a real selling point for them to try out something new, but if it was a relatively low cost, I think I could convince people, if the fees could be minimised in some way. But if it was just run privately… I think it would be out of reach at their private costs for a lot of patients who have gained such benefit from it.* (GP 2)

Patients in particular emphasised that capacity to pay should be considered within the context of other healthcare expenditures, which were substantial for some people.

> *I mean, no, I wouldn't mind paying for it because it is a reasonable sort of service. But having said that, I think the burden that I bear of paying for healthcare services for my condition, I think is above and beyond what's reasonable… I suppose one of my big bug bears is the cost of being someone who has a chronic illness…the normal person in the street would not be spending 3 or $4,000 a year on their medical costs.* (P08_50-59 year-old with lung disease)

One patient also pointed out her willingness to pay was a retrospective judgement based on having experienced benefits from the service and therefore known it to be a good investment.

> *Having experienced it and it has helped, I guess I'm in a position where I can pass that information on to my exercise physiologists and continue on with it, that makes it valuable to me. But I don't know how you get that across to people without, maybe the first session is free or something, or I don't know, an introduction to it.* (P11_woman with heart disease)

Another patient felt that reducing costs by offering the service in a setting other than the home would be false economy from a cost-effectiveness perspective.

> *If it was Medicare rebated, it would be great. But again, if I had to pay physio fees for 4 sessions, I could manage that. But I don't know whether I could manage the fee for 4 home visits. And I feel as though that is one-on-one, home visits are excellent.* (P10_770-79 year-old woman with lung disease)

This finding is consistent with another study that found home-delivery and person-centredness were service characteristics that patients and carers were most willing to pay for, although they were more accepting of outpatient delivery as an alternative.[57]

3.5.5. Acute healthcare utilisation

3.5.5.1. Reduced reliance on the emergency ambulance service

Research on other BIS has found reductions in acute healthcare utilisation, although the degree to which this has been achieved, costs of service delivery and methods used to estimate savings have meant that incremental cost effectiveness ratios ranged dramatically from £-56,242 to £266,333 ($-111,330 to $527,204) per quality-adjusted life year (QALY).[15]

In the ABIS Project, measures only enabled estimation of changes in emergency service use. 29/136 (21%) patients who received at least 2 ABIS home visits reported thinking about calling an ambulance for breathlessness but self-managing instead using the strategies they had learned on 46 occasions (Figure 20). Only one patient reported calling an ambulance that did not require transfer to ED/hospital, while another patient reported being transferred to hospital for an acute medical event which suggests the callout was unavoidable.

Savings on ambulance callouts from the 46 occasions amounted to at least $35,282, based on $767 for the ACT's emergency ambulance service treatment not including transport.[58] This is a conservative estimate because paramedics generally err on the side of caution and transfer to hospital for observation (personal communication with ACT Ambulance Service [ACTAS] and medical record of UK ED admissions).[6]

ACTAS costs escalate to $1,107 per callout if a patient requires transport. According to the National Hospital Cost Data Collection for the 2021-22 period, the average cost per ED presentation in the ACT was just over $1,000.[59] These costs would have been borne by the health system rather than been out-of-pocket for the majority of patients, given that aged pension card holders of 67 years of age or older are entitled to free ambulance services, and ED services are free to everyone. However, one younger patient reported she had saved out-of-pocket ambulance costs as a result of ABIS.

> *For some people, it might help them avoid going to hospital... those ambulance costs, I know I've had enough of those in my time as well.* (P08_50-59 year-old woman under 67 years with lung disease)

In co-design meetings 12 and 13, a patient was discussed who had become socially isolated and reclusive due to breathlessness and had reported calling the ambulance approximately 50 times over the previous year but had not done so again since receiving support from ABIS. The clinician involved attributed this not only to the patient having built confidence and learned strategies to self-manage breathlessness episodes, but also to his developing a trusting partnership with his GP facilitated by the ABIS team. The patient had also become a member of the local Lung Life Support Group and had extended his ADLs outside the house.

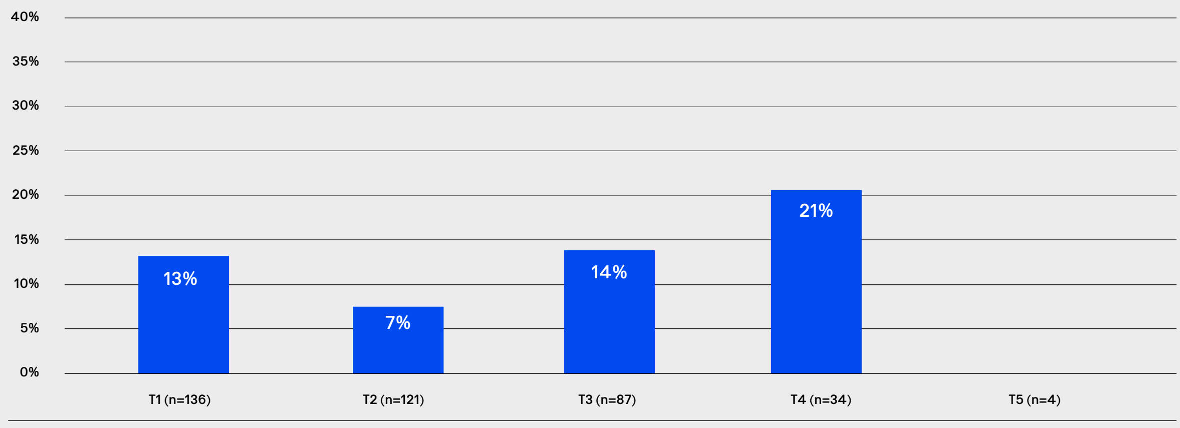


Figure 20. Number/% of patients who had at least one home visit and answered "yes" to the question "was there any time since your last session with Southside Physio that you thought about calling an ambulance for breathlessness but instead managed to control it using the strategies you've learned through ABIS?"

3.5.5.2. Use of other healthcare services

Numbers of patients indicating different kinds of healthcare utilisation at any timepoint since initial assessment included: ED visits (n=6/136, 4%), hospital admissions (n=9/136, 7%), GP visits (n=2/136, 1%), and specialist visits (n=4/136, 3%). Rates of healthcare use were low compared to a South Australian population-based study which found 24% of people with mMRC ≤2 had used the ED over the past 3 months, 97% any outpatient service (ED, specialist or GP) and 24% an inpatient service.[60] As reported in the previous section, the difference between rates in ED use approximate to the 21% of ABIS patients who said they avoided calling an ambulance through using breathlessness strategies learned through the program. Low rates of inpatient services might stem partly from ABIS eligibility criteria, which required patients to be medically assessed as stable. That said, patients who were interviewed perceived that ABIS served an important tertiary prevention purpose by addressing needs that would otherwise escalate and require acute care. As they pointed out, this represented potential cost savings both to them personally and the healthcare system.

> *I mean, the other way, of course is to persuade health services that this is worth the investment because it may be offsetting other costs that people might encounter. For some people, it might help them avoid going to hospital, for example... Yes, those ambulance costs, and I know I've had enough of those in my time as well. And again, that's a cost that I bear as well, not the health service. So, it's just a whole lot of cost shifting that goes around and around and around, really.* (P08_ 50-59 year-old woman with lung disease)

> *What's that worth to a government that's got a very expensive health system built? Is it better to put preventative care? Because that's basically what it is. Not only are you helping people manage a situation like I have, but you're also preventing the inevitable crisis that would've resulted if the program wasn't there ... whatever the program costs, it cannot possibly cost what a cardiologist or a psychiatrist or a week in hospital cost. So, it's in my view, at least for me so far, knock on wood, it's been money well spent by the government. (*P04_60-69-year-old man with heart disease)

> *Well, it's a good preventative program. If you didn't do this with people, then where are they going to end up in the overrun hospital system? So, the government needs to see that there's a big advantage to it.* (P11 _70-79 year-old woman with heart disease)

3.5.6. Adaptations made during service implementation for optimisation

Following the introduction of dietetics in July 2024, 9 patients were referred and received 19 home visits to develop and support individualised nutrition plans.

> *There's also a dietitian. I've had a dietitian visit me on Monday. It comes through this same program. So, we had a pretty good conversation with her as well. And she was quite happy with the way my diet was and she was most interesting as well... she just added a few things, some more protein. But yeah, she was quite happy. A bit more protein to put on weight, but not too much too soon.* (P20_80-89 year-old man with lung disease)

> *It was a little bit to do with the diabetes, but also on the amount of food intake versus the amount of energy I'm using. So yeah, it was predominantly around that.* (P21_70-79 year-old man with lung disease)

Longer-term telephone follow-up phone calls began at the end of March 2024. Of the 140 patients who completed ABIS, 35 (25%) received a 3-month follow-up phone-call, and 40 (29%) received a 6-month follow-up phone-call, with 9 (6%) receiving both. Findings in relation to these are presented under maintenance below.

3.5.7. Summary of findings on Implementation

- The number of ABIS home visits varied between patients according to need from one to 6, with a median of 4 and IQR of 3 to 5.
- Outcomes were similar between the 2 physiotherapists delivering ABIS, consistent with fidelity to BIS approach and content.
- The mean per patient cost of home visits was $1,576.86. Additional costs and wait lists were caused by inefficiencies due to irregular referrals and cancellation of home visits.
- Patients and referring physicians perceived there to have been other cost savings in healthcare utilisation from tertiary prevention but measuring these fell beyond the scope of the Project. Interviewees from all groups thought that patients would be willing to pay for ABIS but felt that costs should be minimised and means-tested to ensure ongoing access for people with lower financial resources.

3.6. Maintenance

3.6.1. Patient level

The ABIS Project was the first BIS evaluation to measure patient outcomes quantitatively at 6 months follow-up.

Figure 21 suggests the majority of patients were able to maintain outcomes since their final home visit, with a small proportion even continuing to make improvements. Delivery by physiotherapists may have resulted in a greater emphasis on the role of physical exercise in building muscle strength and cardiorespiratory fitness with potential to yield increasing benefits over time. In this way, ABIS may have included a greater element of pulmonary rehabilitation than most BIS, an intervention usually focused on people with COPD for which there is substantial evidence of improved exercise and functional capacity 6 months after the program and longer if maintenance therapy is provided, especially in the home-based setting.[61-63] Interviews with patients after 3- and 6-month follow-ups and reports from clinicians at co-design meetings suggested that some patients had continued their exercise regimens as well as maintained breathlessness management strategies.

> *So, I've got to keep up with that as well as trying to maintain the breathing…So, it's a matter of really being strict…that's what [ABIS provider] really focused on because as soon as you get breathless, I would start gasping. It's a matter of changing the whole routine of breathing, which I am getting better at, I think.*
> (P14_80-89 year-old woman with lung disease)

Figure 21. Proportions of patients with improvements, no change or deterioration compared to the minimally important difference (MID) for each outcome from final home visit to 3- and 6-month telephone follow-ups

Patients who were interviewed after their final home visit explained that knowing the clinician would phone them 3 months later motivated them to maintain exercise and breathlessness strategies. This was confirmed by clinicians reports that these follow-up calls were sometimes eagerly awaited (co-design meeting 10). Interviews and clinician reports alike suggested that follow-up by telephone rather than home visit was sufficient for 'booster' purposes.

> *Well, she's booked in to come back in 3 months to see how I'm getting on, so I'm hoping to be a big improvement in 2 months with the things she's got me to do.* (P17_70-79-year-old man with lung disease)

However, a small proportion of patients reported a deterioration in outcomes at longer-term follow-up. Based on clinician report, declining health was likely contributory in some cases. Interviews conducted with patients 6 months after completing the Westmead BIS suggest that mild cognitive impairment is also a common barrier to maintaining self-management, at least among people with COPD.[45]

3.6.2. Ongoing support for people with breathlessness in the ACT level

The ABIS Project generated substantial interest among healthcare providers within the ACT in finding ways to continue supporting people with persistent breathlessness beyond the project timeline.

Initial all-day training on 7th February 2023 was attended by 32 clinicians from Canberra Health Services and Clare Holland House hospice, including 11 occupational therapists, 9 physiotherapists, 7 specialist physicians, 4 nurses and one pastoral care professional. All except one attendee responded to an anonymous feedback survey, with all respondents answering "*excellent*" or "*good*" across learning outcomes relating to various aspects of breathlessness management.

The second 1-hour CPD-accredited webinar on 12th July 2023 was attended by 12 clinicians, including 4 nurses 5 GPs and 3 allied health professionals. All 12 clinicians completed an anonymous feedback survey, and all indicated that learning objectives had been met. Most people highlighted non-pharmacological strategies as the most useful learning content for their practice.

