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Using the Ophelia (Optimising Health Literacy and Access) approach to generate and drive healthcare improvements in Respiratory Disease

Interim report and summary – June 2016



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Executive Summary (1)

Background and data collection

- The Respiratory team were keen to more effectively meet the needs of people with long-term lung conditions by addressing [Health Literacy](#) using the [Ophelia process](#)
- This project was supported by a successful bid to the Health Foundation's Innovating for Improvement project in September 2015
- At a North Tyneside respiratory team meeting in May 2015 it was decided an appropriate initial focus would be people with Chronic Obstructive Pulmonary Disease (COPD) attending the specialist clinic at North Tyneside hospital
- 100 [Health Literacy Questionnaires](#) were completed in June and July 2015, led by Stephen Gundry
- The HLQ data was processed into [clusters](#) by Alison Beauchamp and team at Deakin University
- The clusters were then developed into clinical stories or 'vignettes' by Simon Eaton

Executive Summary (2)

Focus group and generation of issues and ideas

- The vignettes were presented at [focus groups](#) on:
 - 25th November 2015 – Clinicians
 - 25th January 2016 – Citizens (patients and community members)
- During the focus groups participants were asked to consider some of the health literacy related issues faced by people described in the vignettes, and what might be helpful to the person.
- To facilitate this, the participants were posed the questions:
 - Does this person seem to be like someone you might know/ one of your patients?
 - What are this person's main problems in relation to their health?
 - What could be done to help improve things for this person?
 - What about if there were lots of people like this in your community/clinic? What could be done to support them?
- All of the issues and ideas/suggestions were recorded on flipcharts
- [Click here](#) to view the vignettes and the issues identified from each of the focus groups

Executive Summary (3)

Theming of issues and ideas

- The local Ophelia project team then identified themes from the issues and ideas generated to present to the combined ‘co-production’ focus group
- The themes identified are listed below:
 - Understanding your condition
 - Clarity of diagnosis; understanding your care and your condition; what to expect
 - Preparing for your visit
 - Having enough information; making the most of your visit; understanding what to expect
 - The clinic experience
 - Purpose; navigating around the clinic system; who does what?; consultation style and length
 - Beyond the clinic
 - Community support; what keeps people well; GP/community nurses/community health service
- [Click here](#) to see the issues listed under each theme (blue from Citizen group; green from clinician) and the ideas linked to these

Executive Summary (4)

Co-production of interventions – early thoughts

- The combined clinician and citizen ‘co-production’ focus group took place on 20th May 2016
- Participants were invited to go to the table with the issue theme of their choice. On the table, were all of the ideas related to that theme. Participants were asked to sort and prioritise the ideas and/or sub-themes according to what they would like to see implemented and what could really make a difference.
- They were then asked to add some detail to these '[early thoughts](#)' on a template provided, including consideration of what the intervention would look like and what needed to be done to achieve this.
- Tables were asked to present these to the group. These were summarised on a flipchart and participants were asked to vote on what they would like to progress further during this session (2 votes per person, indicated as ticks on the chart) – [click here](#) for details.

Executive Summary (5)

Co-production of interventions – early thoughts

- From the voting, two main interventions were identified. Participants were asked to go to the intervention idea of their choice and make a detailed plan for how this could be delivered using the '[Ideas into action](#)' templates, which firstly considered details of what the intervention would look like and aim to achieve, followed by specific action planning. The interventions were (full details available by clicking hyperlink):
 - [It's all about you!](#)
 - A variety of interventions aimed at ensuring people were more able to participate in, and get more from, the clinic appointments, including:
 - Prompts for pre-appointment preparation
 - More information about the clinic
 - Encouraging people to bring a friend or buddy with them
 - [COPD social club](#)
 - A community-led initiative to increase social and community support, along with potential educational and physical interventions, for people with COPD
 - The next step is for the teams to take these plans forward as they had agreed.

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Introduction to Health Literacy and the Ophelia approach



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What is Health Literacy (1)?

Health Literacy describes how people find out about health, and understand and use that information to achieve better health. Addressing health literacy is increasingly seen as an important way to reduce health inequalities and improve health outcomes, especially for those with long-term conditions.

Recent definitions of health literacy have moved beyond a person's ability to read and understand information about health, towards a multi-dimensional concept covering the personal characteristics and social resources needed for people to find, understand and use information and services to make decisions for health.

Health literacy considers the ***personal characteristics and social resources*** that individuals and communities need in order to ***access, understand, appraise*** and ***use*** information and services to ***make decisions about health***, or that have ***implications for health*** including the ***capacity to communicate, assert and enact*** these decisions.

As such it includes an individual's ability to:

- access and utilise health care
- interact with health services and providers
- self-manage and care for their own health and that of others
- participate in health discussions and decision-making

What is Health Literacy (2)?

Health literacy has gained international interest as a determinant of health outcomes. Lower levels are shown to relate to poorer access to services, less engagement in health promotion or self-management behaviour, higher use of emergency services, higher healthcare costs and may explain health inequalities among people of different race and differing educational attainment.

It is important to note that while health literacy refers to the competencies of individuals, it implies a responsibility for organisations and health providers to respond appropriately and effectively to the health literacy needs of the consumers they serve.

Known as ‘health-literacy responsiveness’ this puts the onus on the healthcare provider to develop and deliver services which recognise and support health literacy needs.

Many policy documents now recognise the significance of health literacy, not just at a ‘person’ level, but also as a concept that health services can measure and respond to.

Further reading

www.ophelia.net.au

http://www.searo.who.int/entity/healthpromotion/documents/hl_toolkit/en/

www.healthliteracy.org.uk

RW Batterham, M Hawkins, PA Collins, R Buchbinder RH Osborne. Health literacy: applying current concepts to improve health services and reduce health inequalities. *Public Health* 2016;132;p3-12

The Ophelia Process

Optimising Health Literacy and Access

The Ophelia approach is a robust and highly engaging process to enable clinicians, service users and community groups to coproduce meaningful and effective interventions within clinical and personal/community settings.

Originally developed in Australia, and tested in Thailand, South Africa and Denmark, it has not previously had widespread use in the UK.

