

# IW NHS Trust Respiratory Department Evaluation Report

November 2015

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# Contents

Section	1: Executive Summary	3
1.1	Introduction	3
1.2	Limitations of the Report	3
Section	2: Project Method	3
2.1	Project overview	3
2.2	Project staffing and training	3
2.3	Participants	4
Section	3: Evaluation	4
3.1	Intended Output	4
3.2	Standardised Questionnaires	5
3.3	Experiential Questionnaires	5
Section	4: Findings	5
Section	5: Summary and Conclusions	7
Section	6: References	7
Section	7: Appendices	9
7.1	Project Timeline	
7.2	Project Poster	
7.3	The Warwick-Edinburgh Mental Health Wellbeing Scales	
7.4	Self-Efficacy for Managing Long Term Respiratory Conditions 6 item Scale	
7.5	End of Project Questionnaire	
7.6	Semi-structured Telephone Interview	

#### **Section 1. Executive Summary**

#### 1.1. Introduction

The most common debilitating symptom of long term respiratory conditions is breathlessness (Thorax, 2004), which often leads to inactivity, isolation and dependence on healthcare professionals. Treatment depends upon what symptoms are present, the extent of the lung damage and consists of managing the condition where possible to keep it stable over time. It has been recognised that 'management' of respiratory conditions happens in partnership between the individual with the condition and healthcare providers and that self-management can be taught through increasing knowledge, teaching breathing techniques and encouraging physical activity (NIHCE, 2010).

The IW NHS Respiratory Department currently promotes self-management for service users through three main approaches: advice provided by healthcare professionals individually or through training/open days, pulmonary rehabilitation and BLF Active 'Breathe-easy' groups. However, for persons newly diagnosed and those unable to exercise there is potentially inequality in access to self-management support because social needs remain unaddressed. In concordance with national findings, consultation with IW NHS Respiratory Department service users has highlighted that building a strong social support network at an early point helps to sustain a positive identity outside of health, confidence in self-managing and living well alongside the condition.

Singing for Breathing is based on a recognised form of therapy specifically developed for individuals with a respiratory condition. Extensive research has been carried out in this area, with flagship projects being delivered at the Royal Brompton and Harefield Hospitals. Using the same model, this project aims to to improve the quality of life, health and wellbeing of those who have been diagnosed with a respiratory condition. The intended outcome is that individuals have increased confidence to self-manage their condition.

### 1.2. Limitations of the Report

Unfortunately due to a change in personnel, questionnaires for the majority of the participants were not available and this has limited formal analysis of the project. All findings must therefore be treated conservatively as this is a small sample of the total projected number of participants.

#### **Section 2: Project Method**

#### 2.1. Project Overview

The Singing for Breathing project launched in October 2014 with sessions delivered until June 2015. The project was delivered as a rolling 12 week programme with 36 weeks total direct delivery. In order to maintain a stable level of attendance and reduce waiting time for service users there were 3 entry/exit points across each of the 12 weeks (See Appendix 7.1: Project Timeline).

#### 2.2. Project staffing and training

Sessions were conducted by Sandy Kealty, a Natural Voice Practitioner and existing SingAbout practitioner. Sessions were supported by the Project Manager and Assistant from Independent Arts with access to IW NHS Respiratory team members for specialist support. To ensure that Sandy had access to evidence-based breathing techniques and that she felt confident working with individuals with long-term respiratory conditions, she attended a number of training events provided by the IW NHS Trust Respiratory Team. Members of the IW NHS Trust Respiratory Team, IW Trust Healing Arts and Independent Arts attended the Royal Brompton Hospital to observe their flagship Singing for Breathing programme and to talk to the singing leaders. 'Graduates' from each cohort were encouraged to support new members and were supervised by Independent Arts.

A second music practitioner, Carolyn Kramlik, who works on the Independent Arts SingAbout project in the community was brought in to deliver the singing component of sessions for 6 weeks as Sandy Kealty suffered a fall resulting in a broken pelvis and the need of an emergency hip replacement.

Breathing techniques were delivered by the Project Manager from Independent Arts in conjunction with the IW NHS Trust Respiratory Team.





#### 2.3. Participants

Participants could be referred into the project by any member of the IW NHS Trust Respiratory Team, through self-referral from advertising within the Respiratory department, or via GP Practise Nursing Teams (see Appendix 7.2 for advertising poster). Participants were a mixture of longstanding patients, recent graduates of IW Respiratory Team Pulmonary Rehabilitation and those newly diagnosed. The invitation was extended to families and carers of service users in recognition of their need for positive peer support, knowledge of breathing techniques and role in creating a supportive environment for a service user. Participants had access to the specialist knowledge of the Respiratory Team through regular input to the group and through their existing care plans.