The third workshop, held all day on 27th November 2024, was attended by 32 clinicians including 10 occupational therapists, 8 physiotherapists, 4 nurses, 3 exercise physiologists, 3 social workers, 2 palliative medicine advanced trainees and 2 paramedics from a range of services and settings. 13 attendees from a range of clinical backgrounds who completed an anonymous online feedback survey all indicated that learning outcomes had been "*entirely met*" and answered "*yes*" to the question "*are you likely to take action or change anything in your practice as a result of this workshop?*". When asked what they had found most helpful in increasing their knowledge and confidence for managing breathlessness, most highlighted learning about non-pharmacological strategies. Interestingly, one nurse educator responded with "*knowing that you can't die with breathlessness*", showing that health professionals as well as patients require education in this regard. The panel discussion held at the end of this workshop identified the following ideas for building capacity within the ACT's health sector to provide ongoing support for people with breathlessness after the ABIS Project ended:

- Establishment of a *community of practice* through which interested clinicians might share resources and identify service gaps and opportunities for collaboration.
- Development of a *directory of services* to help people in the community navigate across various health providers offering support for breathlessness.
- Distribution of the hand-held fan by the Community Care team as a routine piece of equipment to enable patients to access this freely.
- Focused education by the Pulmonary Rehabilitation team on managing breathlessness as part of their program.
- Further collaboration with ACTAS on how to incorporate management of breathlessness episodes within their Extended Care Paramedic service, building on a UK model.[64]

At the request of clinicians from Clare Holland House, the Westmead BIS Respiratory CNC made a site visit to the hospice on 28th November 2024 to discuss models that could be used to re-establish the outpatient BIS run between 2019 and 2021 but discontinued due to lack of resources. .

Members of the CHN's Palliative Care Planning Team agreed to coordinate ongoing education and networking opportunities to help the clinicians maintain breathlessness support for community members. The team is now linked in with a number of educational and networking opportunities in NSW and will serve as a conduit for sharing learnings with the ACT.

3.6.3. Summary of findings on Maintenance

- Although limited in sample size, ABIS follow-up data provide the first quantitative evidence that outcomes can be maintained, and in some cases even improved, 6 months after patients complete a BIS program. An expectation that they will be followed up longer-term may serve to motivate patients to maintain exercise regimens and breathlessness self-management strategies.
- The ABIS Project garnered significant interest among the ACT's healthcare providers and created momentum for leveraging current services and building further capacity to provide ongoing support to people living with breathlessness in the community.

> The ABIS Project generated substantial interest among ACT healthcare providers in finding ways to continue supporting people with persistent breathlessness beyond the project timeline.

3.7. Learnings for the provision of ongoing support to people living with breathlessness in the ACT

Combining evidence from the ABIS Project with previous research and an expert consensus process conducted in the UK,[65] learnings are as follows:

- Support for people with persistent breathlessness should be person-centred, ensuring that goals and strategies are tailored to each patient's preferences, needs and daily living so they have the motivation, opportunity and skills [66] to integrate behaviour change into everyday routines. Whilst outpatient BIS have been found effective in some cases,[13-16] at least some component of home-based delivery is optimal to inform understanding of each person's context. Where available and willing, informal carers should be considered integral members of the self-management team, with dyadic coping a key focus for improvement.
- Although the ABIS Project did not enable a formal cost-effectiveness analysis, findings suggest that tailoring the number of home visits to patient need may lead to greater efficiencies and reduce per patient costs compared to standard numbers offered by most BIS to date. Resources can be transferred to patients who need more home visits and to enable telephone 'booster' sessions at 3-monthly intervals following discharge to maintain behavioural change and benefits.
- While controlled, head-to-head comparisons are needed, evidence across BIS to date suggest that approach (self-management framework, coaching, therapeutic alliance) and content (non-pharmacological breathlessness strategies, exercise, diet) may be more important than which disciplines are involved in delivery, except where patients have specific complex needs that require specialist referral. Patient education resources are available that cover the gamut of self-management strategies and have been designed by discipline-specific experts but can be delivered by any healthcare provider.
- Further to the above and considering that as many as 10% of Australian adults may be impacted by breathlessness,[1, 2] capacity should be built to integrate BIS approach and content across health services and settings to maximise access for older adults regardless of whether they receive specialist medical services. The relative strengths of private (responsiveness/flexibility) versus public (integration) providers make partnership models especially strategic. Distributed and networked models offer an alternative to multi-disciplinary BIS for providing patients with support from different disciplines on an ongoing basis to help them maintain self-management, as well as reduce the likelihood of wait lists or, conversely, loss of efficiency due to idle time. Whilst primary care is a key stakeholder, many GPs lack capacity to take a central role in coordinating or providing the majority of support for people living with breathlessness. The ACT's *Digital Health Record* represents a new tool for decentralised integration of support across providers.
- Efforts to build breathlessness-related capacity among public healthcare providers should leverage innovations prompted by the ABIS Project as discussed in the previous section, including a community of practice, directory of services, planned responses by the Community Care and Pulmonary Rehabilitation teams, as well as expertise among ABIS and other clinicians.
- There is an opportunity to build on a UK model [64] by training and resourcing ACTAS Extended Care paramedics to support patient and carer self-management of breathlessness episodes where these do not require transit to hospital for treatment of an acute medical event.

3.8. Strengths and limitations

ABIS was the first reported BIS model to have been co-designed and continuously improved through a partnership between people with lived experience, carers, clinicians and researchers. Co-design partners with lived experience and carers led the design of several novel BIS features, including the selection of patient-prioritised ADLs as the primary outcome, tailoring the number of home visits to each patient's needs, and a particular focus on carer confidence in managing breathlessness episodes. Unfortunately, however, the progressive nature of health conditions causing breathlessness meant that one person with lived experience and one carer had to discontinue their roles on the co-design team part-way through the Project, in the former case because she was approaching the end of life and subsequently died.

While the Project's evaluation yielded useful learnings, limitations in methodology mean that findings should be considered hypothesis-generating rather than conclusive. As is typical of QI projects, the ABIS evaluation did not include a comparison group, relied on assessments administered by clinicians to also serve as outcome measures, and collected minimal personal data from patients and carers to protect privacy and reduce burden (most notably omitting variables relating to mental health and social determinants, which may have been informative).[49] Attempts to ameliorate these limitations included: integrating qualitative with quantitative data to study outcome patterns across home visits, clinicians and patient sub-groups; standardising administration of assessments; and not reminding patients/carers of their previous ratings until after repeated measures. However, further controlled and blinded comparisons are needed that replicate the Project's findings, especially given that ABIS' efficacy exceeded results from previous randomised trials of BIS, despite being delivered by only a single discipline rather than the predominant multi-disciplinary approach.

As noted above, a further limitation concerns the lack of interviews with patients, carers and physicians who did not engage with ABIS to better understand their reasons for not doing so. Even among people who did engage with ABIS, the proportions in each group who volunteered for interview were small, especially among carers (4/123, 3%). Interviews were conducted by researchers at UTS who were not involved in delivering the service, but participants were recruited by ABIS clinicians, potentially biasing the sample towards those more favourably disposed. Attempts to mitigate limitations in interview data included: information sheets and topic guides explicitly inviting critical appraisal of the service and communicating that data would be de-identified and care would not be influenced by negative feedback; and inclusion of co-design meeting minutes in the dataset to provide additional insights into barriers, facilitators and contexts.

Generalisability from the Project's findings is limited by the ACT's unique context and delivery of ABIS by only 2 physiotherapists. Canberra's design as Australia's capital has resulted in an unusual combination of population size, demographic profile and ease of transit that offers special opportunity for home-based services focused on patient education. While outcomes were largely consistent between the t2wo clinicians, they worked in close collaboration, and no attention control was used to distinguish impacts from the program's content versus the personal and professional attributes clinicians brought to therapy that may be difficult to protocolise.

3.9. Summary

The ABIS Project was the first to co-design a home-based BIS that was delivered by physiotherapists and varied the number of visits according to patient need, using patient-selected ADLs as its primary outcome. Integration of quantitative and qualitative findings deepened understanding of BIS characteristics supporting benefit. The Project also documented systemic challenges with relying on general practice to play a central role in referring and partnering with breathless patients for self-management. Interpretation of findings are limited by methodological shortcomings and the ACT's unique context. Controlled and blinded trials are needed to further test findings of interest that have implications for designing the most cost-effective BIS models, especially head-to-head comparisons of single versus multi-disciplinary delivery.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4. References

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5. Appendices

5.1. Appendix A: Co-design key decisions and rationales

Key decisions	Rationales
Development Phase (co-design meetings 1 to 6, November 2022 to March 2023)	
Terminology	
ABIS users will be called ‘patients’ and ‘carers’	Compared with terms such as ‘service user’ and ‘client’, co-designers decided that ‘patient’ and ‘carer’ create a necessary distinction between people who will be serviced by ABIS but have different needs.
Patient eligibility criteria	
Agreed inclusion criteria	
Must be adult (age ≥18 years)	The BIS model has been designed for adults and has not been tested in the paediatric setting where asthma is the most common cause of breathlessness.
Can live anywhere in ACT	Travel times throughout ACT are fast enough to make home visits feasible to any part of the Territory. Conversely, funding by CHN means ABIS cannot be offered to people living in NSW, even though travel times to some parts of the state are feasible and NSW patients are sometimes seen by Canberra Health Services.
Screen positive for reduced ADLs from breathlessness that causes bother	Lived experience and carer co-design partners and published evidence agree that reduced ADLs is the most important impact from breathlessness for people living with it and their families.[1] Reduction in ADLs from breathlessness seriously impacts quality of life by impairing role functioning and reducing people’s sense of self-worth, even self-identity. BIS evaluations suggest that non-pharmacological strategies taught through ABIS can help people with advanced chronic disease reduce the impact of breathlessness on ADLs to a more reliable extent than reducing breathlessness severity itself, given that persistent breathlessness, by definition, cannot be cured. Co-design partners considered distress / bother important to include in this criterion because some people with advanced disease may have accepted reduced ADLs as a coping strategy to the extent that they will be less motivated to implement non-pharmacological strategies taught through ABIS. Screening for this criterion was decided to follow a two-step process, including: • a modified Medical Research Council (mMRC) Scale Grade 2 (“*on level ground, I walk slower than people of the same age because of breathlessness, or I have to stop for breath when walking at my own pace on the level*”) or more severe impairment; • the open question, “*what has breathlessness made you less able to do in everyday life that bothers you?*”. This question was considered preferable to one asking about severity of breathlessness because many people avoid activities that might make them breathless so might rate severity as being mild. Co-design partners identified a need to accompany this question with an infographic providing examples of ADLs to give both referrers and patients an idea of the parameters of ADLs that might benefit from ABIS. This was considered sufficient and easier to communicate than referring to taxonomies of basic, advanced and instrumental ADLs.[2] An open question was considered preferable to standardised assessments of ADLs because: such assessments either summarise only a small number of ADLs or are too lengthy to administer in a medical consultation; such assessments rarely ask about bother; a conversational approach will both provide referrers with greater insights into patient priorities and build the therapeutic relationship. The above approaches to screening are used successfully by Westmead BIS, as described by co-design partner and respiratory clinical nurse consultant, Mary Roberts.

Key decisions	Rationales
Wants to receive the service once potential benefits have been summarised by the referrer	The criterion includes a reminder for referrers to explain potential benefits of ABIS to enable patients to self-appraise whether the service is a good fit for them and heighten motivation to engage where they deem it is. Co-design partners considered it important to make this criterion explicit because some referrers may mistakenly assume that all patients will want a free service that is recommended by their doctor. Also, limited funding for ABIS makes it important that the service focuses on people who are motivated to engage with education and implement the strategies they learn.
No criteria regarding medical diagnoses	Eligibility criteria should be focused on impacts of breathlessness and potential to benefit rather than disease-focused. Evidence from BIS evaluations suggest people with a range of conditions can benefit.
Agreed exclusion criteria	
Breathlessness has persisted for less than 8 weeks	International breathlessness expert Prof Miriam Johnson, who led a consensus definition for chronic breathlessness as a syndrome,[3] advised that a new version of the International Classification of Diseases (ICD version 11) would specify 8 weeks as the period defining chronicity.[4]
Breathlessness is caused by an acute medical event (e.g. infection). Rescreen 3 months after resolution	Breathlessness from acute causes is usually reversible and would benefit from medical intervention rather than non-pharmacological strategies, including hospitalisation where appropriate. This exclusion criterion was preferred over an inclusion criterion that underlying disease should be optimally medically managed (which features in the consensus definition of chronic breathlessness mentioned above). ABIS is a complementary layer of care, not a replacement for medical care. Non-specialist referrers may lack confidence that disease is optimally managed, creating a barrier to referral. Advice from the ABIS medical advisory group and Prof Johnson suggested that safety concerns could be satisfactorily addressed by means of exclusion criteria. Including the potential to rescreen 3 months later reduces the risk that someone with breathlessness from chronic illness that is worsened by an acute event might miss the opportunity to receive ABIS.
Breathlessness is caused by long COVID	Long COVID is a complex syndrome that requires management of breathlessness in concert with other symptoms and targeted treatment of underlying pathophysiology.[5] People identified with long COVID should be referred to the Post-COVID Recovery Clinic. However, people with breathlessness caused by chronic illness worsened by COVID-19 should remain eligible for ABIS due to likely benefit.
Breathlessness has no established cause	A lack of established cause requires further investigation by GPs and specialists to rule out reversible pathophysiology. People with no discernible pathophysiology who may be experiencing breathlessness as a component of the respiratory subtype of panic disorder are likely to benefit from psychiatric treatments that ABIS cannot provide.[6]
Cognitive impairment or limited English that will impede patient education, with no support from carer or interpreter	The effectiveness of BIS relies on patients being able to implement strategies they learn through education within a self-management paradigm. Given how common mild cognitive impairment is in people with breathlessness-causing chronic illnesses such as COPD and heart failure,[7] it is important that ABIS uses strategies to ensure patient education is accessible and sustained, including attention to reading-level, visual learning supports and memory prompts. However, people with more significant cognitive impairment or limited English proficiency in the absence of a carer or interpreter are less likely to benefit without supports that lie beyond the scope of ABIS.