The process starts with identification of a particular part of the healthcare system that is not meeting the needs of, or engaging with, those it aims to serve. The Health Literacy Questionnaire enables the needs, capabilities and lived experience of such populations to be profiled. The process reports HLQ data in a highly engaging 'vignettes' of typical community cases. Healthcare consumers and providers then focus on these to enable local wisdom to emerge. In this way solutions are co-produced and used to drive and deliver service redesign and improvement.

Further reading

www.ophelia.net.au

RW Batterham, R Buchbinder, A Beauchamp, S Dodson, GR Elsworth, RH Osborne. The OPTimising HEalth LIterAcy (Ophelia) process: study protocol for using health literacy profiling and community engagement to create and implement health reform. BMC Public Health 2014, 14:694 <http://www.biomedcentral.com/1471-2458/14/694>

The Ophelia Process

Phase 1
Identify health literacy strengths and limitations of local community

- Collect data (health literacy, demographic, service use) from target group of interest
- Feed back results to clinicians / community members in workshops to generate intervention ideas

Phase 2
Co-creation of health literacy interventions

- Local stakeholders work together to identify which interventions have potential to address local health literacy needs or improve information/ service access

Phase 3
Implementation, evaluation and ongoing improvement

- Health literacy interventions are applied within quality improvement cycles and continuously evaluated to improve effectiveness, uptake and sustainability

The Health Literacy Questionnaire identifies the specific health literacy strengths and limitations of people & communities across 9 domains



HLQ Scale	Item location in the HLQ	Interpretation - what do the scale scores mean?
1. Feel understood and supported by healthcare providers	Part 1 - Q 2 Part 1 - Q 8 Part 1 - Q 17 Part 1 - Q 22	<p>High: Has an established relationship with at least one healthcare provider who knows them well and who they trust to provide useful advice and information and to assist them to understand information and make decisions about their health.</p> <p>Low: People who are low on this domain are unable to engage with doctors and other healthcare providers. They don't have a regular healthcare provider and/or have difficulty trusting healthcare providers as a source of information and/or advice.</p>
2. Have sufficient information to manage my health	Part 1 - Q 1 Part 1 - Q 10 Part 1 - Q 14 Part 1 - Q 23	<p>High: Feels confident that they have all the information that they need to live with and manage their condition and to make decisions.</p> <p>Low: Feels that there are many gaps in their knowledge and that they don't have the information they need to live with and manage their health concerns.</p>
3. Actively managing health	Part 1 - Q 6 Part 1 - Q 9 Part 1 - Q 13 Part 1 - Q 18 Part 1 - Q 21	<p>High: Recognise the importance of and are able to take responsibility for their own health. They proactively engage in their own care and make their own decisions about their health.</p> <p>Low: People with low levels don't see their health as their responsibility, they are not engaged in their healthcare and regard healthcare as something that is done to them.</p>
4. Have social support for health	Part 1 - Q 3 Part 1 - Q 5 Part 1 - Q 11 Part 1 - Q 15 Part 1 - Q 19	<p>High: A person's social system provides them with all the support they want or need.</p> <p>Low: Completely alone and unsupported.</p>
5. Appraise health information	Part 1 - Q 4 Part 1 - Q 7 Part 1 - Q 12 Part 1 - Q 16 Part 1 - Q 20	<p>High: Able to identify good information and reliable sources of information. They can resolve conflicting information by themselves or with help from others.</p> <p>Low: No matter how hard they try, they cannot understand most health information and get confused when there is conflicting information.</p>

HLQ Scale	Item location in the HLQ	Interpretation - what do the scale scores mean?
6. Ability to actively engage with healthcare providers	Part 2 - Q 2 Part 2 - Q 4 Part 2 - Q 7 Part 2 - Q 15 Part 2 - Q 20	<p>High: Is proactive about their health and feels in control in relationships with healthcare providers. Is able to seek advice from additional health care providers when necessary. They keep going until they get what they want. Empowered.</p> <p>Low: Is passive in their approach to health care, inactive, i.e., they do not proactively seek or clarify information and advice and/or service options. They accept information without question. Unable to ask questions to get information or to clarify what they don't understand. They accept what is offered without seeking to ensure that it meets their needs. Feel unable to share concerns.</p>
7. Ability to navigate the healthcare system	Part 2 - Q 1 Part 2 - Q 8 Part 2 - Q 11 Part 2 - Q 13 Part 2 - Q 16 Part 2 - Q 19	<p>High: Able to find out about services and supports so they get all their needs met. Able to advocate on their own behalf at the system and service level.</p> <p>Low: Unable to advocate on their own behalf and unable to find someone who can help them use the healthcare system to address their health needs. Do not look beyond obvious resources and have a limited understanding of what is available and what they are entitled to.</p>
8. Ability to find good health information	Part 2 - Q 3 Part 2 - Q 6 Part 2 - Q 10 Part 2 - Q 14 Part 2 - Q 18	<p>High: Is an 'information explorer'. Actively uses a diverse range of sources to find information and is up to date.</p> <p>Low: Cannot access health information when required. Is dependent on others to offer information.</p>
9. Ability to understand health information well enough to know what to do	Part 2 - Q 5 Part 2 - Q 9 Part 2 - Q 12 Part 2 - Q 17 Part 2 - Q 21	<p>High: Is able to understand all written information (including numerical information) in relation to their health and able to write appropriately on forms where required.</p> <p>Low: Has problems understanding any written health information or instructions about treatments or medications. Unable to read or write well enough to complete medical forms.</p>

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HLQ cluster analysis, vignettes and focus groups



