COPD Care Checklist
Putting data in the hands of patients to drive care quality and reduce hospital admissions
Project credits

Lead organisation
NHS Redbridge

Partner organisations
NHS ONEL (Outer North-East London)
UCL Partners
Whipps Cross University Hospital NHS Trust
NECLES HIEC
Barts and the London School of Medicine and Dentistry Queen Mary University
Innovation Unit

Lead clinician
Professor Mike Roberts

Supported by The Health Foundation SHINE 2011 programme

May 2012
Contents

5 Project summary

The problem
6 COPD care context

7 Aims of the project

Hypotheses
8 Patient engagement
9 Impacts

Methods
10 A patient-led methodology

The COPD Care Checklist
12 The final checklist design
17 What was not included?

Measuring impact
18 Quantitative and qualitative impact

Key findings
20 Statistical data
22 What patients told us
26 What clinicians told us
29 Opportunities for system improvement

Analysis
30 The impact of the project

Learning from the project
32 Patient education and engagement
33 The importance of relationships
34 A new model of patient education and engagement
36 The process: a patient-led methodology

38 Conclusion
Chronic Obstructive Pulmonary disease (COPD) affects 1 million people in the UK and costs the NHS £491 million a year, primarily due to secondary care. COPD exacerbations account for over a million bed-days a year in England alone.

Through talking to patients we know that they want to be active partners in dealing with their condition and that they appreciate the value of personalised information. When given the right support, they are keen to take recommended self-management steps and engage with clinicians to demand and create better care.

The aim of this project was to explore and test the impact of providing COPD patients with personalised information on their condition and the level of quality they should expect to receive in their care, together with information on care costs. We wanted to understand how patients would react to this information and what subsequent actions they might take. It was predicted that this would drive both improvement in primary care and encourage better self-management, in turn lowering secondary care costs.

The project team worked closely with patients, carers and clinicians in NHS Redbridge over a period of 12 months. The key intervention, the development of a COPD Care Checklist, encouraged a new form of relationship which centred around patients being informed and confident enough to become significant and active partners in the management of their condition.
The problem

COPD care context

Chronic obstructive pulmonary disease (COPD) is an umbrella term for a number of chronic lung conditions, including chronic bronchitis and emphysema.

The condition affects 1 million people in the UK and in 2010 was the sixth most common cause of death in England and Wales. It’s estimated that by 2020 it will be the third largest cause of death globally. Much of the £491 million NHS spend centres around secondary (often emergency) care following often-preventable exacerbations (or ‘flare-ups’) of the condition. These exacerbations account for over a million bed-days a year in England alone.

Though several interventions have been proven to reduce exacerbations and hospital admission rates, these aren’t always translated into practice and a high proportion of patients are not receiving optimal care (as defined by the 2010 NICE guidelines).

The cost of unscheduled care is largely unappreciated by patients and is not linked to quality of care at GP and commissioner level. Adherence to NICE guidance is seen as being medically desirable but is not explicitly linked to costs and commissioning.

Key barriers were identified as:

— Patients and carers are often unaware of what constitutes optimal care, or of the community-based services available to them.

— When an exacerbation occurs, many patients go directly to A&E. The vast majority of these patients had not previously been given self-management advice or the tools to handle times of crisis.

— Patients often notice changed symptoms for some days before the admission occurs, suggesting that preventive intervention is possible if patients know how to, and feel able to, access appropriate services at the onset of warning signs.

— Patients do not feel able to manage their own care or feel in control of the decisions being made – care is ‘done to them’ rather than decided with them.

— Confidence and competence levels also vary among clinicians, and there is limited joint working and joint decision making between primary care clinicians and patients.
Aims of the project

The aims of the project were as follows:

1. Provide individualised information to patients on their care within the NICE COPD Quality Standards, using a checklist approach.
2. Provide general cost information to people with COPD.
3. Provide information to primary care clinical teams on their care delivery against the NICE Quality Standards.
4. Enhance patients’ confidence in their ability to manage their condition.

To support these aims, a series of desired impacts were identified:

Impact on patients

Altering the balance of power between patients and the health-care system, enabling them to become active partners in the management of their condition and to drive improvements in care provision.

Impact on GPs

Ensure GPs are supported to develop skills in the management of patients in line with the 2010 NICE guidelines. As patients become more able to manage their long-term condition the weight of responsibility felt by their GPs will reduce.

Impact on the wider system

A reduction in avoidable hospital admissions, with the dual benefits of cost savings and increased ability to treat patients who are critically and acutely unwell.
Hypotheses
Patient engagement

The driving hypothesis for the project was that providing personalised information on COPD care to both GPs and patients would result in a set of changes, in the categories of: awareness, engagement, specific actions taken, and changes to long-term behaviour.

