

Using a patient passport to assess experiences of COPD treatment and support



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BMA Patient Information Awards Winner



Introduction

COPD patients report variation in the services and support they receive. This has been reflected in the Respiratory Atlas of Variation¹ and the current COPD Audit.²

National Institute for Clinical Excellence (NICE) guidance on COPD is clear on optimum care for patients³ but the levers to implement this are weak. The range of treatments and services may also be confusing for patients.

“I would love to have something in my hand when I go see the doctor to say I filled this in with the BLF and this is what I want to talk to you about.”

Our approach

In 2012, the UK's northwest respiratory team piloted a patient passport describing seven steps to COPD care that were based on current guidelines and quality standards. The BLF worked with PCRS-UK to relaunch the passport both as printed information and a digital tool, that provides a personalised report for patients to discuss with a health care professional.

The passport has three objectives:

- inform patients of care that they should expect;
- provide a discussion tool to use during consultations;
- develop a picture of patient experience.

The passport was redeveloped through a review of the evidence, consultation with members of PCRS-UK and consultation with members of BLF Breathe Easy groups.

The printed passport was distributed to every GP practice in the UK and the digital tool was promoted widely online through the BLF website, other websites and social media.

References:

1. Respiratory Atlas of Variation, Department of Health 2012
2. COPD – Who cares matters – National Clinical Audit report 2015, HQIP
3. NICE Guidelines CG101, 2010

Results

To date, 9,336 people have completed the digital tool.

Initial results show the following percentages responding “yes” to each question:

		% Yes	Count
Q1	My diagnosis of COPD was confirmed with a lung function test (spirometry).	81	7578
Q2	I understand my COPD and my health care professional has explained where to find information, advice and emotional support.	43	4039
Q3	I am supported to manage my care and I have agreed and been given a copy of my self-management plan.	26	2383
Q4	I have contacted my GP to get a free flu vaccination by November each year. I have also had the one-off pneumonia jab.	53	7102
Q5	If I smoke, I am offered support and treatment to stop every time I meet with a health care professional.	66	2316
Q6	I know the importance of keeping active and eating well.	82	7613
Q7	I have had a referral to pulmonary rehabilitation.	37	3473
Q8	I have received advice about ongoing exercise and nutrition.	41	3846
Q9	I know what all my medicines are for and when to take them.	77	7233
Q10	My health care professional reviews how I use my inhaler every time I meet with them.	48	4486
Q11	I can spot the signs of a flare-up - this is sometimes called an exacerbation.	52	4884
Q12	If I have a flare-up, I know who to contact and what medicines to take.	53	4982
Q13	I see my nurse or doctor at least once a year to review my health, care and treatment, and to discuss all the points mentioned previously.	74	6919

Of the respondents, 3,073 provided a postcode. Although the numbers were too small to provide an analysis at CCG or health board level, at a regional or nation level the results were generally consistent:

	Q1 % yes	Q2 % yes	Q3 % yes	Q4 % yes	Q5 % yes	Q6 % yes	Q7 % yes	Q8 % yes	Q9 % yes	Q10 % yes	Q11 % yes	Q12 % yes	Q13 % yes	Total per region
Scotland	86	38	26	54	57	85	39	39	82	45	50	54	77	221
NI	83	60	56	72	84	84	50	59	88	62	56	72	87	82
Wales	81	32	14	53	67	88	38	36	81	46	55	53	73	166
England	86	44	24	55	68	82	41	41	82	49	54	55	76	2604
Lond & SE	85	45	26	56	71	81	45	44	84	47	54	56	75	1124
South West	84	46	22	57	76	86	38	41	81	54	56	57	76	329
Midlands	91	44	25	54	60	83	41	39	78	44	57	54	73	380
N East	87	44	20	54	67	84	36	42	84	53	55	54	81	408
N West	84	41	21	57	66	80	39	33	82	52	51	57	79	363
Not given	79	43	26	52	65	81	35	41	75	48	51	52	73	6263

Discussion

While this is clearly a self-selecting group of people with COPD and not necessarily a representative sample, there is a variation in their reported access to the best standards of treatment and care. The highest reported was for respondents knowing the importance of keeping active and eating well at 82%, followed by diagnosis being confirmed by a lung function test at 81% and three quarters

reported receiving an annual COPD review. Only 26% of respondents reported being supported to manage their care through a self-management plan and only 37% being referred to pulmonary rehabilitation. This demonstrates that although some patients are receiving the right care, there is significant room for improvement in the treatment and support that COPD patients receive across the UK.

We are now carrying out qualitative research on the use and impact of the COPD passport and in the future we plan to promote the passport to CCGs / health boards as a tool to use to help in reviewing local respiratory services.

To access the COPD Patient Passport go to www.blf.org.uk/passport

Conflict of interest and funding: Supported by an educational grant from AstraZeneca