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HLQ clusters

	Number of people in cluster	Average age	% Female	% Lives Alone	Average Educ	% Finish secondary	% Retired	% Works full/part-time	% Incapacitated to work	% Assisted with HLQ
"Alan"	16	76.5	25%	38%	3.0	63%	69%	6%	13%	25%
"Brian"	37	70.4	43%	38%	3.2	62%	68%	5%	16%	46%
"Claude"	9	67.4	44%	22%	3.9	22%	67%	11%	11%	0%
"Dee"	13	73.7	54%	46%	3.3	69%	77%	8%	15%	62%
"Edith"	4	77.4	100%	100%	2.3	75%	100%	0%	0%	100%
	Number of people in cluster	Average number of health conditions	% COPD	% Arthritis	% Back Pain	% Heart	% Cancer	% Depression/anxiety	% Diabetes	% A+E in past 12 months
"Alan"	16	1.9	81%	31%	19%	19%	6%	13%	19%	81%
"Brian"	37	2.6	92%	32%	38%	19%	11%	24%	19%	59%
"Claude"	9	3.1	89%	44%	33%	44%	33%	0%	11%	44%
"Dee"	13	3.0	100%	31%	38%	46%	15%	31%	8%	85%
"Edith"	4	2.3	100%	25%	25%	50%	0%	0%	25%	100%
	Number of people in cluster	Understood and supported by healthcare providers	Having sufficient information	Actively managing my health	Social support for health	Appraisal health information	Active engagement with healthcare providers	Navigating the healthcare system	Finding health information	Understand health information to know what to do
"Alan"	16	3.81	3.77	3.50	3.88	3.32	4.50	4.37	4.27	4.48
"Brian"	37	3.20	3.05	2.87	3.20	2.84	4.29	4.01	3.90	4.12
"Claude"	9	3.00	2.42	2.84	2.62	2.82	3.49	3.47	3.71	3.96
"Dee"	13	2.44	2.67	2.40	2.96	2.28	3.06	3.05	3.05	3.31
"Edith"	4	2.44	2.44	2.34	3.30	1.90	2.20	1.85	1.65	1.65

Ophelia Focus Groups

'A process to embrace local wisdom'

Clinicians – Nov 2015

- 3 Doctors
- 7 Respiratory Specialist Nurses
- 1 Respiratory Care Worker
- 1 Assistant Psychologist
- 1 Outpatients Clinic Nurse

Citizens – Jan 2016

- 7 participants
 - Clinic attendees
 - Local Breathe Easy Group
 - Other Patient Leaders
 - British Lung Foundation

Co-production – May 2016

- 3 Doctors
- 9 Respiratory Specialist Nurses
- 2 ‘Patients’
- 1 representative from British Lung Foundation

Brian

Number of people in cluster	Average age	% Female	% Lives Alone	Average Educ	% Finish secondary	% Retired	% Works full/part-time	% Incapacitated to work	% Assisted with HLQ
37 (47%)	70.4	43%	38%	3.2	62%	68%	5%	16%	46%
Number of people in cluster	Average number of health conditions	% COPD	% Arthritis	% Back Pain	% Heart	% Cancer	% Depression/anxiety	% Diabetes	% A+E in past 12 months
37 (47%)	2.6	92%	32%	38%	19%	11%	24%	19%	59%

Number of people in cluster	Understood and supported by healthcare providers	Having sufficient information	Actively managing my health	Social support for health	Appraisal health information	Active engagement with healthcare providers	Navigating the healthcare system	Finding health information	Understand health information to know what to do
37 (47%)	3.20	3.05	2.87	3.20	2.84	4.29	4.01	3.90	4.12

Brian is a 70 year old retired insurance clerk. He and his wife had been living pretty well into their retirement, but recently she has been starting to get a bit frail and has developed some memory problems. He has been trying to look after her, but his health problems, including his breathing and his diabetes, are getting on top of him, and frankly he has been getting pretty down. He gets on well with the doctors at the chest clinic, but is never quite sure who he is going to see and what they are going to do. He doesn't see his GP that regularly either. He is aware this is all part of getting older, but he can't quite see a light at the end of the tunnel at the moment.

Brian – Issues identified

Issues identified by both the citizen group and respiratory team:

Depression/low mood/feeling down

Worried about wife- needs help?

Don't know what is going on/who is who/not sure where to go with what

Lack of continuity of care

Theme	What are the issues for Brian – citizen group	What are the issues for Brian – respiratory team
Impact on how you feel	<p>Feeling like when you get to a certain age people (HCP) aren't bothered</p> <p>Feeling terrified</p> <p>Anxiety causing breathing to be worse</p>	<p>Getting older</p> <p>Loss of independence</p> <p>Struggling – not 100% fit</p> <p>Progression of his long term condition</p> <p>Multiple long term conditions</p>
Clarity of diagnosis	<p>Clarity of diagnosis – what you have and not just what you don't have</p> <p>Clarity about ongoing healthcare and what to expect (but it can be difficult to make a diagnosis)</p> <p>How good are people at explaining things so that he will understand?</p>	
Who you see	<p>Having no control over who you see – might not get on with the doctor or nurse</p> <p>Always seeing the nurse when you would like to see the consultant too</p> <p>Seeing the right person in the team on the day</p>	<p>Conflicting advice from professionals</p> <p>Might understand/have rapport with some people more than others</p> <p>Conflicting advice from health care providers</p> <p>Seeing lots of different health care professionals- privacy and intrusion</p>
Other issues		<p>Neglecting himself (more worried about his wife)</p> <p>Not that proactive</p> <p>Gives the impression he understands – may not be taking it all in</p> <p>Might tell people (HCP) in their environment(clinic) what they want to hear</p> <p>Is it clear what he wants?</p>

Dee

Number of people in cluster	Average age	% Female	% Lives Alone	Average Educ	% Finish secondary	% Retired	% Works full/part-time	% Incapacitated to work	% Assisted with HLQ
13 (16%)	73.7	54%	46%	3.3	69%	77%	8%	15%	62%
Number of people in cluster	Average number of health conditions	% COPD	% Arthritis	% Back Pain	% Heart	% Cancer	% Depression/anxiety	% Diabetes	% A+E in past 12 months
13 (16%)	3.0	100%	31%	38%	46%	15%	31%	8%	85%

Number of people in cluster	Understood and supported by healthcare providers	Having sufficient information	Actively managing my health	Social support for health	Appraisal health information	Active engagement with healthcare providers	Navigating the healthcare system	Finding health information	Understand health information to know what to do
13 (16%)	2.44	2.67	2.40	2.96	2.28	3.06	3.05	3.05	3.31

Dee is 74 years old. She is a retired shopkeeper and lives with her husband Stewart. She has COPD, which can be troublesome at times and she was in hospital for a few days last winter. However, her main problem day-to-day is her back pain, which limits her mobility and, she feels, is responsible for her ongoing weight gain. Together these things really do get her down.

