Title: Communicating uncertainty: contrasting the communication experiences of patients with advanced COPD and incurable lung cancer.

Running Title: Communicating uncertainty in advanced COPD.

Article category: Qualitative study

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Key messages

- Patients with COPD experience limited effective communication with professionals.

- Communicating even an uncertain prognosis can be helpful for patients.

- Information-provision should be equitable across different diseases.

- HCPs often struggle to communicate the uncertainity of COPD with patients.

Abstract

Background

Due to the uncertain disease trajectory and variable rate of progression in Chronic Obstructive Pulmonary Disease (COPD), health care professionals are challenged in explaining what the future may hold for patients compared to those with lung cancer. Support and communication of timely information can significantly improve health outcomes.

Objective

This study sought to identify factors that impact communication and support and recommend ways to improve patients' understanding of living with life-threatening illness.

Methods

Semi-structured interviews with patients with lung cancer (n=22) and advanced COPD (n=18), their informal carers (21 lung cancer, 18 COPD) and health care professionals (n=51). Patients were recruited from primary and secondary care in the East of England, United Kingdom, during 2010-2012.

Results

Directness and clarity characterized communication in lung cancer, whereas uncertainty and limited explanations predominated in COPD. Discussions on how the disease might impact on decisions and preferences to be made in the future were less common in COPD.

Information for lung cancer patients was mainly from hospital clinicians, and any information for COPD patients mainly from primary care clinicians.

Conclusions

The experience of COPD patients could be improved by professionals soon after diagnosis explaining to them the typical pattern of decline in COPD, highlighting the inherent uncertainties about when exacerbations and death may occur. This conversation should lead to planning for the different challenges which the patient and informal carer recognise as most important to them. This contrasts with the "breaking bad news" conversation which oncologists are highly trained to deliver.

Keywords: Advance care planning, Chronic Obstructive Pulmonary Disease (COPD), health communication, lung cancer, primary health care, uncertainty.

Lay summary

People living with lung cancer or chronic obstructive pulmonary disease (COPD) have poor health-related quality of life. However, more people with lung cancer receive holistic palliative care (which involves supportive advance care planning) than those with COPD. We interviewed patients with lung cancer or COPD, their informal carers (family/friends who support them), and health care professionals about their experiences and our findings confirmed this: health care professionals said the uncertainty of COPD prognosis made starting advance care planning conversations challenging. The level of uncertainty and unpredictability is very different in lung cancer and COPD: the cancer diagnosis is made at a single point in time with mortality immediately on the agenda, while COPD is a chronic condition that develops over many years. We urge clinicians to share this uncertainty with patients, and to try to explain and communicate it sooner than later. These conversations

should also continue as a recognized part of on-going care so that COPD patients can benefit from understanding the uncertainties they are dealing and living with. Lung cancer and COPD should be approached differently to meet patients' condition-specific needs, in order that the existing disparity in holistic care can be remedied.

Background

Recent research including a 2020 systematic review highlight that the needs of people with advanced COPD remain poorly addressed, with patients suffering from prolonged debilitating symptoms, frequent hospital admissions, and more likely to receive aggressive care than palliation [1–4]. This is despite well-established evidence of their unmet needs compared to advanced cancer patients [5,6]. By contrast, patients with inoperable lung cancer receive supportive holistic care from both general and specialist services, despite similarities in palliative care needs in the two patient groups. Palliative care beyond oncology is largely ignored[7,8].

Communication and information are central to a patient-centred approach to care [9–11]. Research still shows that difficulties with communication occur in cancer care as well as COPD [12]. However, in COPD, communication difficulties occur due to prognostic uncertainty and the condition's uncertain trajectory especially on issues related to end of life care. In the long term, this uncertainty leads to a poor understanding and interpretation of possible outcomes of the condition [13,14]. The main objective of this paper is to compare the differences in prognosis communication between patients with advanced COPD and patients with inoperable lung cancer, further highlighting the continuing need for better communication and planning.

Methods

Design

To capture multiple dimensions of personal interactions and experiences, we planned to recruit "clusters" consisting of a total of seven individuals (**Figure 1**) [a lung cancer (LC) patient, their informal carer , key professional, and General Practitioner (GP), and the same for an advanced COPD patient] in East England between October 2010 and June 2012. Inclusion criteria for lung cancer patients was undergoing treatment with palliative intent while for COPD it was that the patient had two or more of: $FEV_1 <=30\%$, long term oxygen therapy, MRC Dyspnea scale 5, one or more exacerbations / admissions in the past 12 months[15]. The study design changed as we were unable to recruit complete 'clusters' because the GPs and nurses were rarely the same for lung cancer and COPD. We sought assistance from the Primary Care Research Network who approached GP practices asking GPs to recruit one or both of lung cancer and COPD patient. Clinicians from hospital lung cancer clinics and primary care practices identified and approached eligible patients and passed on contact details to the research team to contact the patient and explain the study further.