An assumed model of patient engagement and behaviour change was used to support this hypothesis, which shows the points of influence at which the project inputs and GPs could assist patients’ progress.

**Aims**
- Increased use of primary care and self-management
- Reduction in secondary/emergency care
- Cost savings

**Better use of care pathways**
Making better choices in terms of both personal health and local health economy

**Better care management**
Change in behaviours

**Increased engagement**
Patients are able to identify symptoms, pre-empt crises and become proactive in their care management

**Increased interest**
Leads to increase in demand from patients

**Increased knowledge**

**Patient disengagement**

**Input:**
- Data on options available and information on costs

**GP actions:**
- Improvements in quality of care (NICE guidelines)
- Better referrals/signposts to providers; encourage use of primary care services
- Respond to patient demand to meet NICE guidelines
- Collect and share data
More specific impacts on patients, clinicians and the system were predicted to be as follows:

**Impact on patients**

— Increase in knowledge of options, routes for help, what to do in a crisis, better understanding of condition and how to manage it – leading to increased confidence.

— Patient empowerment, autonomy and an increase in responsibility and control, leading to improved self-management, adherence to prescription medications (compliance stemming from understanding) and good health behaviours. All encouraged by an increased awareness of the impact of poor use of healthcare services in both health and financial terms.

— Increased engagement with condition resulting in both specific actions taken and long-term behaviour change.

**Impact on clinicians**

— A change in GPs’/nurses’ working practices as a reaction to patients articulating needs / demanding change and through access to visualised and personalised data about a patient’s condition.

— GPs able to identify gaps in care at individual patient level through the provision of data on quality of care and costs.

— Greater appreciation of the impact of poor use of healthcare services in terms of patients’ health outcomes and the local health economy.

**Impact on the system**

— Increase in patient demand for quality services through increased awareness of the gap between NICE standards and current quality received, driving improvements in quality of care and embedding NICE guidelines into GPs’ working practice.

— A positive altering of the relationship between patients and clinicians.

— Increased use of primary care services (and, by extension, a reduction in emergency care).

— Cost-savings due to the reduction in exacerbation-triggered secondary care use (emergency and hospital admissions).
Methods

A patient-led methodology

Ten GP practices within the NHS Redbridge area volunteered to participate in the project, comprising a total of 588 COPD patients.

The demographic of the project user group required a process that would enable a patient-led and iterative design process. COPD patients, as a group, have below-average literacy levels and a lower than average access to technology. Many in the user group had not been presented with personal data in a similar format before, especially not concerning their health.

We therefore used a patient-led methodology, involving the use of workshops, interviews and discussions with clinicians and patients, and iterative prototyping of an information tool design.

From these initial conversations a prototype COPD Care Checklist was developed, using a traffic-light system to indicate where each patient’s care was (or was not) meeting targets.

In order to develop an effective checklist, we identified the need to utilise qualitative primary research and a process of prototyping to help shape its design and communication. A number of core methods of gathering insights into patient experience were used.
Focus group and co-design sessions

This was carried out with a diverse mix of 40 patients in September 2011. The session adopted a co-design process, where patients engaged in discussions and activities with GPs, practice nurses and the project team. Visual design tools were used to support and capture thinking.

Patient recommendations and insights into the barriers and enablers for patients to engage with data were worked into the checklist design. Several versions of the checklist were tested with patient focus groups to refine content and style.

Home-based interviews and prototyping

The prototype was used to support two-hour conversational interviews with patients in their homes.

These explored broader contextual and situational barriers and enablers to engagement with information received about their condition and care. Researchers also explored ways of communicating information in order to have the biggest effect on patient behaviour.
The COPD Care Checklist
The final checklist design

The COPD Care Checklist takes the form of a folded A3 sheet of paper. The front cover comprises:

— An explanation of the purpose of the checklist, the ‘traffic light system’ and what patients should do if they have any amber or red lights.

— A prompt for patients to take their checklist with them to their GP or nurse and use it as a tool with which to talk about their care.
COPD Care Checklist:
Mike Roberts

Issue Date: 1st January 2012

This is your personalised COPD checklist. It is part of a scheme being run by the NHS to help you to better understand your COPD and to know what support there is available in order to better manage your condition.

How to use your Checklist

This checklist helps make you better aware of your condition and highlights what areas might need attention. It uses a simple traffic light system to show how you are doing in your six key COPD areas. A red indicator is not an emergency, but if you have a red or amber traffic light you should contact your GP or Practice Nurse. Green lights indicate you are up to date in that area of care.

If you have any red or amber, you will need to take the actions described. Green indicates you’re up to date in that area of care.

You can contact your GP or one of the other services listed.