It was anticipated that 50 individuals would complete the project in total.

#### **Section 3: Evaluation**

#### 3.1. Intended Output

Within the Singing for Breathing project, there was an over-riding aim:

To improve the quality of life, health and wellbeing of those who have been diagnosed with a respiratory condition. Individuals have increased confidence to self-manage their condition and improve quality of life and independence.

Quantitative and qualitative approaches were used to capture data. Two standardised questionnaires were used at the outset of the programme as baseline and then on completion of each cohort's programme. Two semi-structured questionnaires were used to capture participants' experience of the singing sessions, particularly the social aspect of the group.

#### 3.2. Standardised Questionnaires

The Warwick-Edinburgh Mental Wellbeing Scale (WEMWBS; *Appendix 7.3*) and the Self-Efficacy for Managing Long Term Respiratory Conditions 6 item Scale (SUPREC; *Appendix 7.4*) were used to explore if perceptions of wellbeing and confidence changed significantly for participants across the whole project.

The WEMWBS was identified and chosen because it describes positive states of being, thinking behaving and feeling and avoids measuring improvement through the traditional reduction in negative symptoms. This was important as the project was open to IW NHS Trust Respiratory Team existing long term service users who may already feel confident and positive in the self-management of their respiratory condition.

The Self-Efficacy for Managing Long Term Respiratory Conditions 6 item Scale is an adapted version of the Self-Efficacy for Managing Chronic Disease 6 item scale developed by Stanford University Patient Research and Education Centre. Permission was obtained from the authors to replace the words 'chronic disease' with long term respiratory condition. The 6 items address perceptions of confidence in self-managing i) the common symptoms and effects of the respiratory condition, ii) to reduce healthcare usage and iii) to sustain quality of life.

#### 3.3 Experiential questionnaires

An End of Project 6 item questionnaire (End of Project Questionnaire; *Appendix 7.5*) developed by Independent Arts was given out to participants to obtain their feedback at the end of their participation in the project. This information is held by Independent Arts.

A semi-structured telephone interview (Semi-structured Telephone Interview) consisting of 6 questions was carried out once the project had finished as part of the follow-up plan (Semi-structured Telephone Interview; *Appendix 7.6*). This questionnaire was a version (adapted for local use) of the questionnaire used in the original flagship study by Royal Brompton and Harefield Hospitals (Lord et al. 2010). 12 participants (2 participants from each cohort) were randomly selected from those who completed both pre-and post questionnaires. Responses from 6 of these participants were obtained (2 telephone numbers were incorrect and 4 were not available). No participants refused to give feedback.



#### **Section 4: Findings**

Completed baseline and post-questionnaires were available for 18 participants across 6 cohorts.

The mean score for the WEMWBS for this sample at baseline was 53.33 (Std Dev 2.78). The average population mean is 51 (Stewart-Brown & Janmohamed, 2008). On completion of the 12 week programme the mean score for participants was 56.94 (Std Dev 2.36). Although formal statistic analysis was not appropriate due to the small sample size, at an individual level a difference of 3 points between before and after time points is considered to be meaningful (Stewart-Brown & Jammohamed, 2008). The inference here is that the Singing for Breathing project was successful in improving the wellbeing of participants.

There was no change in mean scores of self-efficacy between baseline and completion of programme: mean baseline score 6.37 (std dev 2.78) and mean score on completion 6.57 (std dev 2.36). The average population mean reported by the authors is 5.17 (std dev 2.22) (Lorig, Sobel, Ritter, Laurent, & Hobbs, 2001) inferring that participants were already feeling confident about self-managing their respiratory condition in comparison.

No information is available at this time for the End of Project Questionnaire.

Findings from the 1 year follow-up semi-structured interview were very positive. In summary, physical benefits were reported and sustained. Participants described that techniques were well incorporated into the singing practise. Emotional benefit was almost universally perceived by participants for the duration of their participation and was associated with group participation. Some participants reported emotional benefit was sustained past completion of their programme and this appears to be linked to a perception of continued physical benefit from regular practise of breathing techniques or continued involvement with a supportive group, singing or other. Many participants described that they missed the group once their time ended. One participant (C320) described that she felt "bereft" and "missed it dreadfully".

