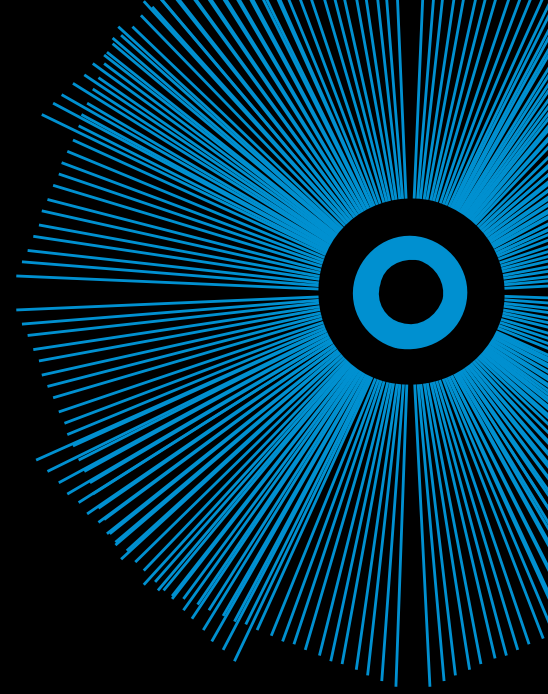




Shine



Shine 2014 final report

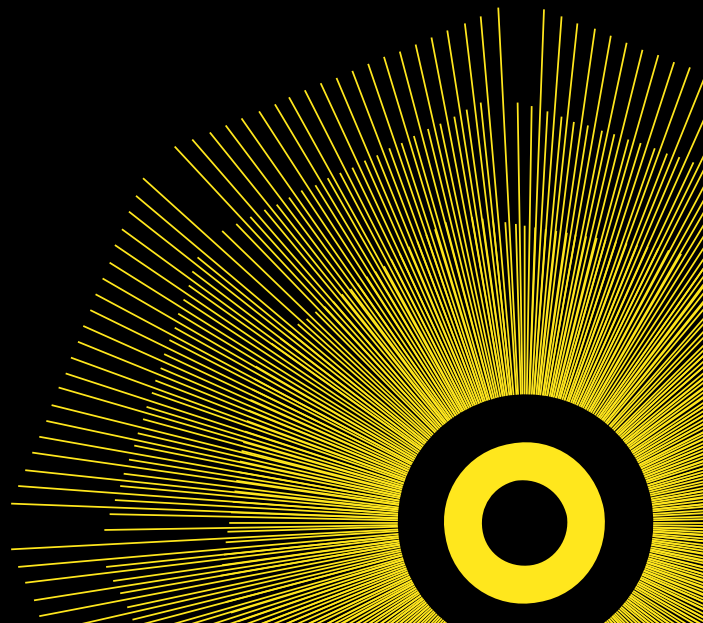
RIPPLE

Respiratory Innovation: Promoting Positive
Life Experience

University Hospitals Coventry and Warwickshire NHS
Trust, Coventry University

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The Health Foundation
Tel 020 7257 8000
www.health.org.uk



Part 1: Abstract

Project title: RIPPLE (Respiratory Innovation: Promoting Positive Life Experience)

Lead organisation: University Hospitals Coventry and Warwickshire NHS Trust

Partner organisation: Coventry University

Lead Clinician: Dr. Colin Gelder

Abstract (500 words)

The RIPPLE project applied an asset-based community development approach to improve wellbeing and reduce the high levels of anxiety and social isolation observed in individuals with severe Chronic Obstructive Pulmonary Disease (COPD) in Coventry.

Individuals with COPD suffer from chronic ill health and are at risk of early death and high utilisation of healthcare resources. Its symptoms, including breathlessness and cough, can lead to and amplify anxiety, low self-esteem and social isolation. These in turn lower mental wellbeing and can result in both poor self-management and a lack of engagement with key treatments for COPD such as smoking cessation and pulmonary rehabilitation. People with COPD can become trapped in a negative cycle where poor self-management/engagement leads to worsening symptoms, further anxiety and social isolation and thus poorer self-management/engagement and further worsening of symptoms, increased exacerbations, visits to GPs and hospital admissions.

A whole system approach was taken. A partnership was set up involving patients and carers, primary and secondary care clinicians, Chaplains, academics, public health, and third sector organisations to develop innovative solutions to the social isolation and anxiety we had observed in individuals with COPD. This led to an asset-based community development approach where we matched individual patients to existing community assets such as painting classes or fishing clubs. However, the high levels of anxiety and low self-esteem observed in our client group hampered this model. Following patient consultation we decided that an informal community-based clinic would act as a catalyst for increased involvement. We piloted this by bringing our most socially-isolated patients together for a Christmas party in a local community centre. This event was well received; patients reported feeling less isolated and more cheerful. This led to a rethink and a move in February 2015 to a group model where we blended an informal clinic/education session with social activities such as bingo, quizzes, singing and seated yoga every Monday afternoon in a community centre. This clinic has now successfully run for six months and we are negotiating ongoing funding with Coventry and Rugby Clinical Commissioning Group.