Goodmayes Medical Centre

Your local surgery can:

- Answer your questions about COPD care.
- Help you monitor your COPD and make sure you get the right medication and support when you need it.
- Put you in touch with other support services.
- Make living with COPD better for you and those who support you.
The inside spread is divided into sections covering six of the NICE guidelines on COPD care quality:

— Annual COPD Review (length of time since last review).
— Post-bronchodilator spirometry test.
— Smoking cessation status.
— Referral to pulmonary rehabilitation.
— Inhaler technique.
— Support with self-management plans and rescue packs.

This data is personalised for each patient according to his or her GP records. Each section is allocated a green, amber or red light. If a light is green, no actions are required; a red or amber alerts patients to take actions including booking a GP appointment.
1. Annual COPD review
You have had a review in the last twelve months.
You should see your doctor or nurse at least once a year for a COPD review. During your review, you should be asked how well your medicines are helping with your symptoms and whether you have had any side effects.

2. Spirometry test
You have not had this test and should contact your surgery at the first opportunity.
Your diagnosis of COPD should be confirmed by a post-bronchodilator spirometry, also known as a ‘blow’ test. This test checks how well your lungs work by measuring the amount of air you can blow out. This helps to decide upon the treatment your doctor should offer.

3. Stopping smoking
Your records show you are currently a smoker and are trying to quit.
Giving up smoking and sticking to it is extremely important if you have COPD. Your doctor should encourage and help you to do this.

4. Inhaler technique
You have been shown how to use your inhaler.
The medicines you use depend on how severe your COPD is, how it is affecting your everyday life, and what side effects you may experience. You should only be given an inhaler once you’ve been shown how to use it and you’re confident that you can use it properly. Your technique should be checked annually. If you need a refresher, please contact your surgery.

5. Pulmonary rehabilitation
You haven’t been referred to a course in your local area.
Certain patients could benefit from a pulmonary rehabilitation course. It is a programme of care designed for your individual needs. During the twice weekly session, for 6-8 weeks, you work with a healthcare professional in your local area to help you to make the most of your physical abilities and to become as independent as possible.

6. Support with self-management
Contact your GP to talk about getting a self-management plan with a rescue pack.
Sometimes your symptoms may become particularly severe. These are called “exacerbations” or “flares-up”. You should be given advice about how to spot these early and prevent them from getting worse. You may be given a rescue pack to keep at home to help prevent exacerbations.
The back page contains:

— Contact details, laid out to suggest a ‘ladder’ of severity, with a 999 call being the last option in the list.
— Example costs of both preventive and emergency care, to demonstrate the cost benefit of preventive care.
— A final paragraph reminds patients about what their next steps should be. They are asked to check the six areas on the checklist and make contact with their local GP or Nurse if they have any red or amber lights.

<table>
<thead>
<tr>
<th>Option</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Self Care</strong></td>
<td><strong>Self Management Plan.</strong> Request a self management plan from your GP. Pharmacies. You will be able to get help at your local pharmacy. <strong>NHS Direct.</strong> Tel: 0845 4647 0845 Open 24 hours for advice.</td>
</tr>
<tr>
<td><strong>Further Support</strong></td>
<td><strong>The Lung Club.</strong> Tel: 020 8999 5546, E: <a href="mailto:thelungclub@talktalk.net">thelungclub@talktalk.net</a>. <strong>Expert Patient Programme.</strong> Tel: 020 8491 1570. <strong>British Lung Foundation.</strong> Tel: 08458 50 50 20.</td>
</tr>
<tr>
<td><strong>Community Help teams</strong></td>
<td><strong>Long term conditions team.</strong> Tel: 0208 491 1570. <strong>Community Pulmonary Rehabilitation services.</strong> Tel: 020 8491 1570.</td>
</tr>
<tr>
<td><strong>GP</strong></td>
<td><strong>Your GP Surgery.</strong> Tel: 0208 590 1169. <strong>GP Out of Hours Services.</strong> Tel: 0845 0750487.</td>
</tr>
<tr>
<td><strong>NHS Walk-in Centre</strong></td>
<td><strong>Loxford Polyclinic.</strong> 417 Ilford Lane, Ilford, Essex IG1 2SN. Tel: 020 8822 3800. Open 8am-8pm, 7 days.</td>
</tr>
<tr>
<td><strong>A&amp;E</strong></td>
<td><strong>Whipps Cross University Hospital.</strong> Whipps Cross Road Leytonstone London E11 1NR. Tel: 020 8533 5522. <strong>King George Hospital.</strong> Barley Lane Goodmayes IG3 8YB. Tel: 0845 130 4204. <strong>Queen's Hospital.</strong> Rom Valley Way Romford Essex RM7 0AQ. Tel: 0845 130 4204.</td>
</tr>
<tr>
<td><strong>999</strong></td>
<td><strong>If you feel your symptoms are so severe that you can't attend A&amp;E, then call 999.</strong></td>
</tr>
</tbody>
</table>

**Keeping your COPD under control.**

We want to make sure you live well with your COPD and your condition is as well managed as possible. There are key things you can do to prevent COPD flare ups/exacerbations, which can be disruptive to you or to your families’ lives. This will also ensure NHS resources are best used. For example, correct use of your inhalers, taking part in pulmonary rehabilitation classes or stopping smoking and using your rescue pack may prevent costly emergency hospital admissions.