Key decisions	Rationales
Rapidly deteriorating / clinically unstable	This criterion provides an additional safeguard against reversible causes of breathlessness and flags the need to consider more complex underlying problems that might benefit from comprehensive assessment and management rather than targeting one symptom in isolation. "*Rapidly deteriorating / clinically unstable*" were selected as preferred terms based on advice from the medical advisory group that different medical practitioners may tend to use one more than the other, and that both offer an advantageous degree of flexibility regarding interpretation that encompass the necessary safeguards.
Referral pathway	
A time-limited trial of GP-only referral, broadening to include referrals from specialists if GP referrals are insufficient	In addition to ABIS being CHN funded and therefore especially interested in involving GPs, the rationale for focusing on GP referral included: • GPs see people with a wider variety of chronic diseases that might cause breathlessness than specialists; • GPs have an holistic understanding of the broader health and social context in which breathlessness occurs for each patient; • GPs are best-placed to form an ongoing partnership with patients to support self-management after patients have completed the ABIS program; • GPs are coordinators for and 'gateways' to other health services as required; • Patients who receive specialist services (especially respiratory medicine or palliative care) are more likely to have already received at least some support for breathlessness; • No BIS model to date internationally has focused only on GP referral; the ABIS Project represents an opportunity to add to the knowledge base. The decision to trial GP-only referral in a time limited way acknowledged the number of eligible patients seen by each practice may be relatively low compared to some specialist services, and breathlessness may not be prioritised among the range of health problems GPs are expected to manage. To counter these challenges, the team decided to focus on a small number of practices identified through the Pen CS Clinical Audit Tool data as seeing large numbers and/or proportions of patients with illnesses commonly causing breathlessness, as well as those with existing relationships with Southside Physio.
Advertise ABIS direct to patients by means of flyers, posters in general practice waiting rooms	Advertising ABIS in general practice waiting rooms might give patients permission to bring up breathlessness with their GPs in the context of research suggesting that breathlessness may often go unrecognised by GPs.[8-10] Exertional breathlessness caused by travel will often have resolved while patients wait, reducing the likelihood that GPs will identify it, and/or other matters may take priority in the consultation.

Key decisions	Rationales
Model of care	
Limit the number of disciplines involved in delivering ABIS	Physiotherapy and registered nursing clinicians are sufficient to deliver ABIS on the basis of: constraints in the disciplines available; a lack of evidence from previous BIS trials that more disciplines leads to better outcomes;[14] availability of a wide range of educational resources designed by clinicians from relevant disciplines that can be delivered in a transdisciplinary way. Interviews with patients on completion of the Westmead BIS program found they varied in their understanding of disciplinary roles but welcomed reinforcement by multiple team members, especially a physician. It was agreed to encourage referring physicians to provide reinforcement. See below for changes made to disciplinary involvement during the service period.
Each patient will be assigned to a single member of ABIS personnel	Assignment to a single personnel member enables deepened understanding of patients' breathlessness within health and psychosocial contexts, building of therapeutic relationships and improved continuity of care.
The initial visit will be in the patient's home but follow-ups will be either at home or via telephone according to patient preference	An initial home visit ensures comprehensive and individualised assessment of each patient's needs within the context of their everyday lives. However, some patients may like the option of telephone rather than home visit to avoid exposing themselves to risk of infection and remove the burden of feeling they have to get dressed and tidy the house. At the same time, co-design partners were wary of telephone follow-up being used as a default, cheaper alternative that did not afford the same level of communication and person-centredness.
Follow-ups will vary in number according to need	Different patients may require more or fewer follow-ups depending on their needs for consolidating learning about non-pharmacological strategies (e.g. in the context of mild cognitive impairment) and coaching aimed at building therapeutic relationships and motivation. Limited research is available on the optimal number of follow-ups, but one study suggests a median of four may be sufficient to improve mastery of breathlessness.[12]
A variety of patient educational resources will be pooled and provided in a tailored manner to align with each patient/carer's needs and preferences	A number of patient/carer resources were collated by the UTS team for co-designers to determine which they thought were most useful. After discussion, it was agreed upon that a comprehensive guide on self-managing breathlessness (the Breath Easier Booklet provided by North Western Melbourne Primary Health Network) may be useful for most patients. Clinicians will work with each patient to determine which resources best align with their individual needs and whether these are provided electronically or in hard-copy. Having the hard-copy option was highlighted as important, given some older people may have limited access to computers or digital literacy.
Clinical assessments / outcome measures	
Measures should serve a double purpose for clinical assessment and outcome evaluation	Selection of assessments should be driven by how meaningful they are to patients and carers and informative to care, reducing the likelihood that measures will be perceived as burdensome by participants. While using routine assessments for evaluation reduces the rigour of evaluation, the approach is typical of quality improvement (QI).

Key decisions	Rationales
Patient perspective	
Measure self-appraised independence in activities of daily living (ADLs) identified to be important to each individual	Lived experience and carer partners emphasised the value of independence in ADLs for maintaining normalcy, self-identity and self-worth. Different people attach value to different activities; ADLs considered trivial by one person (e.g. making a bed) might be highly meaningful for another. The Patient-Specific Functional Scale (PSFS) was chosen as ABIS's primary clinical assessment and outcome measure because it enables patients to choose up to three ADLs they consider important and would like to improve independence in.[13] The PSFS uses a numerical rating scale (NRS) from 0 to 10, with 0 being "*unable to perform activity*" and 10 being "a*ble to perform activity at the same level as before injury or problem*". The upper limit is indicative of its original design for lower back pain and may be unattainable for people with severe persistent breathlessness. However, lived experience and carer co-design partners felt this anchor remained a useful benchmark for appraising progress against and did not believe it would cause distress. Published guidance on minimally important differences (MIDs) were followed as being 2 points for the mean score across 3 ADLs and 3 points for each individual ADL given that the reliability of patient-reported outcome scores typically increases with number or items. Measuring ADLs separately for 'good days' and 'bad days' was considered necessary because health status commonly fluctuates for people with health conditions causing breathlessness.
Measure the degree to which people feel in control of breathlessness and its inverse relationship with distress	Co-design partners with lived experience spoke about feeling robbed of 'who they are' by breathlessness, it taking over every aspect of their lives. Evidence from research was discussed showing a lack of control is especially associated with acute-on-chronic breathlessness 'episodes' that can manifest as: a) anticipatory fear leading to a vicious cycle of activity avoidance and deconditioning; and b) panic leading to Emergency presentations that are not medically indicated.[14] The measure identified to best capture both control and distress elements is the 'mastery' scale of the Chronic Respiratory Questionnaire.[15] This measure consists of only 4 questions, has been validated and had MIDs identified,[15] and has been found responsive to BIS in at least one randomised controlled trial (RCT).[16] Questions about fear/panic and confidence were considered especially informative to individual care, as well as being useful for evaluation across patients.
Measure 'worst' breathlessness severity	There was agreement that breathlessness severity should be measured to provide context for other measures rather than as an outcome in its own right because a substantial improvement might not be expected in most people given its 'persistent' nature and, indeed, breathlessness might worsen when people are encouraged to increase their ADLs rather than avoid exertion for fear of becoming breathless. It was also agreed that 'worst' breathlessness might be more important than "*best*" or "*average*", given it is more distressing and impedes ADLs, and is therefore the focus for coping strategies. It was therefore agreed to include a single question adapted from those commonly used in previous studies asking: "*How severe has your breathlessness been at its worst over the last 2 weeks/since your last session with Southside Physio?,*" using a numerical rating scale from 0 to 10, where 0 means "*the best you can imagine*", and 10 means "*the worst you can imagine*". A MID of ≥1 has sometimes been used for between-group comparisons in trials, but ≥2 points was considered to instil greater confidence for interpreting change scores in individual patients, which tend to have lower reliability.

Key decisions	Rationales
Carer perspective	
Measure carer confidence in supporting management of breathlessness episodes	It was agreed that one question should be asked to a family member or friend who; 1) the patient identifies as giving substantial support to help with their breathlessness; and 2) is involved in education during ABIS sessions. Self-identification with the term 'carer' was not required following agreement that many people consider provision of support to be integral to their familial role. Carers on the co-design team highlighted the special importance of feeling confident to provide support during an acute episode of breathlessness given how frightening and disempowering these can be. Given no relevant validated assessments could be found in the literature, agreement was made to generate a new item: "*During the last 2 weeks/since the last session with Southside Physio, how would you rate your confidence in supporting (patient name) when his/her breathlessness gets suddenly worse?*" Response options agreed upon included "*very confident*", "*somewhat confident*" or "*not confident*". In the absence of published evidence for a MID, it was agreed that a change of one would be considered important.
Health system perspective	
Measure healthcare use	The potential for ABIS to reduce the need for acute care services is important from a cost-effectiveness perspective. This had not been demonstrated by research on other BIS up to the time measures were chosen in early 2023, but more research has been conducted since.[17] Given the challenges in accessing hospital or MBS data, it was agreed that measurement should rely on patient self-report. While the experience at Westmead BIS has been that patient self-report can be unreliable, it was agreed that this might be less of a problem if monitoring within-patient rather than between-patient changes over time, and that recall bias could be minimised by asking patients about healthcare use at every ABIS follow-up. It was also agreed that self-reported use of healthcare would be valuable for prompting discussion about what led to such use that might inform care and further support. Given evidence that breathlessness episodes can often precipitate unhelpful ED presentations which represent low cost-effectiveness for the health system and inconvenience to patients,[18] patients were asked: "*Was there any time since your last session with Southside Physio that you thought about calling an ambulance for breathlessness but instead managed to control it using the strategies you've learned through ABIS?*" with a "*Yes*"/"*No*" option provided. It was agreed upon that at each consultation, patients would also be asked "*During the last 2 weeks/since your last session with Southside Physio, what if any healthcare have you needed to help with your breathlessness?*" Co-designers agreed to include tick-box options patients allowing more than one option, including: '*None*', '*Emergency Department*', '*Hospital Admission*', '*Corticosteroids*', '*GP visit*', '*Specialist visit*', or '*Other*'. Corticosteroids were included as the only pharmacological intervention because they are commonly used to treat lung conditions that worsen breathlessness.

Key decisions	Rationales
SERVICE DELIVERY AND CONTINUOUS IMPROVEMENT - PDSA Cycle 1: March – May 2023	
Optimising the referral pathway	
Offer an online education session to promote ABIS to primary care	Intensive engagement has been provided to three general practices to elicit referrals to ABIS. Only two have been referring, and at a slow rate. A 1-hour video-conference workshop was scheduled for the evening of 12th July 2023 as a way of reaching GPs interested in improving breathlessness management who might also refer to ABIS. As well as non-pharmacological management, the workshop included content on inhalers for respiratory conditions, which had been highlighted as an educational need to CHN.
Accept referrals from respiratory specialists	To increase potential to attain SMART goal 1 (100 patients completing ABIS within the first year) and reduce likelihood of losing funds to idle time from fluctuating number of referrals from general practice, ABIS opened to referrals from respiratory specialists at Canberra's hospitals. The decision was made to not to extend referrals to specialist palliative care because their greater focus on symptom management means that patients are more likely to already be receiving support for breathlessness and therefore need ABIS less.
Advertise ABIS direct to the community to elicit consumer-driven referrals	Inviting people in the community to approach their GP for a referral is consumer-driven, provides an opportunity to reach people in need whose general practice is not already referring, and also to reach new general practices that might refer other patients once they hear about ABIS. An information session was provided to the ACT's Lung Life Support Group, which has 51 members, many of whom are likely to be eligible for ABIS, as well as via its newsletter. Public notices and stalls (e.g. World COPD Day) offer other means of direct-to-consumer promotion.
Allow indirect referrals from specialist palliative care via patients' GP	A specialist palliative care nurse from Canberra Hospital who had attended the education session on July 12th approached Southside Physio to ask if referrals can be accepted from specialist palliative care. While the team were hesitant to open referrals to palliative care for reasons stated above, allowing indirect referral via a GP was considered to increase integration of care and offer another way of engaging new general practices.
Optimising eligibility criteria	
Retain mMRC ≥2 eligibility criterion but provide one education session and a follow-up phone call to motivated people with mMRC 1	Three patients referred were found ineligible based mMRC 1. Two indicated few problems from breathlessness but the third was keen to learn strategies. Upskilling people in self-management before their breathlessness becomes more severe may have a preventative effect. Lived experience and carer partners identified that breaking 'bad' habits later is challenging. However, it is often difficult for people to anticipate how bad their breathlessness will become in the future and therefore to be motivated to engage fully enough with ABIS to warrant the full program at an opportunity cost to someone with mMRC ≥2.
Keep mMRC criteria the same for both GP and specialist respiratory referrals	To increase ABIS' reach to people with greater need, consideration was given to raising the mMRC threshold to ≥3 for specialist respiratory patients. However, a review of referral data identified a majority of patients from general practice with mMRC ≥3, reducing the incentive to change.