Results:

- Reduced social isolation
- Reduced anxiety
- Increased mental wellbeing
- Transformation change in individual lives as evidenced by personal stories
- Improved confidence in ability to self-manage
- Preliminary evidence of a reduction in unplanned admissions
- An innovative and integrated model of service

Key Challenges:

- The scale and depth of the social isolation and poor mental well-being in people with COPD can be overwhelming to the individual and to the healthcare system
- Some health care professionals found the integrated approach challenging and required time to adapt to and accept this model.
- NHS organisational procedures optimised for hospitals are not always suited to a community-based holistic care model.
- Innovation requires risk-taking, time, and perseverance.
- Responsive project management can be challenging within NHS reporting/governance structures.

Lessons Learnt:

- Integration of health care and social activities has delivered transformational change.
- Significant cultural and organisational differences between NHS and third sector organisations can be overcome with creativity, trust, and compassion.
- The support of senior management at an early stage for innovative projects is essential.

Part 2: Quality impact: outcomes (974 words)

People with COPD are heavy users of the NHS, however they're likely to spend less than 1% of **their** time in contact with health professionals. Patients need to be empowered to self-manage their own conditions.

RIPPLE developed from a stakeholder event involving local patients and carers, health professionals, third sector organisations and academics where we discussed innovative solutions to the loss of wellbeing caused by COPD. We then engaged people with COPD and their carers in further discussions, which led to our theory of change:

INPUTS	ACTIVITIES	OUTPUTS	Short-Term OUTCOMES	Long-Term OUTCOMES	GOAL
<p><i>have conversations with people with COPD and those close to them (baselines)</i></p> <p><i>map existing assets in the community, including hospital ward volunteers,</i></p> <p><i>map assets, strengths and existing networks of patients</i></p> <p><i>identify gaps in current community assets and support their initiation</i></p>	<p><i>growth in the informal community supports used by patients</i></p> <p><i>Connect patients to their communities via their strengths and interests</i></p> <p><i>Introduce people to activities and opportunities (new and existing)</i></p> <p><i>Build circles of informal support</i></p> <p><i>Form a COPD choir</i></p> <p><i>Enable patients to join self help group; meet up with other COPD people to keep informed about how to cope</i></p> <p><i>Enable patients to join community groups, exercise groups to stay as well as you can and get new interests</i></p>	<p><i>a comprehensive and sustainable support network</i></p>	<p><i>Increased self 'management' of COPD as a by product of a more engaged and fulfilled lifestyle</i></p>	<p><i>greater resilience</i></p>	<p><i>Healthier and less vulnerable community of people with COPD</i></p> <p><i>reduced COPD hospital admissions and fewer, earlier better managed exacerbations</i></p>

Initially we commissioned a local charity (who match people with learning disabilities to community resources) to undertake the activities in the second column above. While we observed some examples of improved social integration and wellbeing, uptake was disappointing and the levels of anxiety found in our client group were well beyond their usual experience, proving very hard to overcome.

We also discovered that some of our planned evaluation activities were problematic. Social web and NDTSI mapping were counter-productive, as participants' well-being was worsened by realising how isolated they had become.

We were already considering informal clinic provision and we consulted with patients regarding their preferred location and nature of venue. We had facilitated a successful launch event which had seen high levels of patient involvement and engagement. We therefore decided to replicate this by holding a Christmas Party. This was very well attended and patients reported greatly enjoying the social interaction. We rethought our tactics, and devised a hybrid informal clinic which blended fun activities with gentle exercise, relaxation, and self-management support.

This community based clinic now takes place every Monday in a community centre in a deprived area of Coventry. A COPD consultant and nurse are available to answer questions,