**Some examples of preventative costs**

- Cost of an inhaler to the NHS: £3-£38
- Cost of a rescue pack to the NHS: £6
- Avg. cost per pulmonary rehab session: £60
- Avg. cost of a GP consultation: £36
- Annual review with your nurse: £15

**Some examples of emergency costs**

- GP Emergency call out / home visit: £120
- Consultation with a specialist in hospital: £158
- A&E attendance: £97
- Emergency hospital admission costs up to: £2,749
- Calling 999 costs up to: £279

**What are your next steps?**

- Check all the six key areas on your checklist. If you have any red or amber lights make contact with your GP or Practice Nurse and if you have any doubts about anything then get in touch with your local surgery.
- You can bring a friend or family member with you.
- If required, ask about social or emotional help that is available to you or people around you.
What was not included?

Medication information

The checklist was originally designed to include personalised medication information, specifically on inhalers. There were practical difficulties in achieving this due to issues with data and confidentiality. Conversations with patients also revealed that they were much more concerned that they knew how to take their medications (specifically inhaler technique) rather than which they had been prescribed.

Information on flu and pneumonia jabs were also not included as research shows that practices were already handling these mass-vaccination programmes effectively.

Personalised cost information

Personalised costing information was included in the prototype checklist design — again, practical data-collection issues made this difficult to achieve. More importantly, feedback from patients was that this ran the risk of being counterproductive, conveying an ‘accusatory’ tone with the possibility of alienating patients further. A recurring theme during workshops and interviews was a desire on the part of patients not to be a ‘burden’ to the NHS and those caring for them — the personalisation of costs in many cases increased this worry.
Measuring impact
Quantitative and qualitative impact

Quantitative impact

Individual patient-level data relating to the six key areas of focus was collected before and after patients received the checklist. The same data extraction was carried out for the practices in a control group of 10 practices (755 patients) whose patients did not receive checklists. Data was also gathered on COPD hospital admissions to measure the impact on secondary care services.

Qualitative impact

The nature of behaviour change, change in attitudes of patients and the nature of patient-clinician relationships are difficult to capture in quantitative terms. We therefore continued our patient-led methodology through a combination of a number of research methods – workshops, questionnaires, telephone and face-to-face interviews – with both patients and clinicians to build up a picture of the impact of the project in these areas and from which to draw some of our key insights.

The reaction of patients and clinicians to the checklist and its ambitions was overwhelmingly positive.

Patient events and questionnaires

A second workshop in April 2012 focused on gathering patient and practice feedback on the checklist. It explored the perceptions of patients in the following areas, in light of having received the checklist:

— their knowledge of their condition and the options available to them;

— how their viewed the relationship with their GP; and

— how they could be better supported by the checklist and other materials to improve both of the above.

The workshop combined semi-structured discussions with facilitated activities to explore the possible uses of the checklists in different situations. Representatives from primary and secondary care services helped facilitate discussions/activities and answered questions.

At the initial workshop at the start of the project, patients were asked to fill in a baseline questionnaire covering levels of knowledge of their COPD and the treatment and services available; confidence in managing their condition; and what matters most on a day-to-day basis. The questionnaire was repeated at the second workshop with two added filter questions: whether patients had received a checklist and whether the information it contained was accurate and useful.

Telephone interviews

Semi-structured telephone interviews were carried out with 20 patients following the checklists having been sent to patients. These gauged the levels of awareness of and engagement with checklists, whether subsequent actions had occurred and if there had been a more sustained change in behaviour. General feedback on the look and design of the checklist was also gathered.

Face-to-face interviews

Extended home interviews were carried out with four patients. These explored further the themes discussed in telephone interviews, with an evaluation of the checklist and how it could be used as a support tool playing a central role.
Key findings

Statistical data

Data from practices

As the checklist was sent out in February 2012 and the comparison data extracted in April 2012, the data from practices and on hospital admissions covers only an eight-week time span. Given this, the early results are very promising, particularly in the increased numbers of patients receiving spirometry tests, pulmonary rehabilitation referrals and self-management plans.