When she attends the clinic she feels the doctors she sees will often focus on her chest and give her a hard time for her weight and her smoking. She feels as though they don't really understand how difficult she is finding things. She has tried so many times to make changes, but she doesn't quite know what would work best and what has been suggested has never seemed to work.

She really would like to feel better, but isn't sure what to do next.

Dee – Issues identified

Issues identified by both the citizen group and respiratory team:

Main issues and concerns: weight / back pain/low mood

People don't see her point of view/ doesn't feel understood

Theme	What are the issues for Dee – citizen group	What are the issues for Dee – respiratory team
Understanding the patient and meeting their needs	<p>Feeling down</p> <p>Feels discouraged to raise multiple issues</p> <p>Doesn't feel as though consultation is for their benefit</p> <p>No-one is listening to her</p> <p>Not sure what support is available</p> <p>Can't communicate difficulties</p> <p>She is vulnerable</p>	<p>Disengaged by low mood</p> <p>Mostly we want to do things to patients – fix them</p> <p>Doesn't feel understood</p> <p>Does she need to be in chest clinic?</p> <p>Clinic is not fulfilling her needs- Is she seeing the right person?</p> <p>Not necessarily under follow up (check not main problem; been through most things)</p> <p>Heart sink patient</p>
Smoking	<p>May help her get through the day</p> <p>Reluctant to stop smoking – might increase her weight</p> <p>What smoking cessation support has she had?</p> <p>Not helpful to keep telling her off</p> <p>Can she benefit from stopping smoking?</p> <p>Doesn't know where to start</p> <p>Needs help to navigate through options</p>	<p>Main intervention stop smoking</p> <p>Might be rebellion around stop smoking message</p> <p>Smoking cessation services vary</p> <p>Everybody's problem – not specifically respiratory</p>
Other issues	<p>Finding it difficult to exercise</p> <p>Does she have a rescue pack</p>	<p>Guilty – one issue impacting onto another</p> <p>Disengaged by low mood</p> <p>COPD vs. lung cancer (different level of support for latter)</p>

Edith

Number of people in cluster	Average age	% Female	% Lives Alone	Average Educ	% Finish secondary	% Retired	% Works full/part-time	% Incapacitated to work	% Assisted with HLQ
4 (5%)	77.4	100%	100%	2.3	75%	100%	0%	0%	100%
Number of people in cluster	Average number of health conditions	% COPD	% Arthritis	% Back Pain	% Heart	% Cancer	% Depression/anxiety	% Diabetes	% A+E in past 12 months
4 (5%)	2.3	100%	25%	25%	50%	0%	0%	25%	100%

Number of people in cluster	Understood and supported by healthcare providers	Having sufficient information	Actively managing my health	Social support for health	Appraisal health information	Active engagement with healthcare providers	Navigating the healthcare system	Finding health information	Understand health information to know what to do
4 (5%)	2.44	2.44	2.34	3.30	1.90	2.20	1.85	1.65	1.65

Edith is 77 years old and lives alone following the death of her husband 2 years ago. She has COPD and angina. She had attended A&E once in the past 12 months with a chest infection but was pleased that she didn't need to be admitted.

Edith is a retired factory worker, but after losing her husband, and with her current health problems, she really feels quite lost. She sees a number of people at the hospital and at her GP practice, and even has had some nurses visit her at home, but she really isn't sure who is looking after what bit of her and where to go for help.

Her daughter is really supportive of her but can't always accompany her to every appointment. She does get quite nervous in the appointments with the doctors and nurses. She has been given quite a lot of information and leaflets, but doesn't really understand them or what they are for, and feels bad that she isn't looking after herself as well as she could or should do. Edith is also very worried about the future and how she will manage.

Edith – Issues identified

Issues identified by both the citizen group and respiratory team:

Feeling quite alone / isolated/anxious

Theme	What are the issues for Edith – citizen group	What are the issues for Edith – respiratory team
Impact on how you feel	Worried about future Overwhelmed	Completely lost Unable to manage as well Struggling with life
Clinic experience	Low confidence in general – especially coming to hospital Lots to think about / remember in a consultation Don't know what is what in a clinic – really confusing- go from one room to the next to the next in different areas Sees a lot of Health Care Professionals-not clear who does what Why are they coming to see her at home? Can she keep track of everything?	

Claude

Number of people in cluster	Average age	% Female	% Lives Alone	Average Educ	% Finish secondary	% Retired	% Works full/part-time	% Incapacitated to work	% Assisted with HLQ
9(11%)	67.4	44%	22%	3.9	22%	67%	11%	11%	0%
Number of people in cluster	Average number of health conditions	% COPD	% Arthritis	% Back Pain	% Heart	% Cancer	% Depression/anxiety	% Diabetes	% A+E in past 12 months
9(11%)	3.1	89%	44%	33%	44%	33%	0%	11%	44%

Number of people in cluster	Understood and supported by healthcare providers	Having sufficient information	Actively managing my health	Social support for health	Appraisal health information	Active engagement with healthcare providers	Navigating the healthcare system	Finding health information	Understand health information to know what to do
9(11%)	3.00	2.42	2.84	2.62	2.82	3.49	3.47	3.71	3.96

Claude is 67 year old and is a recently retired electrician. He has COPD which has really started to slow him down, finding it difficult to get up the stairs in one go now. He also has arthritis particularly in his hands and has had bladder cancer but had an operation for this 6 years ago and is relieved that all the checks since have been clear.

Claude lives with his wife, but isn't settling into retirement too well as he misses his mates at work. In his former role as a foreman, he prided himself on knowing how to get things done. However, he doesn't really find it easy to talk about himself and his health. He doesn't tend to think about the future very much as his Dad died of an aneurysm when he was 62, so he thinks he has done well to get to 67; he likes his cigarettes too much anyway and doesn't see the point of giving up.