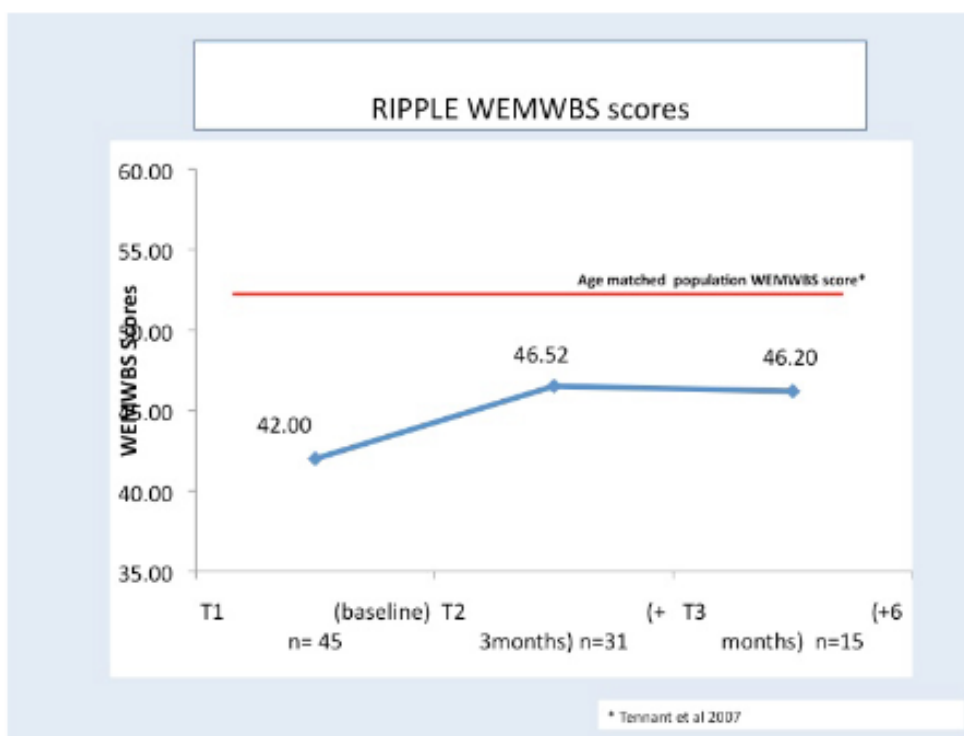
give self-management advice and see patients more formally. We found that patients who would not engage with one-to-one community activities would come for this weekly event.

The participants with COPD share their experiences, engage in social activities and enjoy structured sessions which cover elements of self-management, relaxation, healthy eating, exercise and the use of inhalers, rescue packs and oxygen. Participants are more active and involved in the community and their self-care resulting in increased mental wellbeing and confidence in their ability to self-manage.

Many patient narratives have been captured and in the appendices we relate four powerful representative stories, which provide a rounded picture of the impact of the Monday clinics.

Mental Wellbeing

We used the Warwick Edinburgh Mental Wellbeing Scale to map any changes in mental wellbeing. This validated scale consists of fourteen items; each scored 1 to 5 which produces an overall range of scores from a minimum of 14 to a maximum of 70. Higher scores indicate higher levels of positive mental health. Scores of approximately 50 have been documented in a similar aged population to those participants evaluated in the RIPPLE project (Mason and Kearns 2013). The mean score for RIPPLE participants at the start of their involvement is 42.00 which demonstrate that this is a cohort of patients significantly poor in mental wellbeing. WEMWBS were obtained once a participant had consented to the evaluation (T1) and again at approximately 3 monthly time points (T2 and T3).



Self-Management

The most visible success has been in increasing patients' confidence in their ability to manage their own condition. This cohort of patients are chronically unwell and their mean MRC score is 4.43

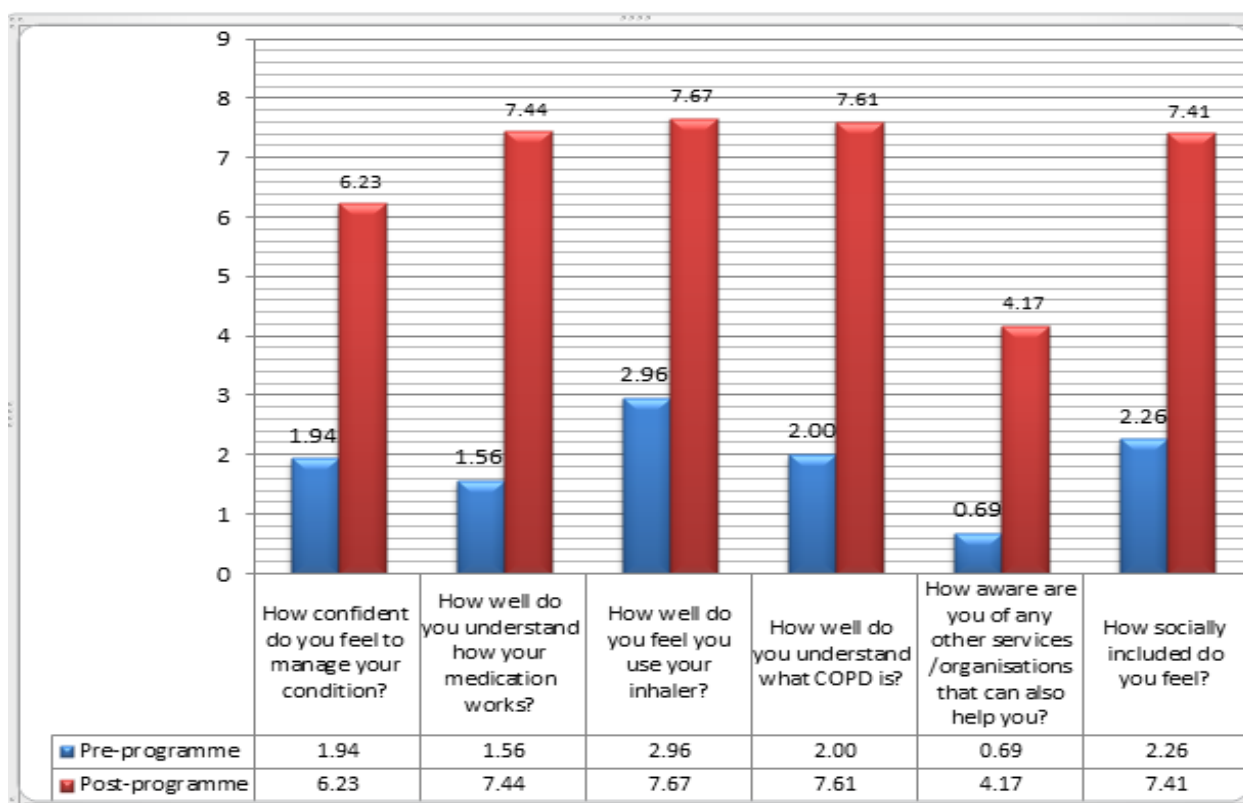
MRC DYSPNOEA SCALE	
Grade	Degree of breathlessness related to activities
1	Not troubled by breathlessness except on strenuous exercise
2	Short of breath when hurrying or walking up a slight hill
3	Walks slower than contemporaries on level ground because of breathlessness, or has to stop for breath when walking at own pace
4	Stops for breath after walking about 100m or after a few minutes on level ground
5	Too breathless to leave the house, or breathless when dressing or undressing