Key

<table>
<thead>
<tr>
<th>Control group</th>
<th>Shine group</th>
</tr>
</thead>
<tbody>
<tr>
<td>7%</td>
<td>9%</td>
</tr>
<tr>
<td>4%</td>
<td>18%</td>
</tr>
<tr>
<td>60%</td>
<td>61%</td>
</tr>
<tr>
<td>74%</td>
<td>70%</td>
</tr>
<tr>
<td>2%</td>
<td>1%</td>
</tr>
<tr>
<td>2%</td>
<td>6%</td>
</tr>
<tr>
<td>9%</td>
<td>7%</td>
</tr>
<tr>
<td>13%</td>
<td>20%</td>
</tr>
<tr>
<td>25%</td>
<td>32%</td>
</tr>
<tr>
<td>23%</td>
<td>29%</td>
</tr>
</tbody>
</table>
Questionnaire responses

The questionnaire responses represent a small sample of around 40 patients; however, the results are extremely positive and reinforced the findings from our conversations with patients and clinicians alike.

How well informed do you feel about your disease?

How much do you know about what doctors/nurses should be doing for you?

How aware are you of the services available to you?

How confident are you about managing your own condition?
What patients told us

Patients noted particular advantages in the areas of increasing knowledge of and engagement with their COPD care, building confidence and empowerment, an increase in their levels of self-management, and an improvement in the relationship with their GP.

Increasing knowledge and engagement

Patients reported that, due to the checklist, they feel more informed about their disease, are much more aware of what their doctors and nurse should be doing for them and feel more confident in managing their own condition.

How far along the engagement scale a patient already was had a strong impact on how useful they found the checklist and, in some cases, whether the amount of information was felt to be overwhelming. Patients who were already unsure about their condition and did not feel they had control over it said that they needed extra help to understand it and how it related to their COPD. For a small number the amount of information was a barrier to the first step of interacting with the checklist – more explanation and support, and not just more information, was required.

Conversely, patients who already had a good grasp of their COPD and issues associated with it found the information on the checklist helpful and said that the design was very straightforward and that it was very useful to have everything in one place. Many commented positively on the inclusion of self-management information and the emphasis on putting control into patients’ hands.

“It’ll help everybody. Most of it I know but it’s a reminder... Other people are apt to give way and become invalids and not try. I think all the explanations will help them.”

“The more explanations you give to people with COPD... it’ll help them see the situation and to give themselves more encouragement and help themselves a bit more.”
Changing behaviour

Most patients interviewed said that they would take the checklist with them to their next GP or nurse appointment, for a variety of reasons:

— For help in understanding the checklist and their condition overall.

— To raise something specific flagged up on the checklist that they wanted more information about.

— To act as a prompt to question their GP about something that their GP hadn’t covered.

As borne out in the quantitative data, patients reported that they had arranged GP/nurse appointments and asked for annual reviews, spirometry tests or about pulmonary rehab because of receiving the checklist – either because it had reminded them they hadn’t had a checkup for a while or because they wanted to talk through a specific issue that the checklist had raised.

“My doctor explained it all to me. That’s why I stay with her, because she’s interested. The other doctors are so busy they’re doing every ailment that comes in the door, but my doctor concentrates on it. It was a good thing having the checklist with me.”
Reaction to generic cost information

Most patients found the cost information interesting and informative but without necessarily making the link between preventive self-management and a reduction in emergency care costs.

For some patients, the impact went deeper and had actively encouraged them to take better care of themselves, not just for their own health but as a way of taking responsibility for their care and explicitly supporting the NHS by ‘doing their bit’.

“A lot of people don’t want to know about the costs. But it opens your eyes to see what the National Health Service are doing for you, and therefore: play the game. If they’re spending all this money then play the game and do the thing properly.”
A small number, however, found it worrying and thought it ran the risk of making people feel guilty for using any services at all, discouraging them from making non-essential appointments. These people saw the GP cost as being quite high without comparing or relating this to the much higher costs of emergency care. At worst, these patients found the information alarming and alienating or thought that it was accusatory in tone.

“If I need an ambulance, I’m not thinking ‘it’s costing 279 quid’, I’m just thinking, ‘is someone going to save my life, because I need it’. What is the point of telling me that a 999 call costs 279 pounds?”

“I’ve still got mixed feelings about why it’s on there. Part of me felt a bit insulted when I read that... this is my entitlement, I’m not going to abuse it but perhaps other people do. I’m sure they do.”
What clinicians told us

Our interviews with clinicians supported the conclusions that the checklist has been a valuable tool in the following areas:

**Combining detailed information**, assisting in monitoring patients’ progress and checking levels of care, and giving clinicians a mandate to request care pathways for patients.

“The attitudes that we have seen change, are patients taking on board that they do have a chronic disease, the checklist has made us focus more on what we put in our notes, how we record everything we are doing with the patient and ensure the patient does understand their condition and why we are doing the things we are doing.”