Key decisions	Rationales
SERVICE DELIVERY AND CONTINUOUS IMPROVEMENT - PDSA Cycle 2: June to August 2023	
Optimising the referral pathway	
Vary intensiveness of liaison across general practices	CHN and Southside Physio have spent considerable time and effort in developing positive relationships and ongoing communication with referring general practices, but referral rates continue to fluctuate and be limited to a small number of GPs at each practice. An interview conducted by UTS with the practice manager and nurse from one practice found they considered liaison to be overly intensive given competing priorities beyond ABIS. There was agreement that additional prompts to some general practices to continue referring to ABIS might be counter-productive and liaison should be modified based on feedback from each practice.
Discharge letters will be sent to referring physician (and GP where referred by another physician)	Discharge letters prompt referring physicians to provide follow-up support for breathlessness and provide an opportunity to educate them about non-pharmacological strategies they can use with other patients. Including GPs on discharge letters will improve integration between specialist and primary care services. Letters to GPs were agreed to also invite future referrals from them for other patients.
Continuing professional development (CPD) points can be applied for by referring GPs	A GP interview conducted by UTS suggested that GPs are increasingly expecting to be incentivised by services like ABIS given this is becoming common for programs such as cancer screening. Offering CPD points will help GPs meet a professional development requirement.
Retain requirement for medical review prior to referral	Members of the Lung Life Group have asked if people can self-refer. However, the decision was reconfirmed that patients should seek referral via their GP to ensure breathlessness is not due to a reversible cause.
GP referrals will continue to be prioritised over specialist	To ensure ABIS reaches patients most in need, specialist referrals should continue to be used as a supplement rather than replacement for referrals from general practice.
Optimising service delivery	
ABIS will be delivered only by physiotherapists	The RN who had been delivering ABIS resigned from Southside Physio for personal reasons. No other RNs were available but a new physiotherapist was joining Southside Physio and could contribute time to ABIS. It was agreed that limiting to physiotherapy-only delivery would not significantly change the service given transdisciplinary collaboration and learnings to date and the availability of patient education resources designed by experts from relevant disciplines.
Evaluation data	
Continue to measure ADLs on ‘good’ and ‘bad’ days despite this distinction not working well in practice	Many patients have been confused by the distinction between ‘good’ and ‘bad’ days, depending on their frame of reference. However, continuing to measure separately is important for consistency when comparing different patients over the service period.

Key decisions	Rationales
SERVICE DELIVERY AND CONTINUOUS IMPROVEMENT - PDSA Cycle 3: September to November 2023	
Optimising referral rates	
Make a promotional video for ABIS that features patient testimonials	With continued fluctuating referral rates from general practice, the co-design team considered patient reports of the benefits they've received from ABIS to be a likely motivator for GPs to refer their own patients. As well as shown at events and made available through the CHN website, the video can be displayed in general practice waiting rooms that have the facility to encourage patients to self-identify with breathlessness during their consultation. This may offer advantages of flyers which experience to date suggests often get lost amongst other promotions.
Optimising service delivery	
Include consideration of summer heat and air pollution in patient/carer education	Extreme heat/smoke events place people with breathlessness at increased risk. ABIS should be proactive about helping patients prepare for summer and only close during the period from Christmas to New Year. Patient education should include reference to air con/fans, watching the weather forecast and pollution levels (e.g. mobile app), air purifiers for pollen, closing windows, and planning/pacing of ADLs. People should be warned about upcoming hazard reduction burns and the need to be careful even if smoke is not visible, due to small particulates.
SERVICE DELIVERY AND CONTINUOUS IMPROVEMENT - PDSA Cycle 4: December 2023 to March 2024	
Optimising referral rates	
Embed the ABIS referral form into GP software	Feedback from two general practitioner interviews highlighted ways to streamline referral with practice systems. Southside Physio can provide support for integrating into practice software.
Optimising service delivery	
Allow re-enrolment for patients whose circumstances have changed	A patient who previously withdrew from the program due to depression has now started antidepressants and expressed an interest in re-enrolling. Re-enrolments should be allowed if a patient's circumstances change in a way that makes them more likely to benefit. Another example might be if a patient now has a carer who can support self-management.
Include longer-term telephone follow-ups 3 and 6 months after the final visit	Interviews with patients with COPD 6 months after completing the Westmead BIS found that many presented signs of mild cognitive impairment and had almost forgotten the program, despite having strongly praised it immediately after finishing,[19] highlighting the importance of continued longer-term follow-up and support to maintain self-management. A GP who was interviewed also recommended longer-term follow-up as a potential service improvement. Discussion highlighted this as being particularly important for those patients who did not have carer support, to see how they were self-managing. Follow-up by means of phone calls with patients at 3 and 6 months also offers the opportunity to readminister measures to assess maintenance.

Key decisions	Rationales
SERVICE DELIVERY AND CONTINUOUS IMPROVEMENT - PDSA Cycle 5: April to June 2024	
Optimising referral rates	
Optimising service delivery	
Expand referrals through HealthPathways and cardiology services	HealthPathways and more specialties at Canberra's hospitals (geriatric medicine and nephrology) present new opportunities to each patients in need, the latter especially because only 14% patients referred to date had heart conditions.
Include the opportunity to refer to a dietician	Many patients receiving ABIS were observed to have progress on ADLs limited by malnourishment or being over or under weight. Some such patients might benefit from personalised dietary plans beyond the scope of more general advice and written information available from physiotherapists delivering ABIS.
Prioritise patients on waitlist	Patients should be prioritised for being seen based on higher mMRC and then time since referral, regardless of whether patient was referred by a GP or specialist.
Evaluation	
Remuneration for GP time spent on participation in interviews	Remunerating GP time spent on interviews at the MBS rate for a short consultation[20] was seen as one way to mitigate the barrier posed by lack of time. A request for amendment to ethical approval was approved on 23rd August 2024.
SERVICE DELIVERY AND CONTINUOUS IMPROVEMENT - PDSA Cycle 6: July to September 2024	
Close referrals to ABIS at the end of September 2024	Closing referrals in September will allow sufficient time for patients to complete the program by the project end date of 31st December, based on a median of 18 days from referral to initial assessment and 42 days from first to last visit. An earlier closing date allows for the likelihood that a few referrals are likely to trickle through afterwards.
Raise awareness among referrers that the ABIS Project is ending	Steps agreed to inform referrers and the community included: • a letter sent by Southside Physio to all physicians who had referred to ABIS; • a notice on the online referral form; • communication with the Health Pathways team; • CHN newsletter
SERVICE DELIVERY AND CONTINUOUS IMPROVEMENT - PDSA Cycle 7: October to December 2024	
Distil key messages in ABIS Project reporting	It was agreed that key learnings from the Project should be emphasised as follows: • the most important service characteristic has been flexibility for meeting patient needs; • quantitative outcome measures only tell part of the story, being limited in their scope and lacking context; • individual cases illustrate service benefits in a deeper way, such as the patient who had previously called the ambulance for breathlessness 50 times over the past year but had not needed to since commencing the ABIS program, or a person who maintained ADLs through the program and then died from his disease 2 weeks after being discharged from ABIS; • the unusual opportunity offered for BIS by the ACT's demography, in particular its residents' high socio-economic status; • the potential for ABIS clinicians to contribute to training clinicians from other services to support people with breathlessness beyond the ABIS Project.

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5.2. Appendix B: ABIS flyer and templates for referral and discharge

Flyer/poster used to advertise ABIS

Experiencing Breathlessness?

ACT Breathlessness Intervention Service

ABIS

- Helps you gain control over breathlessness
- Helps you increase your independence in daily activities
- Run by allied health professionals trained in Breathlessness Management
- FREE!

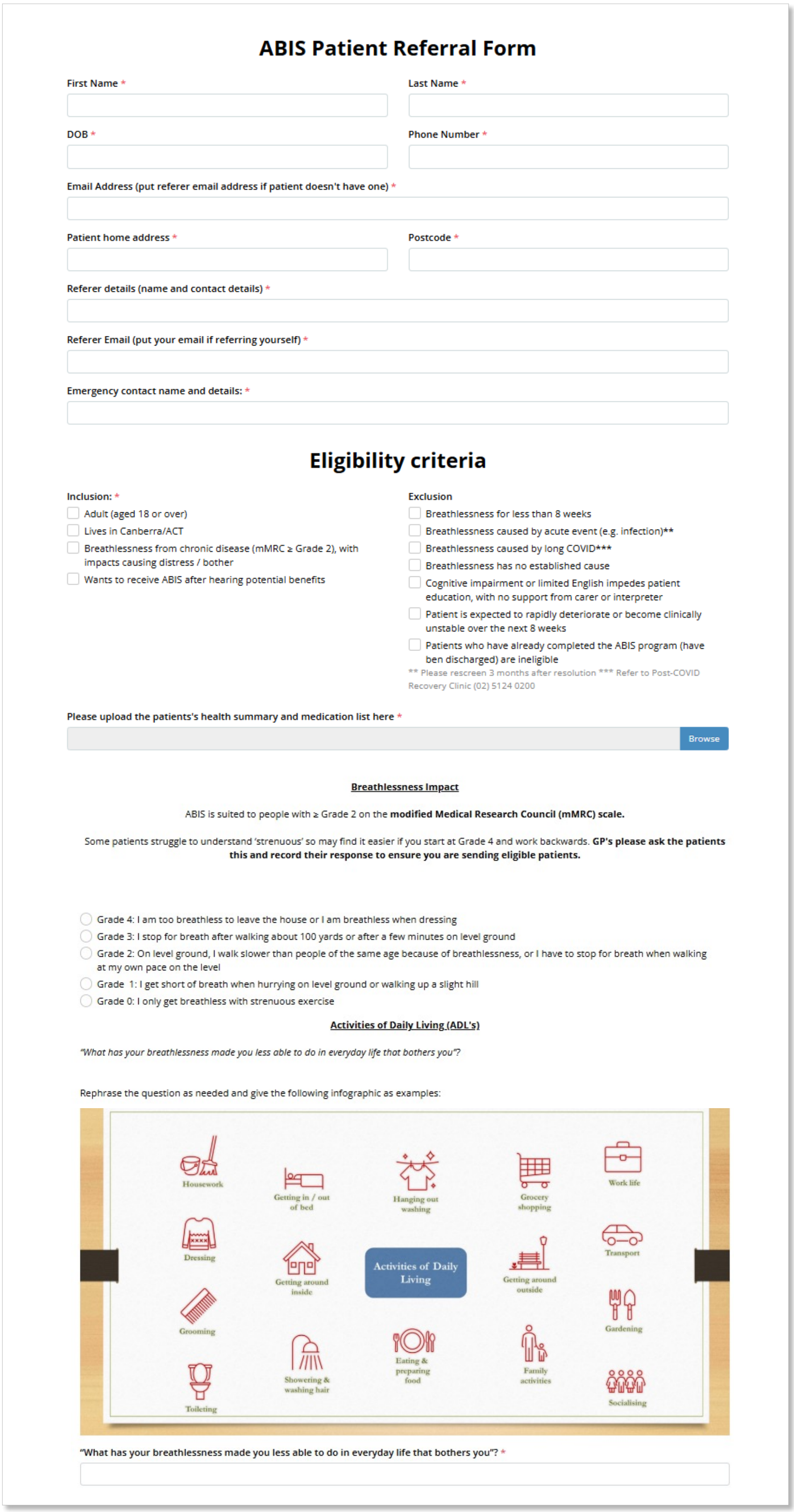
www.southsidephysio.com.au

Southside Physio

phn ACT
An Australian Government Initiative

Capital Health Network
Partnering for better health

ABIS referral form



ABIS Patient Referral Form

First Name *

Last Name *

DOB *

Phone Number *

Email Address (put referer email address if patient doesn't have one) *

Patient home address *

Postcode *

Referer details (name and contact details) *

Referer Email (put your email if referring yourself) *

Emergency contact name and details: *

Eligibility criteria

Inclusion: *

- ☐ Adult (aged 18 or over)
- ☐ Lives in Canberra/ACT
- ☐ Breathlessness from chronic disease (mMRC ≥ Grade 2), with impacts causing distress / bother
- ☐ Wants to receive ABIS after hearing potential benefits

Exclusion

- ☐ Breathlessness for less than 8 weeks
- ☐ Breathlessness caused by acute event (e.g. infection)**
- ☐ Breathlessness caused by long COVID***
- ☐ Breathlessness has no established cause
- ☐ Cognitive impairment or limited English impedes patient education, with no support from carer or interpreter
- ☐ Patient is expected to rapidly deteriorate or become clinically unstable over the next 8 weeks
- ☐ Patients who have already completed the ABIS program (have ben discharged) are ineligible

** Please rescreen 3 months after resolution *** Refer to Post-COVID Recovery Clinic (02) 5124 0200

Please upload the patients's health summary and medication list here *

Breathlessness Impact

ABIS is suited to people with ≥ Grade 2 on the **modified Medical Research Council (mMRC) scale.**

Some patients struggle to understand 'strenuous' so may find it easier if you start at Grade 4 and work backwards. **GP's please ask the patients this and record their response to ensure you are sending eligible patients.**