The literacy level of our client group was low and we found they could not understand commonly used self-management material. Therefore individual and localised self-management materials were developed with the British Lung Foundation.

Assessment of patients' confidence regarding their ability to self-manage COPD

In the clinic we utilised a Visual Analogue Scale (VAS) measured along a 10cm line because it is easy for people with low levels of literacy to complete. Twenty patients who are regular attenders on Mondays agreed to help us. Six questions were asked linked to the central aims of self-management and patients were asked to describe their ability to self-manage their condition before they started to attend the clinic compared with now. The scale effectively ranges from 0-10 with 0 being not at all, and 10 being fully positive.

**Patients ability to self-manage their condition
(mean score; pre and post programme)**



Hospital Admittance

To give us an informal understanding of whether involvement in the RIPPLE clinic might affect Hospital Admittance, we compared admittance data for those who had attended the clinic against admittance data for those who had declined.

We examined a six-month period of the running of the RIPPLE clinic from Feb – July 2015 and compared this with the same period in 2014.

Patient cohort	Total number of unscheduled admissions Feb – July 14	Admission rate	Total number of unscheduled admissions Feb – July 15	Admission rate
41 patients not attending Ripple but of similar MRC/Severity	11	27%	15	36%
31 patients who are regular Ripple attendees	13	42%	10	32%

This particular patient cohort is severely unwell and one would expect deterioration in their condition with an increased associated admission rate. This is seen in the cohort of patients who did not attend the clinic, but was not seen in the patients that do attend; in fact their admissions have reduced.

Part 3: Cost impact (497 words)

We estimate the marginal cost of running a RIPPLE community clinic to be £60000 per year. This is based on the following elements:

Nurse Involvement	10000
Community Animateur	18000
Venue Costs	12000
Catering	4000
Transport	7000
Administration	9000
	60000

The venue needs to be a 'normal' community venue that is located within the relevant community location with adequate public transport. Additional support with transport was necessary as was basic refreshments. These elements were not costed into the SHINE bid and were found through additional funding channels.

The cost/social impact of mental ill health is well recognised. Anxiety is estimated to cost the NHS £8.9bn a year, good mental health and wellbeing, and not simply the absence of mental illness, have been shown to result in health, social and economic benefits for individuals, communities and populations (No health without mental health: A cross Government mental health outcomes strategy for people of all ages 2012). It is difficult to estimate the specific potential efficiencies for people regarding mental well-being within the project apart from to report that their wellbeing improved as a result of the project.

The people who chose not to participate in Ripple had an increase of 9% in admittances as opposed to a 10% decrease in those that attended over a similar period.

On the relatively limited data from the project this would equate to a net 19% reduction/prevention in admittance if extrapolated to entire COPD population. The cost of admittance in COPD is estimated at around £2700 on average (NHS COPD care in the North West of England 2014) and in Coventry there are approximately 550 admittances for COPD per year costing £1.5m. If the Ripple figures were extrapolated this would equate to a potential £285K saving. This figure would be unrealistic as it would assume 100% take up of the project. One key aspect of wanting to spread this innovation would be the opportunity to produce a more accurate economic model of the actual potential savings across primary/secondary/pharmaceutical prescribing and health utilisation. Coventry University will produce this economic modelling in the spread.

The change management activity has been resourced internally though UHCW and there has been extensive free support from the Regional Respiratory improvement programme and the ABPI who provided a 6 month period of free project management in the implementation stage. The ABPI are committed to support spread activities where appropriate. UHCW had the bravery to allow a flexible use of internal staffing and resources to allow the project to work.