*Nurse*

“When it comes to the rescue pack, they are now confident in asking for it, and I am confident in going to the GP and saying ‘look, this patient has been told they can have one, lets do one’.”

*Practice manager*
Embedding NICE guidelines into daily practice, acting as a reminder and a tool to prompt conversations with patients, particularly addressing the concerns of newly-diagnosed patients or those who view a COPD diagnosis as having stigma attached.

“...The fact that [patients] come with [the checklist] in their hand, means they are prepared to talk about it, which is sometimes what you need, you need that opening in a consultation.”

Practice manager
Increasing patients’ and clinicians’ awareness of services available and increasing services’ awareness of patients – preventing patients from ‘falling through the gaps’.

“There are definitely people who are getting the checklist and then talking to pulmonary rehab, or that’s how they have been referred... The way that the checklist is particularly good is targeting those people who haven’t been in contact with other services, who are not actually known by other services.”

Pulmonary rehab nurse

Increasing patients’ confidence and appetite for asking questions, requesting explanations, being involved in decisions and pushing for better care. An awareness had arisen that patients often had a number of questions/queries which they did not bring up during consultations – the checklist shows that ‘it’s ok to ask’.

“They feel more confident. Most of our patients who got one came and said ‘I got this in the post, can you explain?’ Which we have done.”

Nurse
Opportunities for system improvement

Some issues with the quality of care and system processes arose from the use of the checklists by patients and clinicians. This in itself indicates a key role for the checklist in highlighting gaps in quality of care and areas in need of attention.

Accuracy of information
Many of the checklists contained inaccurate or out-of-date patient data, demonstrating gaps in GP records. In particular, the lack of sharing information between primary/secondary care providers was shown to be a much more serious problem than some practices were aware.

Communication between patients and clinicians
Many patients felt that GPs were not relating to them or treating them as a whole person but as a series of issues that were dealt with in isolation. In contrast, many GPs felt patients were not asking enough questions or being clear enough about their key concerns.

Continuity of care
For example, seeing a different nurse at every appointment. There is not enough information given to patients on the roles of different clinicians – GP were seen as being the gold standard with patients feeling “fobbed off” if given an appointment with a nurse, despite nurses often being the most COPD-knowledgeable clinicians in a practice.

Difficulties in accessing services
There were concerns raised about long waits for appointments and appointments being too short to cover more than one issue in any depth. More help could be given on different places to go for help (e.g. in the community, pharmacists) and on how to communicate with clinicians.
There have been a number of key impacts of the project on patients, clinicians and on system processes, all of which contribute to an improvement in the quality of care and relocation of control to patients. If leveraged correctly, this will lead to a long-term reduction in reliance on secondary care and a reduction in long-term costs.

Impact on patients

Using the structure from our original hypothesis, the impact on patients can be categorised in terms of:

- Awareness and understanding
- Engagement
- Direct actions prompted
- Long-term behaviour change

More specifically, the COPD Care Checklist resulted in the following changes:

- An increase in patients’ understanding of their condition and how to manage it; knowledge of the options available to them, some of the cost implications involved and the confidence to utilise these; and awareness of what optimal care should comprise and how to take steps towards this.

- An increase in patient self-management, not just of their condition and day-to-day issues but also in terms of taking active direction of their care and better managing the relationship with their GP.

- In general, an increased level of engagement with their condition which has not only prompted patients to take immediate actions as needed but also instilled long-term behaviour change.
Impact on clinicians

— Change to GPs/nurses’ working practices – as a reaction to patients articulating needs and demanding change and through having access to visualised and personalised data about the progress of patients’ conditions.

— Increased knowledge on the quality of care delivered and embedding of NICE guidelines (vs box ticking) into day-to-day practice.

— A positive altering of the relationship with patients – an appreciation of the importance, impact and appetite for partnership relationships with patients, and the role of patient education in this.

— An awareness of the importance of primary care and prevention, resulting in a more proactive approach.

— An awareness of problems in data collection and liaising with primary/secondary/emergency care services.

A third-party confidant

In some practices which were less open to (or did not have the capacity to support) the rebalancing of relationships and increased levels of proactive enquiry from patients, the result was an increase in frustration for patients who felt they were experiencing barriers to self-management. Having been prompted by the checklist to address a particular area of care, there was a sense of “what now?” Patients expressed particular frustration at having to make (and wait for) appointments with a GP in order to ask questions.

An idea posited by patients was that of a third-party confidant – a patient advocate who could act as a point of enquiry, answering questions or concerns about care and next steps and, if necessary, liaise between patients and clinicians. Patients were very open to who this point person could be – suggestions included an “expert” patient from their own practice, better use of the existing PALS service, or a clinician from other areas of care – for example, a pulmonary rehabilitation nurse.