All participants questioned, bar 1, described that learning breathing techniques had been an important and valued part of the experience. The remaining participant interestingly described she "expected there to be more...technique". The same individual felt that the focus had been more on developing and evoking memory and described how the "songs were for older people". Table 1 provides participants' responses.

#### Table 1.

How has the singi	ng group affected you?
Emotionally	"lovely mood – a brighter outlook on life" "talking to others who got the same as me made me feel good" (C144)
	"uneventful" (C120)
	"gave me a high – euphoric. Came out of a dark place" (C38)
	"brought me together with people" "something to get up for" "loved it" (C320)
	"beneficial for emphysema" (C48)
Physically	"much better – taught to breathe differently" (C144)
	"No – more about memory and reminiscence than breathing" (C120)
	"opened up my chest to be able to breathe easier" "strengthened my lungs" (C38)
	"relaxing me" "[natural voice practitioner] helped me" (C320)
	"excellent" (C48)
	"breathing ability" (C78)
Behaviourally	"a brighter outlook on life – always singing at home" (C144)
	"No – expected to use the breathing moremore technique" (C120)
	"[techniques] to help with chest clearancehow to breathe" (C38)
	"gave me confidence" (C320)
What was the	"breathing was so much better" "how to breathing with the singing – what faces to pullwhen to breathe"
main benefit?	"made me feel better and when I'm feeling better I can breathe more easily" (C144)
	"enjoyed it[being] with other people similar to myself" (C120)
	"learning how to open my chest to get more air in" "keep chest healthy" (C38)
	"to be socialisingout of the house" (C320)
	it was a revelationmy breathing afterward was much better and much" (C48)
	"felt the benefits" (C78)
Were there any	"Shocked me how much better I felt when I got home" "less embarrassment about coughing in public" "took my
unexpected	worry down about being with others" (C144)
effects good or	"None"(C120)
bad?	"made me cough more – a good effect" (C38)
	"loved it!" (C320)
	"in just 2 hourslungs clearer and breathing more freely" "it made me tired – [it's]ok because exercised my lungs"
	(C48)

	"felt more beneficial than pills" (c78)
Are you doing	"a lot more singing! Anywhere!" "look on life differentlya jolly look on life" (C144)
anything now	"No" (C120;C320)
that you	"Singing more often at home and in the car" "learning to breathe out before doing chores I find difficult at home"
weren't	"the cd is helping" (C38)
before?	"carrying on with my active life" (C48)
Have you	"So sad when it stopped" (C144)
noticed any	"No – go to breathe easy twice a week"
changes since	"Missed it" "given me an easier way to get out" "[given me]positivity"
the end of the	"yes – not going out as much"(C320)
group?	"holding my FEV countan improvement on last year" "it's good psychologicallyfeel breathing is more under
	control" (C48)
	"it's just easier to do itphysical activity"(C78)
Are you still	"yeswith chores I don't like because it affects my breathing I just start singing. It's genuinely differentreally good"
using singing in	(C144)
your everyday	"No – I can't sing anymorebecause of [my] breathing I'm conscious that I'm not getting the notes or rhythms
life?	right"(C120)
	"yes – I put cds on round the houseuse my ipod more oftenand have TV on but have it on a radio station so I can
	sing along" (C38)
	"no" (C320)
	"yes – was disappointed when endedfound about a singing group in [geographical area] and now go along to
	that every week (C48)
	"nooccasional singalong with the radio" (C78)

## **Section 5. Summary and conclusions**

It is clear from this project that Singing for Breathing is an acceptable and valued intervention by Respiratory Team service users. Although it was not possible to conduct formal statistical analysis on the data available, there was considerable value in what the group experience had for participants and this is demonstrated most clearly in the comments given during interviews. In line with findings from the Royal Brompton and Harefield Hospitals, participants benefitted significantly from the experience. Techniques taught through the group have proved beneficial in the longer term, promoting confidence in self-management and improving quality of life through group participation.

Singing for Breathing has enabled us to open up access to our Services. We have been able to provide high quality information and strategies to manage breathlessness through non-medical management and delivery of care to all service users regardless of diagnosis and comorbidity. We have found it a useful platform to ensure that all those who attend are provided with information, advice and techniques – healthcare delivered in a relaxed environment, without the medicalisation of symptom experience. Moreover, participants newly diagnosed have told us informally that they benefited from meeting those with long-established conditions who are already self-managing through informal and supportive contacts with the IW NHS Trust Respiratory Department. We continue to receive expressions of interest and enquiries about future singing groups from service users and are delighted that a 2 year funding plan has been secured to enable the project to be continued by Independent Arts in the community.