The cost of the project has been calculated on the expenditure on Third sector providers/materials, venue and transport/refreshments combined with cost of the project

coordinator. Current clinical staff time has not been costed as this is effectively just a flexing of existing clinic time. There was, however, a need for an additional nursing element as people resources within existing staff were low and they were consequently unable to fulfil anticipated time with the project.

One-off costs for the Project in 2014-2015 are:

Individual one-to-one support	41970
Group activity set-up costs	13504
Evaluation	25000
BLF self-management	6000
Age UK Involvement	5000
Social Inclusion Training	1238
Consultation Events	2000
SHINE Events	1000
TOTAL	95712

Part 4: Learning from your project (988 words)

The RIPPLE project is an innovative way of integrating social and medical models of care for people with COPD.

Delivering the RIPPLE model requires health care specialists to overcome traditional ways of thinking and 'fixing' and instead to approach patients as co-decision-makers, moving towards a more asset-based approach where patients, carers and other stakeholders are able to operate as a collaborative team.

The project has worked collaboratively with diverse stakeholders with different skill sets: firstly, health care professionals, which include consultants, nurses, Chaplains and physiotherapist, and secondly, voluntary sector organisations, including national organisations with specialist knowledge of older people as well as local social enterprises with local knowledge and interest.

A key characteristic of the RIPPLE clinic is the informality of the setting. The process of attending a conventional appointment, including travel, waiting and the fear of outcome means patients may experience increased anxiety before seeing a doctor or nurse which exacerbates symptoms. The clinic enables health care professionals to build rapport with patients, and get to know people based on regular, individual interaction. This gives health professionals a more accurate understanding of a person's health needs. As trust is built between patient and professional, patient confidence increases and any doubts that the patient may have had lessen. With the encouragement of third sector partners, patients actively approach professionals with their questions and thus more actively take responsibility for managing their own health.

The self-management and peer advice sessions reassure patients as they provide medical evidence in response to a 'social query' discussed in the session, i.e. a clinical question related directly to the patient's own priorities. One example is the session on 'planning a holiday': third sector partners provided information regarding holiday possibilities, special offers and insurance, and the clinical team provided information related to preparation of medication and ordering oxygen bottles. Patients themselves shared coping strategies on how to minimise the impact of COPD on their holidaymaking.

The RIPPLE clinic provides a rich environment where ideas and concepts can be explored and developed in partnership between the clinicians and peer group of patients and carers.

We believe the RIPPLE clinic offers a successful model for improving self-management in patients with COPD. We believe that the increase in mental wellbeing and social inclusion we have achieved is critical to the ability of patients to effectively self-manage their care. We believe this is a common factor in other Long Term Conditions where social exclusion and mental wellbeing are also an issue, and that our model will be transferable.

The RIPPLE project provides a platform that enables all partners to have an equal part in contributing ideas and making decisions about a patient's health and well-being – patients are allowed and enabled to become active partners and determine the programme and care based on their needs and interests.

The elements listed below are critical elements of our Community Clinic model:

- Respiratory specialist clinician leadership
- Further multi-disciplinary involvement (Physiotherapists, Community Matrons etc.)
- Community “animateur” to practically pull everything together
- Welcoming community-based location
- Patient transport and refreshments
- A programme of activities that mix clinical and social support
- Asset-Based foundations
- Embedded researcher (only while the project is developing)
- Network of strategic support
- Participatory Methodologies

Learning within the clinical team

We have been able to observe and interact with patients in a more ‘natural’, informal and social context. In some cases these interactions also involved immediate family members, such as a spouse, child and/or carer of a patient. Through conversations and by observing interactions with other participants or staff, co-morbidities and other impairments become more evident. Not only the symptoms of COPD, but other physical and mental health conditions impact on patients’ quality of life and their mental wellbeing – and that of their families.

In the community clinic we can take the complexity of conditions as well as social relations into account when giving advice and support to the individual patient in a more person-centred and holistic manner. Patients’ narratives show how important it is to many people that they could not only talk about COPD but also about the impact of other conditions. We feel that this approach has proved to be more successful than attending to patients in a traditional hospital setting, as it allows observation and interaction with patients over a longer period of time and in a naturalistic setting.

This then enables more specialised and individualised support for patients. In the case of some RIPPLE participants this has led to the correction of misdiagnoses. Observations and interactions also allow us to react to changes in a patient’s condition from an early stage, and advise on prescriptions and medications can be administered easily and more effectively. Some patients reported that usually changes to prescriptions had only occurred after an emergency situation, often involving unplanned and very stressful admission to hospital, which is now avoided.