The nature of the patient-clinician relationship

Beyond the scope of our hypothesis, there is evidence that the checklist has altered the relationship between patients and clinicians by empowering patients to ask questions, acting as a prompt for discussion, and making it clear on both sides the level of care that should be received. That the checklist arrives at the patient’s house and is seen to be owned by them, in addition to its emphasis on self-management, has helped patients to be more proactive and feel more in charge of their care. This has resulted in a significant shift towards relationships that are:

— more equal partnerships, involving shared responsibility and a collaborative approach to self-management, creating personalised care plans and dealing with difficult issues (in those practices which were already open to this); and

— characterised by patient challenge and patients driving change (in those practices which were not).
Learning from the project
Patient education and engagement

Education and enquiry

The traditional model of patient education – providing information to patients about their condition – is helpful and empowering, and having a basic level of information gives patients confidence to ask further questions.

However, this must be coupled with patients being given the tools with which to understand this information. Patients overwhelmingly welcomed being given more information as long as it came with explanations and support attached. Practices likewise said that they’d be wary of including more ‘information without explanation’.

What empowered patients most was when they were able to enter into a spirit of enquiry – being given questions that they might want to think about, and the methods with which they could find out more, was much more effective than being presented with the ‘answers’ that clinicians believed would be most helpful.

The key lessons on patient engagement were therefore:

— The key is instilling a sense of enquiry, of patients knowing where, when and how to find out more for themselves, having the confidence to ask questions and challenge the answers they receive.

— Information must be coupled with explanation. Too much of the former without context results in confusion and further disengagement.

— The impactability of patients is an important factor: the impact of providing information varies depending on how far along the engagement/confidence journey patients already are. There is a risk of driving further disengagement and a sense of ‘floundering’ by overloadng patients with too much information and responsibility before they are ready.

“...If you have too much - too many pages, or too many things - they kind of throw it to the side. But this was just enough.”

Nurse
The importance of relationships

A key finding was that instilling, fostering and managing good relationships between patients and GPs could be just as important as managing and treating the physical aspects of COPD.

A picture of both an ideal and detrimental GP-patient relationship model arose from the conversations we had with patients and clinicians, with a desire expressed on both sides to work together to improve this picture.

Learning from the project

Patient’s needs/concerns not always clearly expressed, or not expressed early enough in the process

Lack of compliance with advice (e.g. stopping antibiotics courses early)

Patients reluctant to ask questions

Stigma of COPD diagnosis – difficult to get patient to talk about it and begin discussions around care

GP’s view

Imbalanced, authoritarian – told what to do with no explanation

Judgemental – particularly around smoking

Overloaded with confusing information

Conversations only on GP’s terms

Difficult to ask questions about the process or question GP’s advice

Not wanting to seem like a burden

Accepting care without question even if it doesn’t feel right or I know I won’t see it through

Patient’s view

Equal partnership with shared responsibility for improving care and condition

Conversations easier and more structured and balanced

Patients able to articulate more clearly their questions and concerns

Patients help embed NICE guidelines into working practice

Have the data, tools and knowledge available to be proactive about patient’s care

GP’s view

Care and self-management plan as a joint endeavour

Know where and how to ask questions

Feel able to influence decisions and initiate a joint decision-making process

Sense of enquiry – able to find out about things myself or with my GP

Able to challenge care received and drive change

Patient’s view

Detrimental GP–patient relationship

Ideal GP–patient relationship
A new model of patient education and engagement

Aims

- Increased use of primary care and self-management
- Reduction in secondary/emergency care
- Cost savings

Better care management (changed behaviour and system view)

Patients are able to identify symptoms, pre-empt crises and become proactive in their care management

Sustained engagement

Establishment of critical relationship with GP

Increased patient-led enquiry

Increased confidence to manage condition, discuss and demand

Increased knowledge

Both personal (of condition) and system (how it works)

Patient disengagement
6 Better care management

**GP actions:** Improvement in quality of care (according to NICE guidelines), continued support of patients’ capacity to manage their care.

**System changes:** Valuing of patient-clinician relationship both contractually and culturally (including allocating time for this purpose).

5 Sustained engagement

**Inputs:** Communication: of data (checklist) and as part of GP-patient relationship, continuity of data (timely, accurate, relevant) and relationships, and turning actions into tangible outcomes.

**GP actions:** Personalisation of referrals, including context, history, patient choice and explanation.

4 Establishment of critical relationship with GP

**Inputs:** Checklist as a relationship/conversation tool.

**GP actions:** Being open to a critical relationship.

**System changes:** Clear and sustained communication pathways between GP and other primary/secondary/emergency care providers.