#### **Section 6: References**

Department of Health (2010a) Consultation on a Strategy for Services for Chronic Obstructive Pulmonary Disease (COPD) in England, London: Department of Health.

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National Institute for Health and Clinical Excellence (2010) Quick Reference Guide: Chronic Obstructive Pulmonary Disease, London: NIHCE.

Stewart-Brown S & Janmohamed, K (2008) The Warwick-Edinburgh Mental Wellbeing Scale (WEMWBS) User Guide Version 1. <a href="http://www.healthscotland.com/uploads/documents/7551-WEMWBS%20User%20Guide%20Version%201%20June%202008.pdf">http://www.healthscotland.com/uploads/documents/7551-WEMWBS%20User%20Guide%20Version%201%20June%202008.pdf</a>

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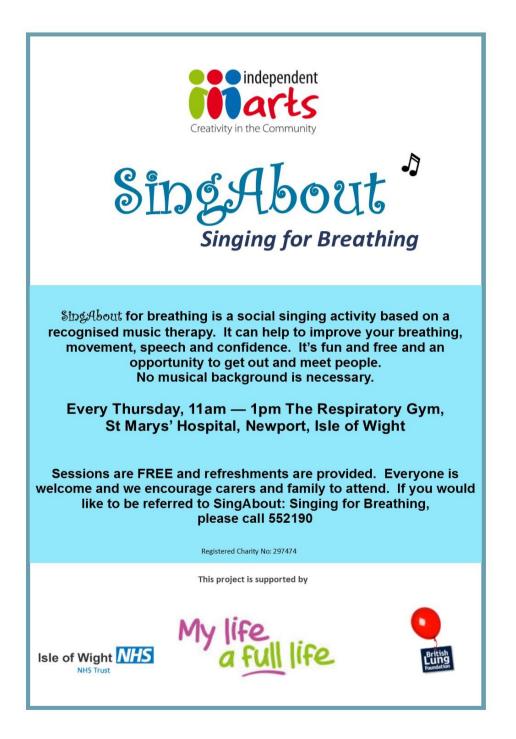
# **Section 7: Appendices**

# 7.1 Project Timeline

Week	Date	Entry Point	Exit Point	Cohorts Attending	Target No of Participants
1	02.10.14	Cohort 1 (10)		1	10
2	09.10.14			1	10
3	16.10.14			1	10
4	23.10.14			1	10
5	30.10.14	Cohort 2 (5)		1+2	15
6	06.11.14			1 + 2	15
7	13.11.14			1 + 2	15
8	20.11.14			1 + 2	15
9	27.11.14	Cohort 3 (5)		1, 2 + 3	20
10	04.12.14			1, 2 + 3	20
11	11.12.14			1, 2 + 3	20
12	18.12.14		Cohort 1	1, 2 + 3	20
		NEW YEAR BREAK	T	22.4	120
13	08.01.15	Cohort 4 (10)		2, 3, + 4	20
14	15.01.15			2, 3, + 4	20
15	22.01.15		0.10	2, 3, + 4	20
16	29.01.15		Cohort 2	2, 3, + 4	20
17	05.02.15	Cohort 5 (5)		3, 4 + 5	20
18	12.02.15			3, 4 + 5	20
19	19.02.15		Cabant 2	3, 4 + 5	20
20	26.02.15 05.03.15	Cohort 6 (5)	Cohort 3	3, 4 + 5	20
22	12.03.15	Conort 6 (5)		4, ,5 + 6	20
23	19.03.15			4, ,5 + 6 4, ,5 + 6	20
24	26.03.15		Cohort 4	4, ,5 + 6	20
24	20.03.13		Conort 4	4, ,5 + 0	20
25	02.04.15	Cohort 7 (10)		5, 6 + 7	20
26	09.04.15	(20)		5, 6 + 7	20
27	16.04.15			5, 6 + 7	20
28	23.04.15		Cohort 5	5, 6 + 7	15
29	30.04.15			6+7	15
30	07.05.15			6 + 7	15
31	14.05.15			6 + 7	15
32	21.05.15		Cohort 6	6 + 7	15
33	28.05.15			7	10
34	04.06.15			7	10
35	11.06.15			7	10
36	18.06.15		Cohort 7	7	10

Cohorts 1, 4 and 7 = 10 pax (TOTAL 30 pax) Cohorts 2, 3, 5 and 6, = 5 pax (TOTAL 20 pax) Overall participant number for direct engagement = 50.