Claude – Issues identified

What are the issues for Claude – citizen group	What are the issues for Claude – respiratory team
<p>Struggling to accept situation</p> <ul style="list-style-type: none">- Now retired- Health issues- Social isolation <p>Fatalistic</p> <p>Got some worries – living with cancer</p> <p>Men – don't like to talk about themselves</p> <ul style="list-style-type: none">- Mood- Health <p>Lost – knew what to do at work</p>	<p><i>This vignette wasn't completed in the professional shorter workshop</i></p>

Alan

Number of people in cluster	Average age	% Female	% Lives Alone	Average Educ	% Finish secondary	% Retired	% Works full/part-time	% Incapacitated to work	% Assisted with HLQ
16 (20%)	76.5	25%	38%	3.0	63%	69%	6%	13%	25%
Number of people in cluster	Average number of health conditions	% COPD	% Arthritis	% Back Pain	% Heart	% Cancer	% Depression/anxiety	% Diabetes	% A+E in past 12 months
16 (20%)	1.9	81%	31%	19%	19%	6%	13%	19%	81%

Number of people in cluster	Understood and supported by healthcare providers	Having sufficient information	Actively managing my health	Social support for health	Appraisal health information	Active engagement with healthcare providers	Navigating the healthcare system	Finding health information	Understand health information to know what to do
16 (20%)	3.81	3.77	3.50	3.88	3.32	4.50	4.37	4.27	4.48

Alan is 77 years old. He lives with his wife and is a retired salesman. He comes to the chest clinic every 4 months or so and gets on well with the team there. He feels his chest problems are pretty well controlled at the moment, but does feel reassured by seeing the doctors and “having a regular check up”. His last admission to hospital was just over a year ago and the treatment changes that were made at that point have really helped. He has a ‘rescue pack’ at home, but hasn’t needed to use it and can’t quite remember what they said about when to use it. He thinks he has a leaflet at home somewhere, which he could probably find if he needed it.

Note: Due to time constraints this vignette was not discussed in either workshop

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Theming of issues and ideas



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Understanding your condition - Issues

Feeling like when you get to a certain age people (HCP) aren't bothered

Feeling down

Doesn't feel understood

How good are people at explaining things so that the patient will understand?

Clarity of diagnosis – what you have and not just what you don't have

Patient doesn't know where to start

Mostly we want to do things to patients – fix them

Can the patient keep track of everything?

Smoking cessation services vary

Clarity about ongoing healthcare and what to expect (but it can be difficult to make a diagnosis)

Worried about future

Disengaged by low mood

Not sure what support is available

Overwhelmed

Conflicting advice from professionals

Lots to think about / remember in a consultation

Patient may give the impression they understand – may not be taking it all in

Guilty – one issue impacting onto another

Understanding your condition - Ideas

Citizens	Clinicians
<ul style="list-style-type: none">• Much clearer information about diagnosis• Clarify all of diagnoses• Explain diagnosis but offer support and outline pathway- what to expect• Patient guidance – “what good care looks like?” – BLF booklet• Talk to someone who has also been through it• Knowing about pulmonary rehab• Ensure pathway includes diagnosis <u>and support</u>• A sheet for the patients to explain what the diagnoses are; what the treatments and options are; and what the plan is• Explain pathway/next steps• Ensure the patients concerns are recorded and recognised in clinic letter• We get a clinic letter but more information would be helpful	<ul style="list-style-type: none">• Understanding his condition (will get worse – does he understand)• Be honest – can't cure breathlessness – so not always searching for answer• Front load information – giving it over weeks• Clarify expectations – what can he expect next 5 years• Be clear when no further interventions• Focus on one thing – that would help them now/at a time• Education – self-management plan for exacerbations• It's their choice – help them understand this• Personalised risk information – things that are relevant to her• Avoid bunch of leaflets• Verbal explanation rather than leaflets• Information prescription• Better multimedia information• Patients involvement in decision making not trying to fix things for him/her• Need to help patients feel understood / supported• Patient to feel understood and listened to• Promote information. Making it easier for all patients to understand more clearly• Support information giving; improved understanding by Healthcare Professional of patients' needs• Video in waiting area of useful topic information• Follow up to ensure patients have understood• Create more time for each patient not rushing at things. Giving enough time to address issues with patients• Time and ability /skills to elicit what the patient wants (involving patient carers / family)• Extend clinic appointments

Preparing for your visit - Issues

Feels discouraged to raise multiple issues

Doesn't feel as though consultation is for their benefit

Can't communicate difficulties

Needs help to navigate through options

Feeling terrified

Doesn't know where to start

No-one is listening to them

Men don't like to talk about themselves

She is vulnerable

Low confidence in general – especially coming to hospital

Lots to think about / remember in a consultation

Neglecting himself (more worried about his wife)

Is it clear what he wants?

Might tell people (HCP) in their environment (clinic) what they want to hear

Gives the impression he understands – may not be taking it all in

Disengaged by low mood

Progression of his long term condition

Not that proactive

Conflicting advice from health care providers

Patient doesn't feel understood

Preparing for your visit - Ideas

Citizens	Clinicians
<ul style="list-style-type: none">• Able to write down what you want to discuss before the clinic appointment – write down an agenda• Create a list of what is bothering you before clinic• Encourage people to be prepared – clear about what the visit is for• ‘How to get the most from your doctor’ sheet• <i>Encourage people to bring a friend/family member- invite this in letters [endorsed x3]</i>• Take a buddy, eg. From Age UK/voluntary sector• Information about what to expect at clinic and what will happen there – how to get there• Tests to expect eg. scans x-rays eg. leaflets with appointment letter / e-mail or on a website?• Provide patients with something to prepare for appointment and to record conversation• Explain pathway/next steps• Ensure the patients concerns are recorded and recognised in clinic letter• We get a clinic letter but more information would be helpful	<ul style="list-style-type: none">• Use of prompts; pre-clinic sheets – clinic appointment prompt• Ensure people know what there for• Involving family – invite them to clinic / let them know they can come in• Encourage family support at clinic• Pre consultation questionnaire eg cough clinic [<i>so don't need to take so much time asking questions they could have already considered</i>]• Home visit at first visit and direct contact with one team member• Better multimedia information• New patients – how team works and how we communicate – all working together• An initial bundle explaining what: the condition is; who their care team are; what their roles are; who they should contact. Could be sent to patient after first initial appointment• Photo and vignette of consultants / nurses in clinic – explains who they are – includes some personal information ie interest, children etc• DVD – video in clinic eg pulmonary rehab – what clinic is• Pre-clinic patient prompt sheet. To be sent with appointment letter or given in waiting room. Includes question such as: what are your main problems; what would you like to know• Clinic templates to be sent to patients so they can structure their thoughts prior to seeing professionals• Use of pre-consultation opportunity (info / prep for clinic) whilst waiting for clinic in waiting room