Third party acting as confidant and point of enquiry for patients.

3 Increased patient-led enquiry

**Inputs:** Personalised data on options available; information on costs.

**GP actions:** Being open and responsive to patient and third-party enquiry

2 Increased confidence to manage, discuss and demand

**System changes:** Increased and reinforced opportunities for data-driven conversations between clinicians and patients.

1 Increased knowledge

**Inputs:** Personal data; self-management plan; checklist as a conveyor of information and explanation.

**GP actions:** Systematic data collection with intent to use.

**System changes:** Better information systems and expanded option formats for holding patient information.
The project process highlighted a number of key elements which need to be in place for a patient-led approach to be successful.

Prototype, don’t just pilot

Adopting a pilot-based approach means creating a single hypothesis to test and evaluate. But when working on an innovation project in a new area, such as personalised data and cost sharing, it is crucial to instead use a process that enables the testing and refining of a number of ideas and hypotheses. This is particularly relevant when adopting a patient-led process of development as multiple hypotheses can be posited, some of which might directly contradict others. Prototyping affords an opportunity to test these ideas while still generating new ideas — saving resources and ensuring the success of an innovation is not dependent on the quality of a single hypothesis.

Having users involved in the design of prototypes also makes the later feedback more valuable and specific.

Build a community of stakeholders — and do it early. Identify the change agents — those individuals who will work to leverage change at different levels of the system. These included practice managers, nurses and GPs (and varied from practice to practice) and patients. Engage patients early (e.g. through informal workshops) so that pressure for change is drawn through a bottom-up process, not top-down.

Working closely with practices was key in both leveraging their engagement and ensuring that data was accurate and delivered effectively. Relationships with patients were paramount to ensuring that they fed honest and productive views into the process.

Make value explicit and tangible

The value of sharing data with patients was an unknown for many practices (and, indeed, patients). As we began to see impact this was quickly fed back to all stakeholders engaged. Videos from patient interviews, quotes and data sources were very useful in engaging people with the value of the innovation and this leveraged support.

Make the ambition clear from the outset

It was key that all project stakeholders knew that the ambition was to trial the innovation in order to role it out across COPD in Redbridge. Communicating this ambition increased their engagement and ensured they were committed to developing the most effective checklist.
Value new forms of evidence

There is often a general understanding that qualitative data entails less rigorous and robust evidence. This is often due to the smaller sample sizes, the more complex ways of reading and representing impacts and the more indirect implications on cost. We would strongly argue that in-depth discussions with key people (e.g., from different defined patient categories), repeated throughout the process, are more valuable than a lot of surface questioning with a huge cohort without continuity.

Recognise the threat of change

Some patients were anxious and/or resistant to new forms of communication and relationships with health care professionals, seeing it as a threat to the existing care they received. Many in the COPD patient group showed high levels of resilience, but for some this translated as resistance to change. Attention was needed to ensure open discussion and communication throughout the project. The new innovation of exposing patients to the costs of services caused a great deal of anxiety in some cases and needed careful explanation in order not to increase disengagement.

Flagging energy levels

The project relied greatly on the project team keeping the momentum going. This meant there was a risk of time drift – day-to-day issues dominated even in the most engaged practices. This can be mitigated by making the case that it will be of benefit to practices in the long-term and getting buy-in early.

Similarly, there was a risk of disengaging patients from the process if relationship not seen as reciprocal – there was a need to demonstrate that progress is being made, changes are happening, the project and health service is not just listening to what they think but also acting on it.

Innovation is difficult

Many practices struggled to achieve simple tasks and needed a great deal of peripheral support. Practices were also aware that collecting and collating data about patient care might highlight gaps in care provision. Relationships between the project managers and practices, as well as linking the work back to the needs of patients as often as possible to keep them high in stakeholders’ minds, were key in ensuring sustained engagement.
The COPD checklist is a significant product in the development of COPD healthcare practices. However, it is just one of a range of innovations that are needed in order to ensure that we maximize the value of the relationships between healthcare professionals and patients. The project highlighted the value created by empowering patients with basic information, communicated in simple terms, on the quality of their healthcare. This presents the NHS with an exciting opportunity to continue to evolve the amount and type of data that is both collected by practices and communicated to patients in order to drive radical improvements in the quality of treatment and management of long-term health conditions.

Watch a video of the project here: www.vimeo.com/42194049
Password: copdchecklist

The project also emphasised the need to effectively involve patients, families, carers and professionals in the design and testing of a healthcare information product to ensure it is meaningful for all involved in managing a long-term condition. This is a progressive move for healthcare innovation and highlights the fact that we cannot rely solely on processes of consultation and engagement, but must instead afford patients and professionals the opportunity to play active and leading roles in design and innovation.