- ○ Grade 4: I am too breathless to leave the house or I am breathless when dressing
- ○ Grade 3: I stop for breath after walking about 100 yards or after a few minutes on level ground
- ○ Grade 2: On level ground, I walk slower than people of the same age because of breathlessness, or I have to stop for breath when walking at my own pace on the level
- ○ Grade 1: I get short of breath when hurrying on level ground or walking up a slight hill
- ○ Grade 0: I only get breathless with strenuous exercise

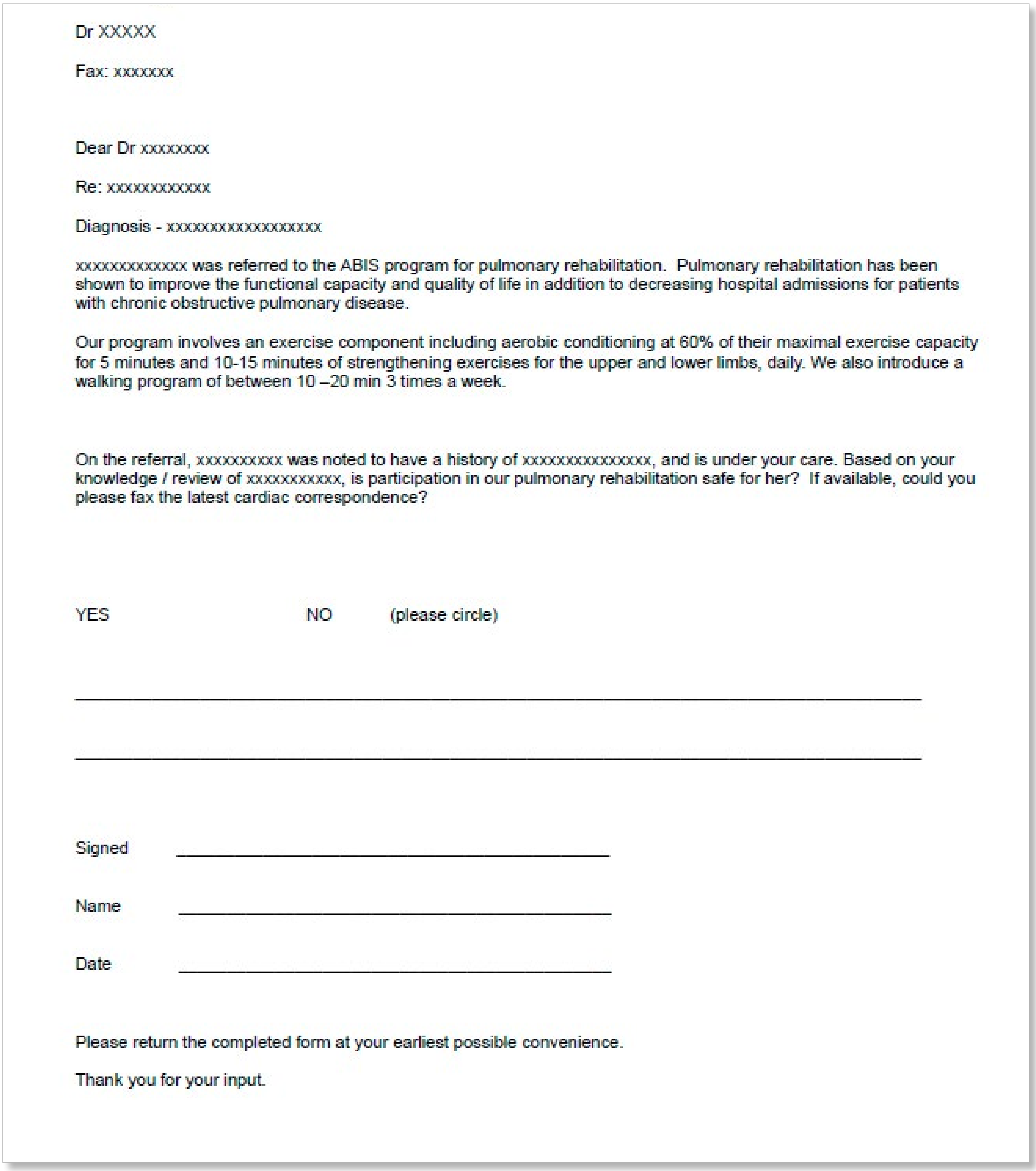
Activities of Daily Living (ADL's)

"What has your breathlessness made you less able to do in everyday life that bothers you"?

Rephrase the question as needed and give the following infographic as examples:

"What has your breathlessness made you less able to do in everyday life that bothers you"? *

Letter of request to referring physician for cardiac clearance



Dr XXXXX

Fax: xxxxxxx

Dear Dr xxxxxxxx

Re: xxxxxxxxxxxx

Diagnosis - xxxxxxxxxxxxxxxxxx

xxxxxxxxxxxxx was referred to the ABIS program for pulmonary rehabilitation. Pulmonary rehabilitation has been shown to improve the functional capacity and quality of life in addition to decreasing hospital admissions for patients with chronic obstructive pulmonary disease.

Our program involves an exercise component including aerobic conditioning at 60% of their maximal exercise capacity for 5 minutes and 10-15 minutes of strengthening exercises for the upper and lower limbs, daily. We also introduce a walking program of between 10 –20 min 3 times a week.

On the referral, xxxxxxxxxx was noted to have a history of xxxxxxxxxxxxxxx, and is under your care. Based on your knowledge / review of xxxxxxxxxxx, is participation in our pulmonary rehabilitation safe for her? If available, could you please fax the latest cardiac correspondence?

YES NO (please circle)

____

____

Signed ________________________________

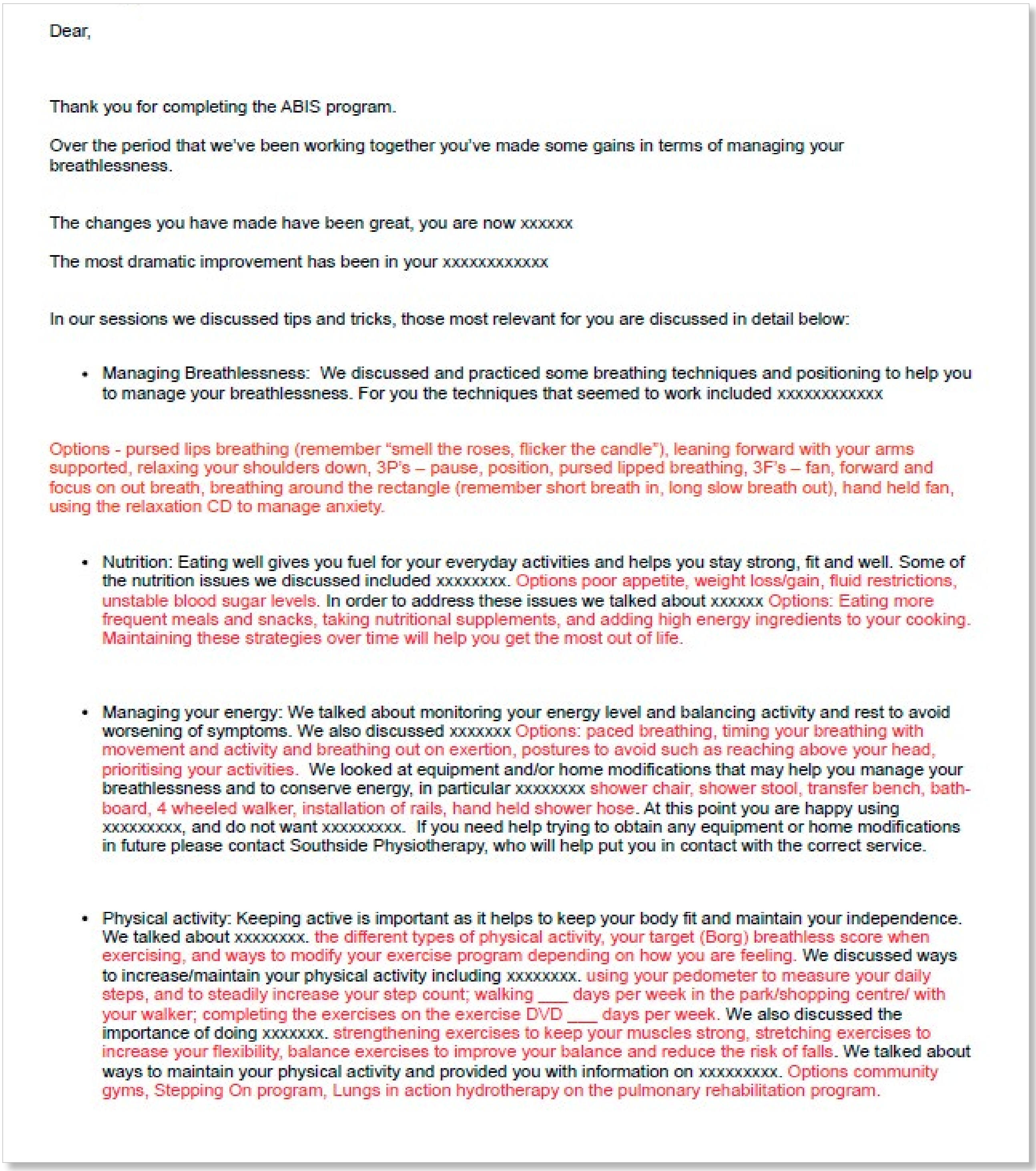
Name ________________________________

Date ________________________________

Please return the completed form at your earliest possible convenience.

Thank you for your input.

Letter sent to patient/carer after initial assessment and education visit



Dear,

Thank you for completing the ABIS program.

Over the period that we've been working together you've made some gains in terms of managing your breathlessness.

The changes you have made have been great, you are now xxxxxx

The most dramatic improvement has been in your xxxxxxxxxxxx

In our sessions we discussed tips and tricks, those most relevant for you are discussed in detail below:

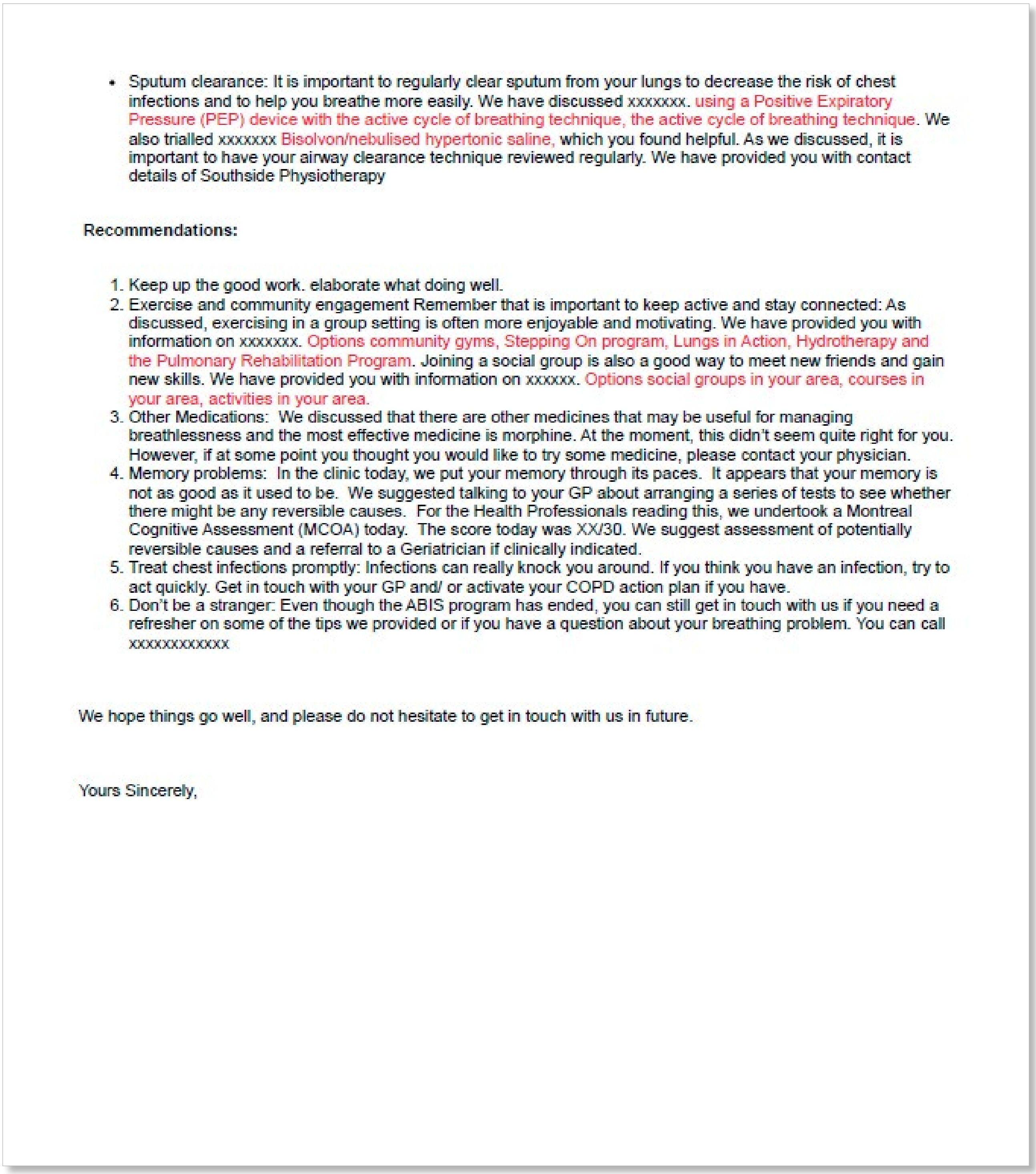
- Managing Breathlessness: We discussed and practiced some breathing techniques and positioning to help you to manage your breathlessness. For you the techniques that seemed to work included xxxxxxxxxxxx

Options - pursed lips breathing (remember "smell the roses, flicker the candle"), leaning forward with your arms supported, relaxing your shoulders down, 3P's – pause, position, pursed lipped breathing, 3F's – fan, forward and focus on out breath, breathing around the rectangle (remember short breath in, long slow breath out), hand held fan, using the relaxation CD to manage anxiety.