The clinic experience - Issues

Having no control over who you see – might not get on with the doctor or nurse

Feeling terrified

Clarity about ongoing healthcare and what to expect

Can't communicate difficulties

Doesn't feel as though consultation is for their benefit

Not helpful to keep telling her off

Seeing the right person in the team on the day

How good are people at explaining things so that the patient will understand?

Sees a lot of Health Care Professionals -not clear who does what

Lots to think about / remember in a consultation

Clinic is not fulfilling her needs

Might understand/have rapport with some people more than others

Is she seeing the right person?

Always seeing the nurse when you would like to see the consultant too

Seeing lots of different health care professionals- privacy and intrusion

Does she need to be in chest clinic?

Mostly we want to do things to patients – fix them

Doesn't feel understood

Can she keep track of everything?

Lack of continuity of care

Don't know what is what in a clinic – really confusing- go from one room to the next to the next in different areas

Might be rebellion around stop smoking message

Conflicting advice from professionals

The clinic experience - Ideas

Citizens	Clinicians
<ul style="list-style-type: none"> • Choice about who you see and how often (and how long for) • Help to navigate all the areas – it's confusing • Access – sit with you at hospital – help you get there • Better organised, so less places to go • Proximity of clinic to x-ray / lung function tests • Information in waiting room – who is who and what to expect • Continuity – if you like them [x2] • More time at appointment , especially early on [x2] • Don't ask how are you (too general – everyone asks that) instead ask " how are you managing your condition?" • Take the time to find out all issues not just medical problems • Ask about anxiety and breathing and how they link? • Listen and understand issues [x2] – work it through with you • Explain options – eg medications/rehab/access to MDT team/progression • Explain pathway/next steps • Counselling or use a counselling approach • Involve carers • A written plan • Colour coding [eg. Lines on floor for clinic rooms and where to go for tests] • Ensure the patients concerns are recorded and recognised in clinic letter • We get a clinic letter but more information would be helpful • Calendar / appointment track – who / where <ul style="list-style-type: none"> ○ Who expecting when / support with that 	<ul style="list-style-type: none"> • What role, if any, is clinic fulfilling for some people? • <i>[We need to offer]</i> continuous resource – does that fit into 3/12 clinic cycle? • ? reduce number of clinics • Bigger opportunity - clinic valuable? • Easier for nurses <i>[as they may have]</i> more time • Carer at clinic to support or advocate • Create mini teams – communication – reduce number of professionals • New patients – how team works and how we communicate – all working together • Handover summaries – what to expect • Communication with each other – standardise • Vignettes about team <i>[who's who and what they do]</i> • Poster- Who's who • Group clinics • Longer clinic times / timing of morning clinics – later • Develop a relationship with person • <i>[Ask]</i> How do you want us to work with you? • Frank conversations • Find out about her life and what's important to her • Find out what he actually wants – ask him – care planning (shared decision making) <i>[x2]</i> • Need to make sure its relevant to <i>[the patient]</i> • Need to help <i>[them]</i> feel understood • Might need to sit and listen • Using summaries during consultation • Goal set – in small bits • Focus on one thing – that would help them now/ at a time • Education – self-management plan for exacerbations • It's their choice – help them understand this • Personalised risk information – things that are relevant to her • Work out what the main issues are for her - What can we improve • Listen to her – work out what matters • Find out where <i>[they are]</i> getting more support • Understanding social context • Information: eg. stopping smoking reduces admission to hospital by 50 % • Use the pulmonary rehab video to advertise • See someone with expertise in behaviour change

Beyond the clinic - Issues

Finding it difficult to exercise

Completely lost

Reluctant to stop smoking –
might increase her weight

Fatalistic

Struggling with life

Struggling to accept situation

Might be rebellion around stop
smoking message

Not helpful to keep telling her off

Multiple long term conditions

Anxiety causing breathing
to be worse

Disengaged by low mood

Can she keep track of everything?