## 7.2 Poster created for the project and displayed at St Mary's Hospital



# 7.3 The Warwick-Edinburgh Mental Well-being Scale (WEBWBS)

Name: Male/Female	IW NUMBER:	Age:	Gender:
Below are some statements abo	out feelings and thoughts.	last 2 weeks.	

Statements	None of the time	Rarely	Some of the time	Often	All of the time
I've been feeling optimistic about the future	1	2	3	4	5
I've been feeling useful	1	2	3	4	5
I've been feeling relaxed	1	2	3	4	5
I've been feeling interested in other people	1	2	3	4	5
I've had energy to spare	1	2	3	4	5
I've been dealing with problems well	1	2	3	4	5
I've been thinking clearly	1	2	3	4	5
I've been feeling good about myself	1	2	3	4	5
I've been feeling close to other people	1	2	3	4	5
I've been feeling confident	1	2	3	4	5
I've been able to make up my own mind about things	1	2	3	4	5
I've been feeling loved	1	2	3	4	5
I've been interested in new things	1	2	3	4	5
I've been feeling cheerful	1	2	3	4	5

<sup>&</sup>quot;Warwick Edinburgh Mental Well-Being Scale (WEMWBS)

The Warwick-Edinburgh Mental Well-being Scale was funded by the Scottish Executive National Programme for improving mental health and well-being, commissioned by NHS Health Scotland, developed by the University of Warwick and the University of Edinburgh, and is jointly owned by NHS Health Scotland, the University of Warwick and the University of Edinburgh.

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## 7.4 Self-Efficacy for Managing Long Term Respiratory Conditions 6 Item Scale<sup>1</sup>

We would like to know *how* confident you are in doing certain activities. For each of the following questions, please choose the number that corresponds to your *confidence* that you can do the tasks regularly at the present time.

		Not at all Totally confident confide					ent				
1.	How confident are you that you can keep the fatigue caused by your respiratory condition from interfering with the things you want to do?		2	3	4	5	6	7	8	9	10
	Not a confidence									otally onfide	ent
2.	How confident are you that you can keep the physical discomfort or pain of your respiratory condition from interfering with the things you want to do?		2	3	4	5	6	7	8	9	10
	Not a confide									otally onfide	ent
3.	How confident are you that you can keep the emotional distress caused by your respiratory condition from interfering with the things you want to do?		2	3	4	5	6	7	8	9	10
	Not a confide									otally onfide	ent
4.	How confident are you that you can keep shortness of breath from interfering with what you want to do?	1	2	3	4	5	6	7	8	9	10
	Not a confidence									otally onfide	ent
5.	How confident are you that you can do the different tasks and activities needed to manage your respiratory condition so as to reduce the need to see a health professional?		2	3	4	5	6	7	8	9	10
	Not a confide									otally onfide	ent
6.	How confident are you that you can do things other than just taking medication to reduce how much your respiratory condition affects your everyday life?		2	3	4	5	6	7	8	9	10

<sup>1</sup> Adapted with permission from Dr Kate Lorig, Director, Stanford University Patient Education Research Centre. Original scale reference: Lorig KR, Sobel, DS, Ritter PL, Laurent, D, Hobbs, M. Effect of a self-management program for patients with chronic disease. *Effective Clinical Practice*, 4, 2001, 256-262.

12

7.5 End of Project Questionnaire  Do you think the Singing for Breathing project has helped your respiratory condition? If ye how?
What difference has Singing for Breathing made to you?
Has this health intervention made you feel like a patient or a person?
Would you continue with Singing for Breathing to manage your respiratory condition?
Do you feel more confident in managing your respiratory condition as a result of Singing for Breathing?
Have you enjoyed it?
What improvements would you make to the programme?
Any other comments?

Appendix 7.6 Semi-structured Telephone Interview <sup>2</sup>
1. How has attending the singing group affected you? Prompts: Physically, Emotionally, Behaviourally
2. What was the main benefit?
3. Were there any unexpected effects good or bad?
4. Are you doing anything now that you weren't before?
5. Have you noticed any changes since the end of the group?
6. Are you still using singing in your everyday life?

 $<sup>^2</sup>$  From: Lord et al. (2010) Singing Teaching as a therapy for chronic respiratory disease – a randomised controlled trial and qualitative evaluation. http://www.biomedcentral.com/1471-2466/10/41