- Nutrition: Eating well gives you fuel for your everyday activities and helps you stay strong, fit and well. Some of the nutrition issues we discussed included xxxxxxxx. Options poor appetite, weight loss/gain, fluid restrictions, unstable blood sugar levels. In order to address these issues we talked about xxxxxx Options: Eating more frequent meals and snacks, taking nutritional supplements, and adding high energy ingredients to your cooking. Maintaining these strategies over time will help you get the most out of life.

- Managing your energy: We talked about monitoring your energy level and balancing activity and rest to avoid worsening of symptoms. We also discussed xxxxxxx Options: paced breathing, timing your breathing with movement and activity and breathing out on exertion, postures to avoid such as reaching above your head, prioritising your activities. We looked at equipment and/or home modifications that may help you manage your breathlessness and to conserve energy, in particular xxxxxxxx shower chair, shower stool, transfer bench, bath-board, 4 wheeled walker, installation of rails, hand held shower hose. At this point you are happy using xxxxxxxxx, and do not want xxxxxxxxx. If you need help trying to obtain any equipment or home modifications in future please contact Southside Physiotherapy, who will help put you in contact with the correct service.

- Physical activity: Keeping active is important as it helps to keep your body fit and maintain your independence. We talked about xxxxxxxx. the different types of physical activity, your target (Borg) breathless score when exercising, and ways to modify your exercise program depending on how you are feeling. We discussed ways to increase/maintain your physical activity including xxxxxxxx. using your pedometer to measure your daily steps, and to steadily increase your step count; walking ___ days per week in the park/shopping centre/ with your walker; completing the exercises on the exercise DVD ___ days per week. We also discussed the importance of doing xxxxxxx. strengthening exercises to keep your muscles strong, stretching exercises to increase your flexibility, balance exercises to improve your balance and reduce the risk of falls. We talked about ways to maintain your physical activity and provided you with information on xxxxxxxxx. Options community gyms, Stepping On program, Lungs in action hydrotherapy on the pulmonary rehabilitation program.



- Sputum clearance: It is important to regularly clear sputum from your lungs to decrease the risk of chest infections and to help you breathe more easily. We have discussed xxxxxxx. using a Positive Expiratory Pressure (PEP) device with the active cycle of breathing technique, the active cycle of breathing technique. We also trialled xxxxxxx Bisolvon/nebulised hypertonic saline, which you found helpful. As we discussed, it is important to have your airway clearance technique reviewed regularly. We have provided you with contact details of Southside Physiotherapy

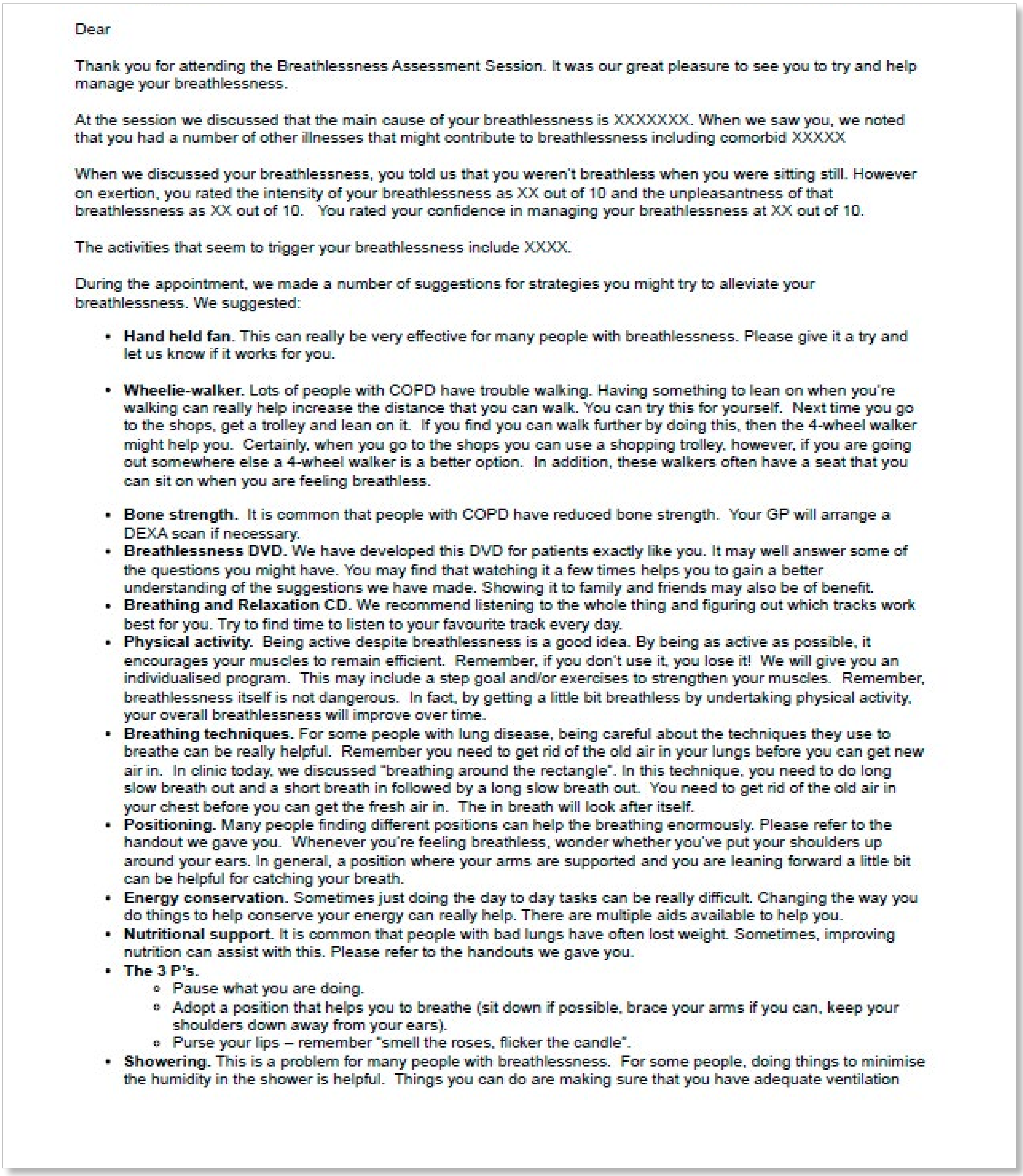
Recommendations:

1. Keep up the good work. elaborate what doing well.
2. Exercise and community engagement Remember that is important to keep active and stay connected: As discussed, exercising in a group setting is often more enjoyable and motivating. We have provided you with information on xxxxxxx. Options community gyms, Stepping On program, Lungs in Action, Hydrotherapy and the Pulmonary Rehabilitation Program. Joining a social group is also a good way to meet new friends and gain new skills. We have provided you with information on xxxxxx. Options social groups in your area, courses in your area, activities in your area.
3. Other Medications: We discussed that there are other medicines that may be useful for managing breathlessness and the most effective medicine is morphine. At the moment, this didn't seem quite right for you. However, if at some point you thought you would like to try some medicine, please contact your physician.
4. Memory problems: In the clinic today, we put your memory through its paces. It appears that your memory is not as good as it used to be. We suggested talking to your GP about arranging a series of tests to see whether there might be any reversible causes. For the Health Professionals reading this, we undertook a Montreal Cognitive Assessment (MCOA) today. The score today was XX/30. We suggest assessment of potentially reversible causes and a referral to a Geriatrician if clinically indicated.
5. Treat chest infections promptly: Infections can really knock you around. If you think you have an infection, try to act quickly. Get in touch with your GP and/ or activate your COPD action plan if you have.
6. Don't be a stranger: Even though the ABIS program has ended, you can still get in touch with us if you need a refresher on some of the tips we provided or if you have a question about your breathing problem. You can call xxxxxxxxxxxx

We hope things go well, and please do not hesitate to get in touch with us in future.

Yours Sincerely,

Discharge letter sent to patient/carer



Dear

Thank you for attending the Breathlessness Assessment Session. It was our great pleasure to see you to try and help manage your breathlessness.

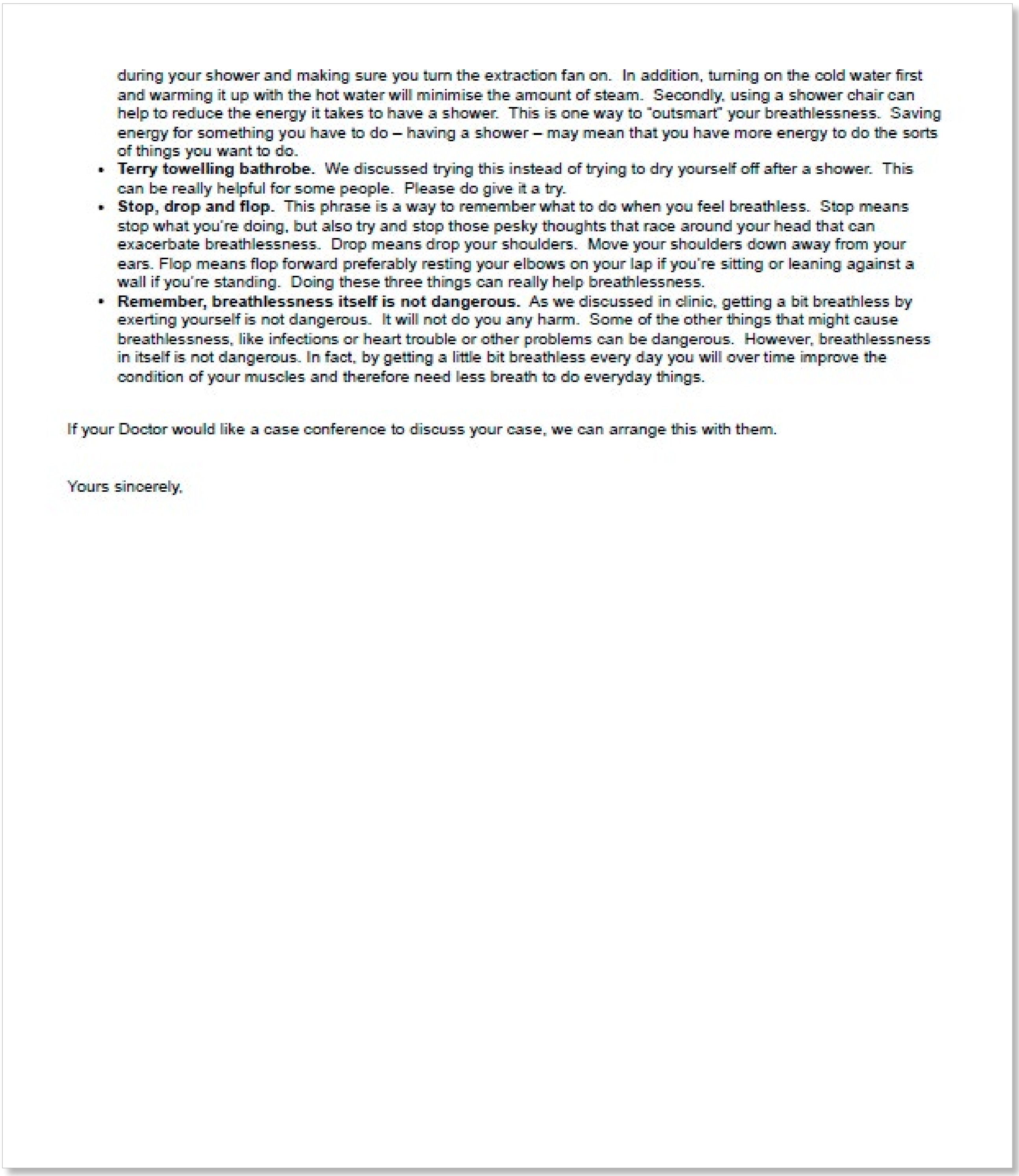
At the session we discussed that the main cause of your breathlessness is XXXXXXX. When we saw you, we noted that you had a number of other illnesses that might contribute to breathlessness including comorbid XXXXX

When we discussed your breathlessness, you told us that you weren't breathless when you were sitting still. However on exertion, you rated the intensity of your breathlessness as XX out of 10 and the unpleasantness of that breathlessness as XX out of 10. You rated your confidence in managing your breathlessness at XX out of 10.

The activities that seem to trigger your breathlessness include XXXX.