Main intervention is stop smoking

Not sure what
support is available

Loss of independence

Worried about future

Feeling down

Struggling – not 100% fit

Overwhelmed

Different level of support offered
for COPD vs. lung cancer

Beyond the clinic - Ideas

Citizens	Clinicians
<ul style="list-style-type: none"> • Involve carers • Talk to someone who has also been through it • Knowing about pulmonary rehab – community based/accessible/more sessions • Support group and volunteers • Support setting up support groups • Linking with community organisations that exist already • Socialising / Relaxation • Age concern course – eg. retirement • New hobby / pastime • Connecting them to things that interest him • See if they want to volunteer • Counselling • Talks to his mates – Cod on the Tyne group • Group settings and one to one • Recognise role of carers and offer support • Age UK <u>voluntary sector</u> ... buddy ✓ • Access to multi-disciplinary team and wider health care team including community when needed • Input from GP – clarify how it links in for patient • GPs knowing/having resources for respiratory community support • Include patients in pathway design- e.g. including anxiety as an example- finish off pathway work • Ensure pathway includes diagnosis <u>and support</u> • Get rid of duplication • Could community nursing teams be more joined up to avoid duplication 	<ul style="list-style-type: none"> • Find out where she is getting more support • Understanding social context • Better multimedia information • Needs to be more timely – smoking cessation • Back to clinic? – transfer to community based care • COPD minibus • More Ian's – community support workers • Use phone calls more [<i>instead of clinics</i>] • Stream / link care – keyworker with link to COPD team • Involving other agencies that can help – voluntary sector • Refer to pulmonary rehab (but many people decline) • Let them see what pulmonary rehab looks like- videos • Peer support – seeing people in a similar situation • Make them aware of services – eg. smoking cessation or weight management • See someone with expertise in behaviour change • Address smoking with family / children – smoking cessation together – in community • Community based support groups • Refer to psychologist • Bereavement counselling • Community matron – support worker – GP link; key worker – social services • What is GP saying? • Involving wide community team • Community support – practically taught how to do everything (appropriate referrals for people in community)? • For some people GP is the main link with advice and input in community from COPD team as required • Sheltered accommodation? (and linked GP) • More patients seen at home by consultants • Home visits – nurse; support workers • More support workers / community: Educate, pace, support on regular visits • Phone call follow ups; link key workers – ie Care managers, community matrons, streamlined systematic approach throughout service, hospital / GP / community • Expansions of community groups for things such COPD; smoking cessation (lead by doctors and nurses) • Integrated care planning and professionals / patients / carers / families • Provide consistency for patients from HCP across the health system spectrum • Identifiable and source of general info eg recognised key worker who can access all issues • Better communication between HCP / health systems – readily available • Enhanced modes of communication between other trusts and GP services

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Co-production focus group Early thoughts



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Early thoughts



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Understanding your condition

Proposed initiative:

Dual approach @ diagnosis.

Medical link on occasions and management by Nursing staff

What would this actually look like, and how would it help?

- Diagnosis by the Consultant / GP then a session with the Nurse
- Post diagnosis aim for regular routine. Reviews by Nurse specialist but have annual reviews by consultant to oversee things to pick up anything complex that may have been missed.
- When well managed drop down to Nursing RV who can act as a link if condition does worsen

Stuff we should just get on with

What actually needs to happen?

- ? automatic referral to respiratory nurses following diagnosis in primary care.

Who is going to do it?

What else do we need to do?

Stuff that needs more work

What actually needs to happen?

Who is going to do it?

What else do we need to do?

Early thoughts



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Understanding your condition

Proposed initiative:

Clinical letter: Ensure that the letter reflects the information for GP but also in a language that patients can understand

What would this actually look like, and how would it help?

Stuff we should just get on with

What actually needs to happen?

- Perhaps an easy to understand summary at bottom of letter

Who is going to do it?

What else do we need to do?

Stuff that needs more work

What actually needs to happen?

Who is going to do it?

What else do we need to do?

Early thoughts



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Preparing for your visit

Proposed initiative:

Bringing someone along to clinic

What would this actually look like, and how would it help?

- Patient bringing friend / relative / carer / buddy to clinic to help answer questions and express concerns.
- Also, provide support – reassurance

Stuff we should just get on with

What actually needs to happen?

- Encourage patients to bring someone

Who is going to do it?

- In clinic letter
- Doesn't have to be compulsory
- Outline that the person can sit in consultation

What else do we need to do?

Stuff that needs more work

What actually needs to happen?

Who is going to do it?

What else do we need to do?

Early thoughts



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Preparing for your visit

Proposed initiative:

Preparing the patient before clinic and what to expect

What would this actually look like, and how would it help?

- Explain who they will be seeing in clinic.
- In the letter explain what their clinic time is but also to expect that we may ask for CXR / Lung function prior so they may have to wait.
- Screen / DVD in clinic explaining who is in clinic at that time.

Stuff we should just get on with

What actually needs to happen?

- ? Need to buy screens patient to come prepared with questions to ask – HCP to encourage this (BLF prompt-sheet) could put this in the clinic letter
- Needs to be generic system

Who is going to do it?

- In letter
- HCPs

What else do we need to do?

Stuff that needs more work

What actually needs to happen?

Who is going to do it?

What else do we need to do?

Early thoughts



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The clinic experience

Proposed initiative:

Relationship between patient and HCP

What would this actually look like, and how would it help?

- Friendly – open relationship
- Easy access
- On-going support
- Earlier appointment if required
- Choice of person to see

Stuff we should just get on with

What actually needs to happen?

- Named HCP of their choice
- Option for earlier appointment
- Phone contact if required
- Longer appointment first appointment
- Group sessions

Who is going to do it

What else do we need to do?

Stuff that needs more work

What actually needs to happen?

- Continuity not always possible in clinics
- Work on relationship

Who is going to do it?

What else do we need to do?

Early thoughts



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The clinic experience

Proposed initiative:
Patient – led services / clinics

What would this actually look like, and how would it help?

- 1st question – directly about condition
- Open
- Listening / less asking – what does patient want / expect??
- How do they want it to work?
- Goal setting / shared decision making
- Make the patient feel that the clinic benefits them
- Increase patient satisfaction

Stuff we should just get on with

What actually needs to happen?

- Make sure opening questions / conversations at clinic are relevant / directed
- Listen more
- Identify patient concerns
- Make patients aware they can involve carers / advocates

Who is going to do it

- Clinicians
- Include it in clinic letter

What else do we need to do?

Stuff that needs more work

What actually needs to happen?

- Meet clinical needs / goals whilst being aware of wider social issues
- Counselling approach / difficult

Who is going to do it?

What else do we need to do?

Early thoughts



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The clinic experience

Proposed initiative:

Consultation more beneficial to the patient

What would this actually look like, and how would it help?

- Consultation – patient led
- Patient pre-prepared prior to consultant to expectation are managed. Explaining the purpose – pathway for them
- Encourage carers to be involved
- Listening to what the patient wants and explain the next steps – pathway - needs to be agreed with the patient and family and take into account their priorities.
- Mutual understanding of purpose and restrictions in the clinic environment.

Stuff we should just get on with

What actually needs to happen?

- Communicate purpose better to patients and carers

Who is going to do it

- All – explaining in a first visit
- Letters – clearer
- Asking patients

What else do we need to do?

Stuff that needs more work

What actually needs to happen?