Involving the partners from the Third Sector and their knowledge and expertise enabled the extension of support and empowerment to address social matters, which subsequently allowed for an integrated approach to health and social care. This local knowledge was also

very useful when other forms of support or information were needed, as Third Sector staff made use of existing networks to link patients with other groups or individuals. In addition, Third Sector partners were also always approachable to support participants to 'help themselves' as part of 'one-to-one' support within the settings of the RIPPLE project and beyond.

Each RIPPLE Clinic involved a session on self-management. Initially, these were mainly led by the clinical staff and/or officers of the British Lung Foundation, however, over time local expertise became more and more part of these sessions and clinical and community partners started to talk 'with one voice' during these sessions. More importantly, from the outset the objective of these sessions was to enable patients to take more and more responsibility and leadership, so that these sessions would become 'true' peer-support sessions.

We now have a further developed logic model:

INPUTS	ACTIVITIES	OUTPUTS	Short-Term OUTCOMES	Long-Term OUTCOMES	GOAL
<p><i>Use a model of relational leadership which enables people to engage.</i></p> <p><i>Use of a diverse multi-disciplinary team across all sectors.</i></p> <p><i>Initial project management input from the private sector.</i></p> <p><i>Development of strategic partnership boards, this included all relevant stakeholders and particularly conversations with people with COPD and those close to them.</i></p> <p><i>map existing assets in the community, including hospital ward volunteers,</i></p> <p><i>map assets, strengths and existing networks of patients</i></p> <p><i>identify gaps in current community assets and support their initiation</i></p>	<p><i>growth in the informal community supports used by patients</i></p> <p><i>Connect patients to their communities via their strengths and interests</i></p> <p><i>Introduce people to activities and opportunities (new and existing) This includes mindfulness, relaxation and appropriate physical exercise.</i></p> <p><i>Build circles of informal support</i></p> <p><i>Form a COPD choir</i></p> <p><i>Enable patients to join self-help group; meet up with other COPD people to keep informed about how to cope</i></p> <p><i>Enable patients to join community groups, exercise groups to stay as well as you can and get new interests</i></p>	<p><i>Bespoke self-management materials taking into consideration cultural issues and learning capabilities.</i></p> <p><i>Greater patient input into the design of their care.</i></p> <p><i>A comprehensive and sustainable support network</i></p>	<p><i>Increased confidence of patients to self-manage their condition as a result of a more engaged and fulfilled lifestyle.</i></p> <p><i>Correction of medication errors and verification of diagnosis.</i></p> <p><i>Increased patient mental wellbeing.</i></p>	<p><i>Greater resilience regarding mental health. People report feeling healthier and happier.</i></p> <p><i>It is acknowledged that the majority of those involved are potentially in the last year(s) of life. The RIPPLE project offers an informal environment that allows people to explore issues and opportunities around end of life care.</i></p>	<p><i>Healthier and less vulnerable community of people with COPD</i></p> <p><i>reduced COPD hospital admissions and fewer, earlier better managed exacerbations</i></p>

Part 5: Plans for sustainability and spread (500 words)

We are now preparing a summary of the project, together with costings and impact, for Coventry and Rugby Clinical Commissioning Group and indications are that funding for the existing RIPPLE model will be available from April 2016. UHCW are committed at board level to supporting the ongoing development of the model and are looking at its potential to deliver improved outcomes in different disease specific conditions. Utilising volunteer support has been an important aspect of the current project; these volunteers have a well-developed skill mix and provide additional linkages to community. Increased use of volunteers within the project in the future will aid sustainability. Beyond this our intention is to more rigorously study the innovative clinic model through roll-out to six sites across the West Midlands pending a successful 'Spreading Innovations' invited bid to the Health Foundation. We outline below our intended project future spread.

The overall aim of the Making Waves (RIPPLE II) project is to spread the model developed within the original RIPPLE project to 6 other local health economies within the West Midlands Region.

The complex and uncertain nature of the environment within which people with COPD are trying to manage their condition and their lives, implies that there remains, to some degree, a need to consider the evaluation of the first project as somewhat developmental, and we have therefore integrated elements of '*double-loop learning*' (Argyris and Schon, 1974) in these follow-up plans so that we can continue to check and revise our theories and assumptions. Thus the introduction of similar projects across the West Midlands will be staged, and we are planning for cross-project systemic reviews of learning and ongoing testing of our theories of change throughout the project.

In the spread we additionally wish to evaluate and learn from a deeper and broader investigation of the issues around patient anxiety for this group of patients. We already have evidence of reduced patient ability to access low cost high value treatments, such as smoking cessation and pulmonary rehabilitation because of anxiety.

We believe Making Waves (RIPPLE II) will lead to additional spread nationally as the model becomes accepted as well-evidenced best practice rather than an interesting single innovation. Consequently robust academic evaluation remains critical to the project, both in terms of the general nature of collaborative community clinics, and also in terms of successful patient self-efficacy for those living with COPD, even if they are socially disadvantaged.