[Figure 1 here]

Each recruited patient nominated an informal carer (a family member or friend who was an unpaid source of support) and a professional central to their care. One participant contacted the study team directly, having seen study information on the CancerHelp UK website. The study was approved by the Cambridgeshire 4 Research Ethics Committee Reference10/H0305/41. Healthcare professionals (HCPs) other than GPs are referred to as "key professionals" in this paper.

Data Collection

Written informed consent was obtained from all participants and face to face semi-structured interviews conducted by CC who is a research nurse. Relevant literature informed the topic guide (supplementary data) which focused on; 1) the participants' past, from their diagnosis and the services they had been referred to and utilized, 2) the present with a focus on the participant' support network using the Pictor Chart (see **Figure 2** for an example), 3) future expectations and interest in a follow up interview. GP and key professional interviews, including a 'Pictor Chart', covered the patient's support needs, illness trajectory and their perspectives of good quality care. Pictor is a patient-friendly visual elicitation technique where participants use a chart and arrow stickers laid out to show the patient and the people involved in their life indicating the features of their relationships [16]. Participants were offered a follow up interview 3 to 6 months after the first interview to check on any changes that might have taken place that they were interested in sharing with the researchers. Triangulation of the data collection from various types of study participants ensured credibility of the findings.

[Figure 2 here]

Interviews were transcribed verbatim, anonymized and imported into QSR NVivo V9 for analysis using a Framework approach of coding, categorization and theme development [17]. The framework was developed collaboratively within the research team and iteratively refined using the constant comparative approach [18]. A stepwise replication approach was used where two researchers (NN and CC) analyzed the same data separately and compared the results to improve dependability of the results. Inconsistences were discussed with the advisory group. Emergent findings were shared with the study User Group (three patients and carers living with COPD, two lung cancer patients, and members of the research team), the Professional Advisory Group (a consultant respiratory physician, four nurse specialists, three User Group representatives, and a representative of the funder), members of the research

team, and key professional interview participants at three discussion groups held at the end of the study. Having user representatives helped improve confirmability of the findings and to ensure that researcher bias did not skew the interpretation of the results.

Results

The 40 patient participants comprised 18 people with advanced COPD (age 51 to 92, median 72 years; 10 male, 8 females; Index of Multiple Deprivation (IMD) range 4.34 to 34.23) and 22 with lung cancer (age 50 to 86, median 69 years; 15 male, 7 female; IMD range 4.63 to 27.88). All but one reported their ethnic background as white British and the one as white Irish. Eighteen informal carers and 13 nurses and allied health professionals with a variety of experience (13 community and hospital specialist nurses, three matrons, a respiratory team lead nurse, a community staff nurse, three practice nurses/nurse practitioners, an oncology dietician and a support time and recovery worker) were interviewed in relation to COPD patients and 21 informal carers and 16 nurses for lung cancer patients, along with 20 GPs.

The recruitment process for the patients is summarized in **Figure 3.**

[Figure 3 here]

Four main themes relating to information and communication emerged: focus of information, communication style, main source of information and end of life care (EOLC) conversations. These themes and supporting data are shown in **Table 1**.

[Table 1 here]

1. Focus of information

COPD patients reported that information was mostly obtained after a crisis and focused on what they themselves could do for their illness. Patients did not think they had the necessary

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information to understand the long-term implications of having COPD or the severity of their condition. They reported feeling, or being told, there was little that could be done. In contrast, lung cancer patients reported being given the information they needed to understand their condition and having their questions answered.

Professionals found it difficult to give definitive information about the future course of COPD, due to the unpredictable trajectory: treatment and rehabilitation options were easier to discuss.

2. Style of communication

A more direct and structured approach in lung cancer provided what patients and informal carers regarded as clarity concerning the diagnosis and prognosis. This communication style included the nature of the problem (terminal) and goals of treatment (slow it down).

A more indirect and uncertain approach was identified in COPD that lacked clarity and, for some, led to dissatisfaction with the information given about the nature of COPD and the long-term future. This resulted in patients and carers having a sense that information was limited or lacking and that not all the necessary information wanted was communicated.