- Does the current system work
- If not, what's the alternative?
- ? Group consultations
- Consultations / clinics especially for non medical issues which will tackle patients personal issues

Who is going to do it?

- Trust / Teams to experiment with alternative to outpatients clinic

What else do we need to do?

- Test alternatives

Early thoughts



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The clinic experience

Proposed initiative: Communication

What would this actually look like, and how would it help?

- Standardised communication
- New patients – how team works and how we communicate and all work together
- Need to help the patient feel understood
- Might need to sit and listen
- Summaries what to expect
- Self management plan for exacerbations
- Frank conversations

Stuff we should just get on with

What actually needs to happen?

- New patients have team works etc
- Help patient feel understood
- Self management plans
- Summarise what to expect
- Standardise communication

Who is going to do it

What else do we need to do?

Stuff that needs more work

What actually needs to happen?

Who is going to do it?

What else do we need to do?

Early thoughts



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Beyond the clinic

Proposed initiative:

COPD Social Club

Breathe easy group / but more!

Socialisation combined with exercise and support

What would this actually look like, and how would it help?

- Regular meetings – social element
- Option may include selected activities for different levels function and interest
- - walking club – dancing – walk to the pub club
- Club could invite professionals (free - volunteers) Physio, health professionals

Stuff we should just get on with

What actually needs to happen?

Who is going to do it

What else do we need to do?

Stuff that needs more work

What actually needs to happen?

- Venue for meeting
- 'chairman / person' committee
- Core group (people COPD)
- Identify from post pulmonary rehab
- More comfortable in each others company @ end of course
- Club secretary, referrals in

Who is going to do it?

- ? Physio leading referral
- Core group
- Clinics – wards – GP surgery – information contents

What else do we need to do?

- Raise some friends
- Beer and Bacon

Early thoughts – presentation of ideas and voting

Information giving – initial diagnosis

Giving diagnosis → get information soon ✓✓✓✓✓

Clinical letter – copies – terminology

- could it be clearer ✓✓

Bringing someone to clinic for support

- buddy / carer – clinic letter ✓✓✓✓✓✓✓

Prepare – what to expect – timing / who + what

Waiting room in clinic screen / DVD

- question prompt ✓✓✓✓✓✓✓✓✓

Making consultation more beneficial to the patient – system / time / our agenda - patient led ✓

COPD Social Club – regular meetings with social element – peer / social

Venue / meetings / interest / activities

- walking / dancing – link rehab ✓✓✓✓✓✓✓✓✓✓✓✓

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Ideas into action...(1)



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Initiative: It's all about you!

What exactly would this look like? What needs to be done?

- Clear letter that should state bring a 'buddy' if they can – what to expect / may run late (tests etc) – medication – glasses
- Also pre clinic information – make the most of your appointments and what questions do you want answered – to say invite into clinic room alone then relatives can come in later / or ask in waiting room
- In clinic confirm that patient is happy that buddy is present
- DVD / Screen in clinic for information to ease anxiety and inform patients – pictures / photos and on clinic room doors
- Ambulance transport is a problem
- Funding for TVs
- Questions on bottom of letter

Potential benefits to health literacy

- Patient knows what to expect

How will we know we have been successful?

- Patients experience
- Survey
- Patients comments

Potential benefits to health outcomes/system

- Anxiety in patients

Anticipated timeline to see benefit

Ideas into action...(2)



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Initiative: It's all about you!

Next step

Who will do it?

By when?

1. Funding for TVs / more them so patients can see the screen – short film with subtitles
 - Snapshots of faces
 - About resp. clinic - information

Liz – TVs
Team to look at film / info etc

6 months

2. Stickers on doors with names and faces so patient is familiar – Velcro
 - Inform Sean Parker to clinic consultants

Nurses and Docs:
Angie / Dawn – WGH
Angie / Clare - NTGH

1 month

3. Letter - info – bring a Buddy – HCP also ask in clinic - time may be lengthy due to CXR / LF tests – Key Q's for your nurse - who they are seeing – if need Drs opinion this will be sought. - bring letter and inhalers with them

HCP to ask patient / L Rutter – draft letter. Clinic nurses - hand out q'naires to evaluate services - secretaries

3 months

4.

5.

6. N.B patients receive letters late or not at all – how to go around this

Ideas into action...(1)



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Initiative: COPD social club

What exactly would this look like? What needs to be done?

- Primarily, this is a social club – this aims to meet the need identified by patients in outpatients related to socialisation
- Regular meetings
- Could have multiple locations
- Activities arranged from meetings – walking clubs, ‘walk to the pub club’,
- Could invite professional to speak
- Led by patients – where possible, patients doing agenda / activities
- [well organised (train with BLF / breathe easy)]

Potential benefits to health literacy

- Discussion / learning between participants
- Education also by external people invited to speak

How will we know we have been successful?

- Ask patients
- Attendances / Longevity

Potential benefits to health outcomes/system

- Experiments / self support
- Well being (if reduce social isolation)
 - - physical
 - - psychological

Anticipated timeline to see benefit

- 12 months

Ideas into action...(2)



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Initiative: COPD social club

Next step

Who will do it?

By when?

1. Find a venue

? Cost - must sell beer

Ronald
And
Marion

1-2 months

2. Identify people – Pulmonary rehab - post group; Clinic

Discharge from ward; - RSN – write referral

GP writing to patients: Nick Lawson & Judith Laurence–find a few at moment

Chris , Guy and Carlos
?Vicky Ferguson; Stephen
Foster - Rehab

3 months

3. Core group (patients) (RSN ? Local knowledge)

TBC
Initial meeting

4.

5.

6.RSN – Chris, Guy , RCT participants – Vicky Ferguson, Post rehab -
Stephen Foster (Physio), Post DC/clinic – Chris, Guy

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Acknowledgements

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The Health Foundation www.health.org.uk

The Health Foundation is an independent charity working to improve the quality of health care in the UK. They support people working in health care practice and policy to make lasting improvements to health services. They carry out research and in-depth policy analysis, run improvement programmes to put ideas into practice in the NHS, support and develop leaders and share evidence to encourage wider change.

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**...and, of course, to the Respiratory Team at
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groups**



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