Appendix 1: WEMWBS Evaluation – further detail

- 46 participants consented to be part of the evaluation of the RIPPLE project.
- 35 participants attended at least one session of the once-weekly self-management session and 9 participants did not attend but received one-to-one input to improve social engagement. The remaining participants received input from Age UK.
- Table 1 details demographic information was received from 45 out of the 46 participants who consented to the evaluation.

Table1: RIPPLE Evaluation – baseline demographics

Age	mean (SD) yrs.	68.62 (8.53)
MRC Grade *	median (IQR)	4 (1)
	Grade 2 (n)	1
	Grade 3 (n)	2
	Grade 4 (n)	11
	Grade 5 (n)	8
Gender	Male: female (n) (%)	22:24 (48%: 52%)
Age left Education n (%)**:	≥ 15yrs	35
	16yrs	6
	17rs	1
	18-20 yrs.	1
	21yrs +	2
Ethnicity (n) (%)**	White - British	40 (89%)
	White - other	5 (11%)
Employment Status (n) (%)**	retired	30 (67%)
	Permanently sick/disabled	13 (29%)
	Unemployed and not actively seeking work	2 (4%)

* MRC grade was only obtained from 18 participants

** 1 x missing data point

- **WEMWBS Data:**

The Warwick Edinburgh Mental Well-Being Scale (WEMWBS) (Tenant et al 2007) is a validated measure of positive mental health. It consists of 14 item questionnaire where participants indicate their experience of each item over the past 2 weeks. Each item is scored 1 to 5 which produces an overall range of scores from a minimum of 14 to a maximum score of 70. Higher scores indicate higher levels of positive mental health. Scores of approximately 50 have been documented in a similar aged population to those participants evaluated in the RIPPLE project (Mason and Kearns 2013). WEMWBS were obtained once a participant had consented to the evaluation (T1) and again at approximately 3 monthly time points (T2 and T3)

Baseline (T1) WEMWBS were received from 45 of the 46 participants who consented to the evaluation. The mean (SD) baseline score was 42.00 (12.38) with scores ranging from 14 to 69. A total 31 WEMWBS were obtained at T2 and 15 at T3. Mean WEMWBS scores for all three time points are shown in Table 2 and a paired analysis is detailed in table 3:

There is currently no published minimal clinically important difference defined for changes in WEMWBS when used with people who have COPD. The standardised response mean (calculated by dividing the mean change in the WEMWBS score by the standard deviation of the mean change score) from T1 to T2 is 0.42. The Cohen's effect size (mean change in score divided by the standard deviation of the baseline score) from T1 to T2 is 0.32 indicating that a small to moderate change has taken place.

Table 2: Mean WEMWBS scores

Time point	n	Mean score	SD
T1	45	42.00	12.38
T2	31	46.52	11.14
T3	15	46.20	6.14

Table 3: Change in WEMWBS over T1, T2

and T3

Time point	n	Mean change	SD	95% Confidence Interval	p value
T1 to T2	31	4.68	11.22	8.79 to 0.56	0.027
T2 to T3	15	0.00	10.29	5.69. to -0.56	1.000
T1 to T3	15	7.87	14.54	15.92 to 0.18	0.055

- **St Georges Respiratory Questionnaire (SGRQ)**

A total of 24 participants completed a SGRQ. Due to missing data scores could not be calculated for each of these participants. The mean scores for each of the three domains and total scores are shown in table 4.

Table 4: Mean SGRQ scores

	n	Mean score	SD
SGRQ symptoms	24	74.36	19.88
SGRQ activity	12	85.03	24.67
SGRQ impacts	18	56.96	26.25
SGRQ total score	18	67.21	23.61

Appendix 2: Patient Stories

'Lily' - *'I know now that I can manage it. That is great for me'*

In many ways, Lily's experience and perspectives were typical of the group of patients the project engaged. These patients would report low confidence and anxieties that made them socially isolated, but also they demonstrated a willingness to let the Monday clinic offer new perspectives on living with COPD.

Lily reported that she had not left the house prior to the Monday RIPPLE clinic for at least two years. Also attending the formal appointments in the hospital had been very stressful for her to achieve, and she reported that she sometimes had just physically not been able to be taken to hospital and she had thus missed assessments – which made her feel guilty.

When Lily attended the clinic for the first time, one of her first indications of her physical frailty – but also potentially her low self-confidence – was that she indicated not wanting to stay for the full RIPPLE clinic of four hours as she thought that she might become too tired, so, she organised someone privately to pick her up after two hours. However, over the weeks, Lily reported she felt more confident:

I feel safe being here. There is medical staff, and also the other staff are always on hand to help me. Everyone is just so nice. And if I get tired, I just take a break and no-one will pressure me.

In week three, Lily started to make use of the taxi service. She indicated that being able to use the taxi transport was a challenge, as she needed to be ready when the taxi driver would ring – but this was one of the goals that Lily had set herself with regard to being better able to manage her COPD:

I do not want the COPD to prevent me from going out anymore. That RIPPLE is on every Monday puts a bit of pressure on me to get ready every week. But I know now that I can manage it. That is great for me.