During the appointment, we made a number of suggestions for strategies you might try to alleviate your breathlessness. We suggested:

- **Hand held fan.** This can really be very effective for many people with breathlessness. Please give it a try and let us know if it works for you.
- **Wheelie-walker.** Lots of people with COPD have trouble walking. Having something to lean on when you're walking can really help increase the distance that you can walk. You can try this for yourself. Next time you go to the shops, get a trolley and lean on it. If you find you can walk further by doing this, then the 4-wheel walker might help you. Certainly, when you go to the shops you can use a shopping trolley, however, if you are going out somewhere else a 4-wheel walker is a better option. In addition, these walkers often have a seat that you can sit on when you are feeling breathless.
- **Bone strength.** It is common that people with COPD have reduced bone strength. Your GP will arrange a DEXA scan if necessary.
- **Breathlessness DVD.** We have developed this DVD for patients exactly like you. It may well answer some of the questions you might have. You may find that watching it a few times helps you to gain a better understanding of the suggestions we have made. Showing it to family and friends may also be of benefit.
- **Breathing and Relaxation CD.** We recommend listening to the whole thing and figuring out which tracks work best for you. Try to find time to listen to your favourite track every day.
- **Physical activity.** Being active despite breathlessness is a good idea. By being as active as possible, it encourages your muscles to remain efficient. Remember, if you don't use it, you lose it! We will give you an individualised program. This may include a step goal and/or exercises to strengthen your muscles. Remember, breathlessness itself is not dangerous. In fact, by getting a little bit breathless by undertaking physical activity, your overall breathlessness will improve over time.
- **Breathing techniques.** For some people with lung disease, being careful about the techniques they use to breathe can be really helpful. Remember you need to get rid of the old air in your lungs before you can get new air in. In clinic today, we discussed "breathing around the rectangle". In this technique, you need to do long slow breath out and a short breath in followed by a long slow breath out. You need to get rid of the old air in your chest before you can get the fresh air in. The in breath will look after itself.
- **Positioning.** Many people finding different positions can help the breathing enormously. Please refer to the handout we gave you. Whenever you're feeling breathless, wonder whether you've put your shoulders up around your ears. In general, a position where your arms are supported and you are leaning forward a little bit can be helpful for catching your breath.
- **Energy conservation.** Sometimes just doing the day to day tasks can be really difficult. Changing the way you do things to help conserve your energy can really help. There are multiple aids available to help you.
- **Nutritional support.** It is common that people with bad lungs have often lost weight. Sometimes, improving nutrition can assist with this. Please refer to the handouts we gave you.
- **The 3 P's.**
    - Pause what you are doing.
    - Adopt a position that helps you to breathe (sit down if possible, brace your arms if you can, keep your shoulders down away from your ears).
    - Purse your lips – remember "smell the roses, flicker the candle".
- **Showering.** This is a problem for many people with breathlessness. For some people, doing things to minimise the humidity in the shower is helpful. Things you can do are making sure that you have adequate ventilation



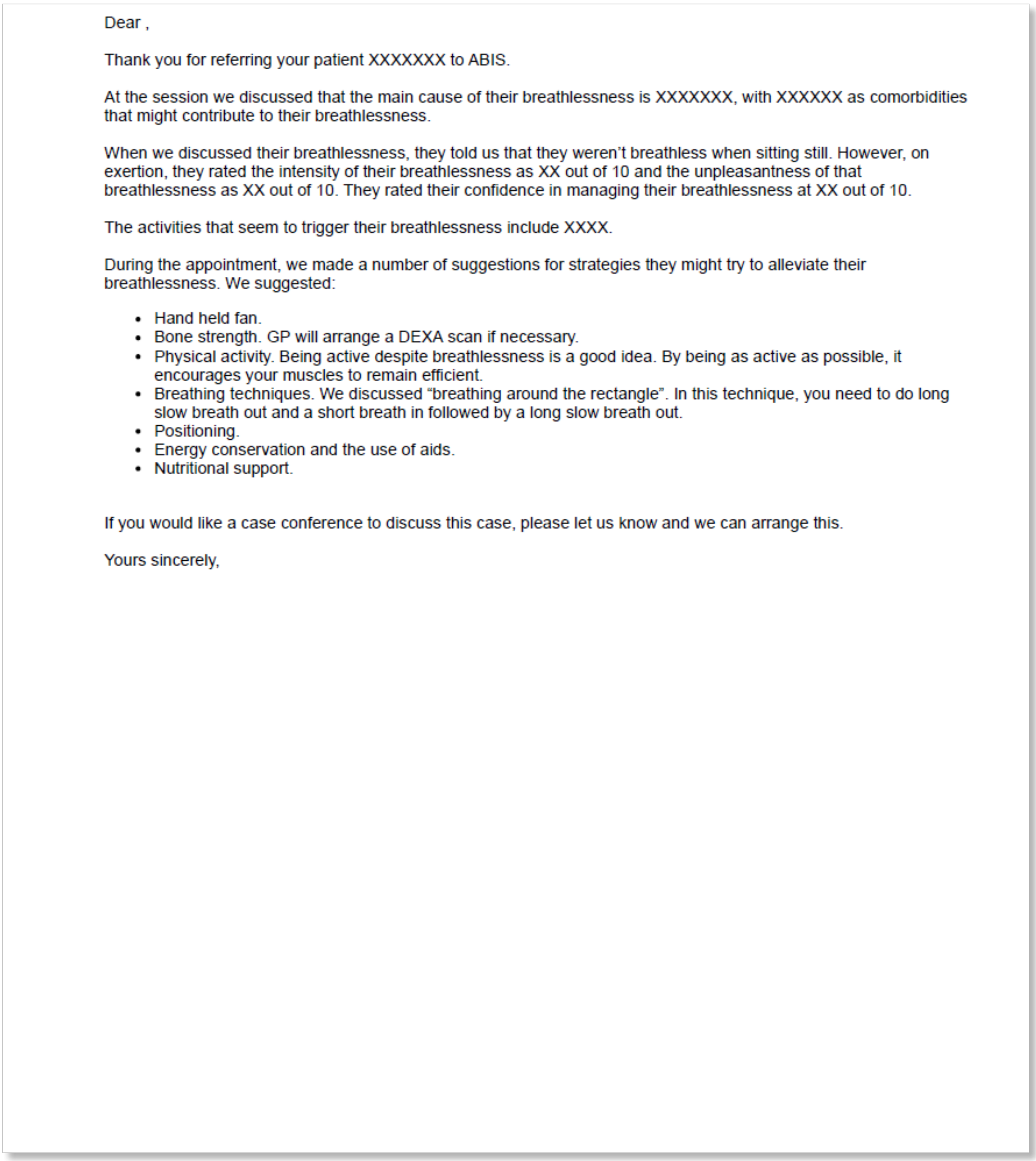
during your shower and making sure you turn the extraction fan on. In addition, turning on the cold water first and warming it up with the hot water will minimise the amount of steam. Secondly, using a shower chair can help to reduce the energy it takes to have a shower. This is one way to "outsmart" your breathlessness. Saving energy for something you have to do – having a shower – may mean that you have more energy to do the sorts of things you want to do.

- **Terry towelling bathrobe.** We discussed trying this instead of trying to dry yourself off after a shower. This can be really helpful for some people. Please do give it a try.
- **Stop, drop and flop.** This phrase is a way to remember what to do when you feel breathless. Stop means stop what you're doing, but also try and stop those pesky thoughts that race around your head that can exacerbate breathlessness. Drop means drop your shoulders. Move your shoulders down away from your ears. Flop means flop forward preferably resting your elbows on your lap if you're sitting or leaning against a wall if you're standing. Doing these three things can really help breathlessness.
- **Remember, breathlessness itself is not dangerous.** As we discussed in clinic, getting a bit breathless by exerting yourself is not dangerous. It will not do you any harm. Some of the other things that might cause breathlessness, like infections or heart trouble or other problems can be dangerous. However, breathlessness in itself is not dangerous. In fact, by getting a little bit breathless every day you will over time improve the condition of your muscles and therefore need less breath to do everyday things.

If your Doctor would like a case conference to discuss your case, we can arrange this with them.

Yours sincerely,

Discharge letter sent to referring physician



Dear ,

Thank you for referring your patient XXXXXXX to ABIS.

At the session we discussed that the main cause of their breathlessness is XXXXXXX, with XXXXXX as comorbidities that might contribute to their breathlessness.

When we discussed their breathlessness, they told us that they weren't breathless when sitting still. However, on exertion, they rated the intensity of their breathlessness as XX out of 10 and the unpleasantness of that breathlessness as XX out of 10. They rated their confidence in managing their breathlessness at XX out of 10.

The activities that seem to trigger their breathlessness include XXXX.

During the appointment, we made a number of suggestions for strategies they might try to alleviate their breathlessness. We suggested:

- Hand held fan.
- Bone strength. GP will arrange a DEXA scan if necessary.
- Physical activity. Being active despite breathlessness is a good idea. By being as active as possible, it encourages your muscles to remain efficient.
- Breathing techniques. We discussed "breathing around the rectangle". In this technique, you need to do long slow breath out and a short breath in followed by a long slow breath out.
- Positioning.
- Energy conservation and the use of aids.
- Nutritional support.

If you would like a case conference to discuss this case, please let us know and we can arrange this.

Yours sincerely,

5.3. Appendix C: Patient and carer clinical assessments that doubled as outcome measures

Manual for ABIS Eligibility and Evaluation Measures

Instructions to clinicians are shown in **red bold font**.

Instructions that SSP should give to each patient are shown in *italics*.

Questions should be directed only to the patient or carer as indicated. If the carer tries to answer on behalf of the patient, politely point out that the measures have been designed for the patient to complete.

Re-establishing Eligibility

Modified Medical Research Council (mMRC) Scale

GPs are asked to complete the modified Medical Research Council (mMRC) scale with each patient as an eligibility criterion for ABIS, with the requirement being ≥ Grade 2.

However, it's possible that a GP will make an error, so it's worthwhile re-administering the mMRC at the first Southside Physiotherapy visit to check. If the patient scores Grade 0 or 1, the visit can be cut short with an explanation that ABIS has been designed for people who are more greatly impacted by breathlessness than themselves and so will not help them.

Print out the following table and show it to patients. Some patients may struggle to understand what's meant by 'strenuous' until they have read the rest of the scale, so it may be best to direct their attention first to Grade 4 and then down the scale until they find the descriptor that best applies.

"Which of the following best describes how breathlessness affects you?"

Grade	Description of Breathlessness
Grade 0	I only get breathless with strenuous exercise
Grade 1	I get short of breath when hurrying on level ground or walking up a slight hill
Grade 2	On level ground, I walk slower than people of the same age because of breathlessness, or I have to stop for breath when walking at my own pace on the level
Grade 3	I stop for breath after walking about 100 yards or after a few minutes on level ground
Grade 4	I am too breathless to leave the house or I am breathless when dressing

Outcome Meaures

All measures have been designed to be **administered by Southside Physio at every consultation** both to:

1. inform individual patient care planning and monitor progress; and
2. evaluate ABIS across patients.

Patient Measures

The Patient-Specific Functional Scale

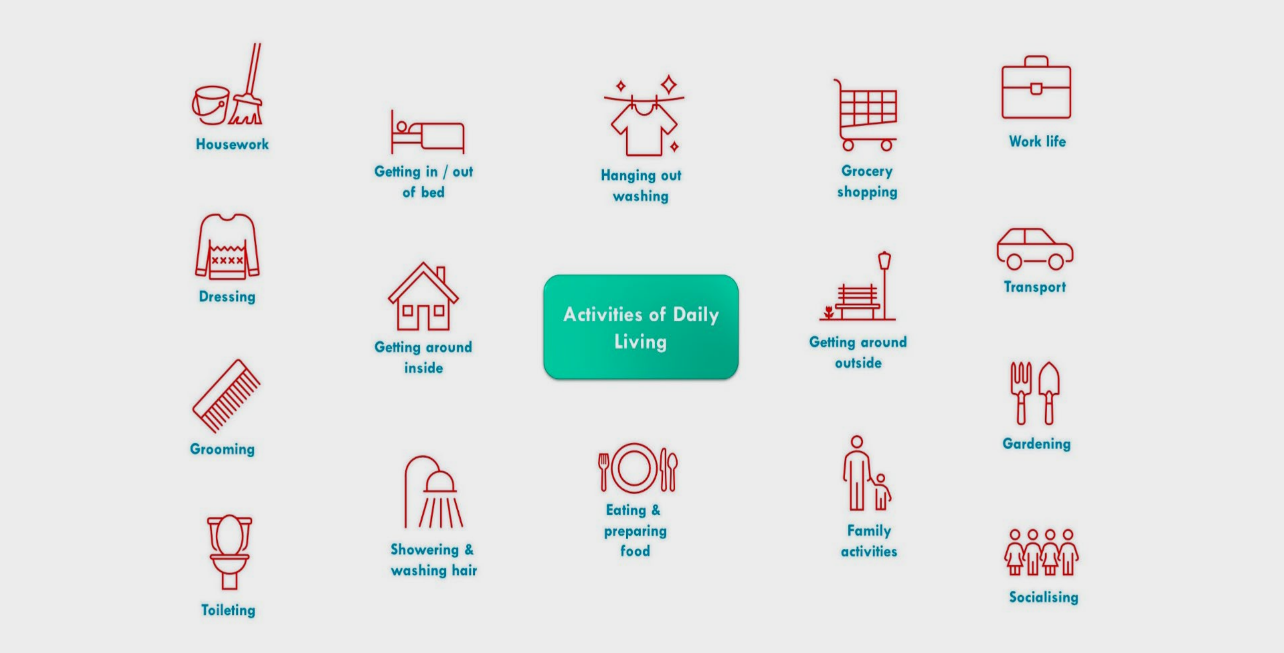
Initial Assessment:

"I am going to ask you to identify up to three important activities that you are unable to do or have difficulty with because of your breathlessness.