3. Main source of information

Lung cancer patients gained most of their information from hospital clinicians, whilst COPD patients received most information from primary care or community clinicians. Lung cancer patients at times felt overloaded with information from hospital clinicians, while COPD patients reported a paucity of information from community clinicians.

4. End of life care conversations

Professionals frequently commented on the difficulty of discussing EOLC with patients, particularly in COPD. They reported that the greater predictability of prognosis in lung cancer and the shorter life expectancy prompted them and made EOLC conversations easier.

The greater unpredictability of COPD made professionals hesitant to discuss EOLC and unsure when to initiate those conversations, which might be deferred to next time or when a prompt came from patients, which rarely occurred. Professionals relied on cues such as physical decline or frequent hospital visits as prompts to EOLC conversations: such triggers were more common in lung cancer.

Discussion

This study set out with the aim of assessing the differences in prognosis communication for patients with advanced COPD compared to those with inoperable lung cancer. The most important clinically relevant finding was how prognostic uncertainty can have a negative impact on the care of a patient, especially with COPD, and how the certainty seeking culture and limited communication skills training for non-oncology HCPs are key barriers to clinicians initiating these conversations. Professionals found it difficult to give COPD patients and their carers information due to greater prognostic uncertainty, where no-one can predict when or if a severe exacerbation will occur. Patients waited for professionals to initiate conversations, while professionals waited for the 'right time', or cues from the patient, which often did not occur. These findings indicate an over reliance on patients' ability to articulate their needs and to initiate EOLC conversations which can be difficult as they do not necessarily have the knowledge and information required to do so[19].

Cancer patients largely reported receiving adequate information giving them the opportunity to explore preferences for future care. This may have been the result of mandatory communication skills training for cancer clinicians, which specifically focuses on breaking bad news and EOLC planning. Oncology clinicians were therefore equipped with the knowledge and skills for initiating and conducting EOLC conversations while their non-cancer colleagues did not necessarily access this training in managing clinical uncertainties.

Lung cancer patients reported that they were mostly cared for by hospital professionals and appeared to have access to detailed information and specialist oncology support, while COPD patients were not usually seen by relevant specialist (e.g., Respiratory Nurse Specialists). The setting where patients are cared for may additionally influence the information patients receive, as well as the process of communication that takes place.

Although both conditions can lead to an early death, the levels of uncertainty are different and equally need different responses to address patient needs. We argue in this paper, as Kimbell and colleagues concluded, that conversations and planning should be initiated sooner rather than later and be a recognized part of on-going patient care [13]. Due to the chronic long-term nature of COPD, HCPs can plan for earlier conversations that focus on explaining that uncertainties were innate with the intention of helping patients and carers plan future care more effectively. Further follow on EOL conversation(s) would be needed to explain what the patient and family should expect, and promoting shared decision making.

Comparison to existing literature

We highlight differences that still exist in inoperable lung cancer and advanced COPD patients' experiences of care as confirmed by two very recent systematic reviews published

in 2020[3,6]. COPD patients' lack of understanding about their illness and their future may in part be due to lack of information of the prognostic uncertainty associated with their condition [20,21]. These results match those observed in studies which demonstrate how the healthcare system tries to ignore uncertainty instead of training and supporting clinicians in how to acknowledge and manage it [22,23].This culture seeks for certainty and does not prepare clinicians to recognize and manage uncertainty within their practice [23–25]. This uncertainty hinders patient planning for self-management and the future [13,26,27]. This uncertainty also impacts on the clinician leading to cognitive, emotional and ethical reactions. These include difficulty in interpreting results, stress and anxiety for their patient thus impacting the nature and content of the conversation they have with patient [22,28,29].

Evidence shows the effectiveness of communication skills training on patient outcomes and in supporting HCPs when breaking bad news [30]. However, research indicates that there is still a modest percentage of HCPs receiving formal training on how to deliver bad news and this continues to affect patients' care and their families[31]. Other research has shown that COPD patients were not seen by Respiratory Nurse Specialists who are best placed to provide a link to other specialist services including palliative care[32]. This can influence patients' perception that specialized secondary care is of 'higher quality' than primary care [33]. This paper takes the literature forward by highlighting that for people with COPD many factors often combine to result in poor communication. These include the innate uncertainty of the illness, the lack of patients feeling able to talk about the future, the lack of COPD clinicians' training in dealing with uncertainty, and the lack of specialist nurses and palliative care specialists currently integrated into COPD patientcare which would also support patients and their GPs.