'Getting ready', was a great challenge for Lily both physically and mentally, as she told the team that she would start to think about getting to and attending the Monday clinic 'by Sunday lunch time'. She initially perceived this as a chore, over the weeks it became part of her life that she looked forward to and she felt that attending was 'actually a great achievement'. She indicated that the Monday clinic had given her week new structure – and in conversation repeatedly called the project 'a lifeline'.

'Martin' - *'A great opportunity to learn about COPD and how to manage it properly'*

Was a member of the first cohort of patients who attended the Monday clinic. He felt that the RIPPLE project would give him and others a great opportunity to learn how to manage COPD on a daily basis, including the correct use of medications for his individual situation. Additionally, he hoped that the RIPPLE project would offer him and others the opportunity to engage with other people who had the same condition and to share experiences of living with COPD. He reported that people with COPD often felt excluded from social activities.

Martin admitted initially that he was unsure if he would gain anything himself from the social element of the RIPPLE project; nevertheless, he felt that it would be very important for others and he seemed always happy to share his experiences. Thus, Martin engaged very actively during the self-management and peer exchange parts of the Monday clinic. By openly asking questions and sharing his experiences, he often encouraged others to also ask questions during the activity, at other times he supported other attendees to talk to the clinical staff and the team members from the third sector organisations.

The conversations and self-management sessions led by the Respiratory Consultant or the COPD nurse, often involved questions about medication, correct use of inhalers or reassurance around using oxygen. Team members from the third sector were approached with questions about social activities outside the RIPPLE project, information on holidays and receiving social care support. Martin reported that being able to talk to both health experts and people with local expertise had greatly increased his knowledge about COPD and how to manage his health condition. This put him in a position where he felt more confident to discuss his medication with his GP and he felt better about asking others for help. He also especially valued the opportunity to meet team members from the third and voluntary sector as they would provide him *'with local knowledge'* and signposting, *'They know the local organisations and the people to go to and ask, or they know who I can ring,'*

'Judith' - *'I am confident to go on holiday again'*

Judith attended the RIPPLE project and especially the Monday informal clinic with the single aim, of wanting to get her confidence to go on holiday again, as she had done before she was diagnosed with COPD. Since her diagnosis she felt like she lacked confidence and rarely left home. She had resigned herself to the belief that she would not be able to leave Coventry, as she feared unexpected flares or *'panic attacks'* would increase when outside her known routines and environments.

She used the Monday clinic as an opportunity to build up her self-confidence when engaging in both social and physical activities, despite her condition. As she felt more comfortable with people she asked questions and gathered information about how to travel safely with COPD.

Other patients also suggested talking about *'going on holiday with COPD'* from the very beginning, thus the RIPPLE team organised three self-management and peer exchange sessions giving participants information about holidays in the UK and abroad, especially about medication and use of oxygen, insurance companies and offers, opportunities for day trips or group holidays as offered by national charities, e.g. Age UK.

For Judith it was important to prove to herself that short physical activities would not aggravate the symptoms of her COPD. She engaged in physical activities provided by one of the third sector partners, such as dance exercises and bowls, as well as gentle activities such as seated yoga.

Finally, Judith felt ready to organise a weekend trip away. The Monday after her return from her holiday, she shared the news with the group. It was special to Judith to tell the staff and other participants about her weekend trip; she felt proud of having achieved this goal. With her experience she encouraged other participants to travel again.

Judith is now planning additional holidays and aims to take the grandchildren to the coast for her next trip.

Tom – ‘Here, I am not just a number’

Tom attended the RIPPLE project initially based on the COPD consultant’s recommendation. He had been in hospital over the winter months, and had survived a near death experience. He reported that he had lost all his confidence, even walking to the end of his road had become a very frightening experience. Whereas before he and his wife used to visit their children in Ireland regularly, he realised that he ‘*dare not go anywhere*’, not even locally in the West Midlands, for fear ‘*there may be a flare up and nothing could be done about it*’.

Tom regularly reads about his condition as to have a better understanding of his health and possible treatments. This has led him to become a ‘*lay expert*’, and he is an active participant in the peer support sessions. He will often share useful tips for self-management, suggestions which really make a difference to other participants’ lives. His wife, who is his carer, reports that it is a surprise to see him like this as he is normally quiet, frustrated and withdrawn. Tom feels the project has given him the opportunity to feel purposeful and he has realised that he has valuable ideas which can help others. The project has also enabled his wife to feel that they have something positive to talk about when they get home, which has greatly improved their relationship.

Tom talked openly about being in hospital over the winter, when he nearly died; this gave the other men in the group an opportunity to talk about their own fears surrounding their conditions, and their fear of death. Their partners reported this as a very important aspect of the session as they find their husbands do not readily open up and talk about their anxieties or emotions to them. As a result of this most men felt that they have a space where they can be more open, and see other people in similar situations.