We will focus on trying to help you improve your ability to do these activities through ABIS.

This picture includes some examples of activities that people often find difficult because of breathlessness. You can either choose from these activities or identify other activities that you are having difficulty with that are more important to you."

Use the ADL infographic to help prompt patient on activities they may be having difficulty with.



Patients can choose 1, 2 or 3 activities to focus improvement efforts on as they prefer.

For each activity chosen by the patient, show the 0 - 10 scale and ask:

"Please rate your ability to do (activity 1) on the following scale, where 0 means you're unable to perform the activity at all and 10 means you're able to perform it at the same level as before you had breathlessness.

Please rate each activity twice – once for how well you can perform it on a good day and then again for a bad day. If you don't have good days and bad days, then just give the same number twice."

0	1	2	3	4	5	6	7	8	9	10
Unable to perform activity										Able to perform activity at the same level as before problem

Repeat the above instructions for activities 2 and 3 if the patient has chosen more than one to focus on.

For each activity, record the two ratings – one for good day and one for bad day - as shown under 'data capture' below.

Follow-up Assessments:

Note: To minimise bias, *do not show patient their previous score until AFTER they have completed this measure for the current consultation.*

“When I assessed you on (assessment date), you told me that you had difficulty with (chosen activities) because of breathlessness.

*Please rate your ability to do (activity 1) **since your last session with Southside Physio** on the following scale, where 0 means you’re unable to perform the activity at all and 10 means you’re able to perform it at the same level as before you had breathlessness.*

*Please rate each activity twice – once for how well you can perform it on a **good day** and then again for how well you can perform it on a **bad day**. If you don’t have good days and bad days, then just give the same number for both.”*

0	1	2	3	4	5	6	7	8	9	10
Unable to perform activity										Able to perform activity at the same level as before problem

Repeat the above instructions for activity 2 and 3 if patient has chosen more than one to focus on.

For each activity, record the two ratings – one for good day and one for bad day – as shown under ‘data capture’ below.

AFTER the patient has completed the measure, show them their previous ratings and discuss any changes over time (or lack thereof), asking them to think about any factors that might be influencing this and could inform refinements to their management plan.

Date capture

Activity	Day	Initial visit	F/up 1	F/up 2	F/up 3	F/up 4	F/up 5
1. Identify here	GD						
	BD						
2. Identify here	GD						
	BD						
3. Identify here	GD						
	BD						
Mean activity score	GD						
	BD						

BD = bad day; F/up = follow-up visit, the number of which will vary between patients; GD = good day

Worst Breathlessness Severity

Show the patient the following question and response options written down. Don't rephrase the questions even if the patient asks for clarification – there are no right or wrong answers and whatever they think the question means will be fine.

Initial assessment:

"How severe has your breathlessness been at its worst over the last 2 weeks?"

Follow-up Assessments:

"How severe has your breathlessness been at its worst since your last session with Southside Physio?"

Chronic Respiratory Questionnaire (CRQ) 'Mastery' subscale

Show the patient the following questions and response options written down. Don't rephrase the questions even if the patient asks for clarification – there are no right or wrong answers and whatever they think the questions mean will be fine.

0	1	2	3	4	5	6	7	8	9	10
Best you can imagine										Worst you can imagine

Initial assessment:

1. *"How often **over the last 2** weeks did you have a feeling of fear or panic when you had difficulty getting your breath?"*

☐ 1 – none of the time
☐ 2 – a little of the time
☐ 3 – some of the time
☐ 4 – a good bit of the time
☐ 5 – most of the time
☐ 6 – almost all of the time
☐ 7 – all of the time

2. *"**In the last 2 weeks**, how much of the time did you feel very confident and sure that you could deal with your illness?"*

☐ 1 – none of the time
☐ 2 – a little of the time
☐ 3 – some of the time
☐ 4 – a good bit of the time
☐ 5 – most of the time
☐ 6 – almost all of the time
☐ 7 – all of the time

*3. "How often **during the last 2 weeks** have you had complete control of your breathing problems?"*

☐ 1 – none of the time
☐ 2 – a little of the time
☐ 3 – some of the time
☐ 4 – a good bit of the time
☐ 5 – most of the time
☐ 6 – almost all of the time
☐ 7 – all of the time

*4. "How often **during the last 2 weeks** did you feel upset or scared when you had difficulty getting your breath?"*

☐ 1 – none of the time
☐ 2 – a little of the time
☐ 3 – some of the time
☐ 4 – a good bit of the time
☐ 5 – most of the time
☐ 6 – almost all of the time
☐ 7 – all of the time

Follow-up Assessments:

0	1	2	3	4	5	6	7	8	9	10
Best you can imagine										Worst you can imagine

*1. "How often **since your last session with Southside Physio**, did you have a feeling of fear or panic when you had difficulty getting your breath?"*

☐ 1 – none of the time
☐ 2 – a little of the time
☐ 3 – some of the time
☐ 4 – a good bit of the time
☐ 5 – most of the time
☐ 6 – almost all of the time
☐ 7 – all of the time

*2. "**Since your last session with Southside Physio**, how much of the time did you feel very confident and sure that you could deal with your illness?"*

☐ 1 – none of the time
☐ 2 – a little of the time
☐ 3 – some of the time
☐ 4 – a good bit of the time
☐ 5 – most of the time
☐ 6 – almost all of the time
☐ 7 – all of the time

3. *"How often **since your last session with Southside Physio** have you had complete control of your breathing problems?"*

☐ 1 – none of the time
☐ 2 – a little of the time
☐ 3 – some of the time
☐ 4 – a good bit of the time
☐ 5 – most of the time
☐ 6 – almost all of the time
☐ 7 – all of the time

4. *"How often **since your last session with Southside Physio** did you feel upset or scared when you had difficulty getting your breath?"*

☐ 1 – none of the time
☐ 2 – a little of the time
☐ 3 – some of the time
☐ 4 – a good bit of the time
☐ 5 – most of the time
☐ 6 – almost all of the time
☐ 7 – all of the time

Healthcare use

This question can be less standardised and more conversational than the previous ones, and does not require you to show the written question and response options to the patient.

Initial assessment:

"***During the last 2 weeks**, what if any healthcare have you needed to help with your breathlessness?"*

☐ None
☐ Emergency Department
☐ Hospital admission
☐ Change in medication
☐ GP visit
☐ Specialist visit
☐ Other (Specify) ______________________________

Follow-up Assessments:

"***Since your last session with Southside Physio,** what if any healthcare have you needed to help with your breathlessness?"*

☐ None
☐ Emergency Department
☐ Hospital admission
☐ Change in medication
☐ GP visit
☐ Specialist visit
☐ Other (Specify) ______________________________

If they DID have healthcare for breathlessness, discuss whether any changes are needed to their management plan and make notes below.

If they DID NOT have healthcare for breathlessness, ask:

"Was there any time ***since your last session with Southside Physio*** *that you thought about calling an ambulance for breathlessness but instead managed to control it using the strategies you've learned through ABIS?"*

☐ Yes
☐ No

Family / Carer

Carer confidence

This question should only be asked to a family member or friend who:

1. the patient identifies as giving substantial support to help with their breathlessness; and

2. is involved in education during ABIS sessions.

Show the carer the following questions and response options written down. Don't rephrase the questions even if the patient asks for clarification – there are no right or wrong answers and whatever they think the questions mean will be fine.

Initial assessment:

*"****During the last 2 weeks,*** *how would you rate your confidence in supporting (patient name) when his/her breathlessness gets suddenly worse?"*

☐ Very confident
☐ Somewhat confident
☐ Not confident

Follow-up assessments:

*"****Since the last session with Southside Physio****, how would you rate your confidence in supporting (patient name) when his/her breathlessness gets suddenly worse?"*

☐ Very confident
☐ Somewhat confident
☐ Not confident

5.4. Appendix D: Interview topic guides

Patients

- **What's your overall impression of the ABIS program?**
- **What benefits if any have you experienced from participating in ABIS?**

  Prompts:

  - Can you tell me about your experience of the program and whether or not it supported you to manage your breathlessness more effectively?
  - Can you tell me about your expectations for the program, and whether these were met?
  - Can you tell me about your confidence in undertaking activities of daily living such as showering, shopping and cleaning, and how that was impacted by the program?
  - Can you tell me about your confidence in self-managing breathlessness and whether this was impacted by the program?
  - Has the program helped to actually reduce how severe your breathlessness is or not?
  - Has the program reduced your use of healthcare? *(e.g. ambulance, ED, hospital admissions, GP visits, other)*

- **What were the most and least useful features of the ABIS service?**

  Prompts:

  - If you could pick one or two of the best things about the ABIS program what would they be? Why? (e.g. *Service model processes:* in-home, phone-call follow-ups, consultation time flexibility, clinician relationship. *Breathlessness strategies:* education material, breathing techniques)
  - If you could pick one or two things to change, what would they be? Why?
  - How did you find working with the ABIS providers/Southside Physio to develop your care plan?
  - What did you think about the number and duration of visits and phone follow-ups – too little, too much or about right?
  - Was there a particular time point where you felt you didn't gain anything more from ABIS?
  - Was there anything missing in the program that you would have liked to be included?
  - Are there any specific comments or feedback you would like to give regarding the information that was presented in the education sessions? Or how it was presented?
  - Did you find completing the measures of activities of daily living and breathlessness useful or not?

- **Would you recommend the service to other people who have challenges with managing their breathlessness, or not? Why?**
- **Are there any other points you'd like to add, that I have not asked you about?**

Carers

- **Can I please what your relation to the person with breathlessness is?**
- **What's your overall impression of the ABIS program?**
- **What benefits, if any, have you observed in (person with breathlessness) from participating in the ABIS program?**

  Prompts:
  - Can you tell me about your experience with the program, and whether you think it has supported (person with breathlessness) to manage their breathlessness more effectively? In what way?
  - Can you tell me about your expectations for the program, and whether these were met?
  - From your perspective, can you explain whether participating in the program as impacted (person with breathlessness)'s level of confidence to undertaking activities of daily living such as showering, shopping and cleaning? In what way?
  - Has the ABIS program reduced (person with breathlessness) use of healthcare? (e.g. ambulance, ED, hospital admissions, GP visits, other)
- **In what ways, if any, has the ABIS program helped you to provide support to (person with breathlessness)?**

  Prompts:
  - Do you feel participating in the ABIS program has improved your confidence in providing support to (person with breathlessness) when their breathlessness suddenly gets worse, or not? In what way?
  - Are there any additional resources/education/features that you think should be added, or might be helpful for a support person?
- **As a support person, what were the most/least useful features of the ABIS service?**

  Prompts:
  - If you could pick one or two of the best things about the ABIS program what would they be? Why? (e.g. in-home, phone-call follow-ups, consultation time flexibility, education material, breathing techniques, clinician relationship)
  - If you could pick one or two things to change, what would they be? Why?
  - How did you find working with the clinicians/Southside Physio to develop (person with breathlessness) care plan?
  - What did you think about the number and duration of visits and phone follow-ups – too little, too much or about right?
  - Was there a particular time point where you felt you didn't gain anything more from ABIS?
  - Was there anything missing in the program that you would have liked to be included?
  - Are there any specific comments or feedback you would like to give regarding the information that was presented in the education sessions? Or how it was presented?
- **Would you recommend the service to other people who have challenges with managing their breathlessness, or not? Why?**
- **Are there any other points you'd like to add, that I have not asked you about?**

Referring Health Professionals

- **What’s your overall impression of the ABIS program?**

- **Have you talked to any of your patients since they started ABIS? If so, what feedback have they given you?**

  Prompts:

  - What if any benefits did you see in your patients referred to the ABIS program? (e.g. increased confidence, ability to self-manage, ability to do activities of daily living, reduced healthcare utilisation)
  - Are there particular features of the ABIS program that you think are most useful to patients experiencing breathlessness? (e.g. in-home service, phone-call follow-ups, consultation time flexibility, education material, breathing techniques, clinician relationship)
  - Was there anything missing in the ABIS program that you would think might have been useful for patients with breathlessness?

- **Has referring patients to ABIS changed the way you manage other patients with breathlessness?**

  Prompts:

  - Did the ABIS program provide you with a level of confidence in supporting patients with persistent breathlessness, or not? Why/why not?

- **How did you find the referral process to ABIS?**

  Prompts:

  - How was your experience with the ABIS providers/SouthSide Physio? Could anything be improved?
  - Was there anything else that could be changed/implemented in the ABIS program to help support health professionals referring to the service?
  - Are there any other specific comments or feedback you would like to give regarding the ABIS program? (e.g. referral process, communication/collaboration, education to patient/carer education/training provided to referrers?)

- **Are there any other points you’d like to add, that I have not asked you about?**

Connect with us

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Images in this report have been taken from the ABIS promotional video at
https://youtu.be/EN1CKhyLSLk

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