Strengths and limitations of study

The study was designed to compare between clusters, but because the GPs and nurses were rarely the same for lung cancer and COPD this direct between-cluster comparison was not possible. Since different professionals involved in the two clinical conditions were interviewed instead of one as planned, difference in communication styles would influence the patient's experiences and the current findings. Future research could repeat the study according to the original design to analyse the same professionals with patients from the two different disease conditions to get an understanding of the differences in information and communication that may exist. The data for this study were collected some years ago, however research published in 2020 support the findings indicating that ACP and EOLC should be initiated earlier than is currently practiced and how GPs have a central role in these discussions[34,35]. Recruitment biases inherent in the approach through lung cancer clinics and GPs are balanced by the success in recruitment of GPs and the involvement of the Primary Care Research Network in the recruitment process. The use of the 'Pictor Chart' facilitated an engaged interview which helped in prompting recall and reflection from participants.

Conclusions and implications

Effective communication and patient-led information-giving are core to good clinical care: neither giving undesired information nor withholding desired information at any point in time. In some conditions, such as lung cancer, relatively clear information can be given about the future; in other conditions, such as COPD, there is greater uncertainty. In both cases there is a need for clinicians to be honest and realistic: balancing a gentle honesty with maintaining realistic hope and acknowledging uncertainty to patients and carers. Managing uncertainty is an important part of a clinician's duty and their confidence in dealing with this uncertainty impacts on their ability to communicate this with patients[36]. Discussing the very uncertain

future in COPD and uncertain prognosis calls for good communication skills for all clinicians involved with GPs playing a central role with these patients who are often cared for at home[37]. These findings contribute to and support the Global Initiative for COPD's global strategy that recommends good advance care planning in the management of COPD and encourages clinicians to recognize the appropriateness of this service and support for patients[38] which is underused[39].

Declarations/ Acknowledgements

Ethical Approvals

The study was approved by the Cambridgeshire 4 Research Ethics Committee Reference10/H0305/41

patient representative, Roberta Lovick who was a user representative, who all contributed in many aspects to this project including research design and recruitment strategies.

The views expressed are those of the authors and not necessarily of the NIHR, NHS or Department of Health and Social Care.

Data availability

The data underlying this article cannot be shared publicly for the privacy of individuals that participated in the study. The data will be shared on reasonable request to the corresponding author.

Disclosure of interest

The authors report no conflict of interest.

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Theme	Quotes related to COPD care	Quotes related to Lung Cancer care
Focus of information	*"And they sent me for, afterwards x-rays, and then they said "you've got a lung condition and there's not really anything we can do with it" basically… He said "well you've really got to try and exercise as much as you can". [COPD patient_13]* *"When he was first diagnosed nobody really explained what it was so I was a bit in the dark as to what his condition was…. You see I didn't know what to expect". [COPD informal carer_13]* *"No, we haven't, we haven't ….It's so difficult, this is the problem with COPD per se, is that it's very difficult to identify when that terminal, proper terminal phase, sets in". [COPD nurse_13]*	*"It was very good, I went to [Hospital] and the lady that I met there, she explained everything". [LC patient_18]*
Style of communication	*"We were told to a certain degree. I mean, I don't think we were ever told everything". [COPD informal carer_11]*	*"Well they explained everything about me illness, they told me it was terminal, couldn't do anything for it, all they could do was try and slow it down". [LC patient_11]* *"Yes, they've kept us well informed… the consultant, he has forwarded me a copy of the correspondence he sends to the GP, so everything is sort of transparent". [LC patient_09]*
Main source of information	*"At his sort of stage he's sort of ticking along, so he's not under any outpatients as far as I'm aware, he doesn't go into the [Hospital], he hasn't seen any of the team at [Hospital]". [COPD nurse_23]*	*"He has been my surgeon and my carer since I had the problem and he continues to do so…(I see him) just about every month at the moment, maybe five weeks or so, but certainly regular". [LC patient_09]*
End of life conversations	*"Well actually, no. In all honesty, no, but it's very much at the fore and it's definitely next on the list". [COPD nurse_05]*	*"We've had conversations about his inevitable decline...I mean we discussed things like in the event of him having a sudden deterioration, would he want his*

	"Quite often I would leave it to the patient to ask me questions and have a way in that way". [COPD nurse_23] *"I might assess it at different means how much he wants to know rather than asking him how much do you really want to know maybe roundabout I assess and again you can know from their cues or their questions being asked depending on that…"* [GP_13] *"I do have a concern that not all our non-malignancies are getting through [onto GP practice end of life care register] …. at the Gold Standards Framework meetings most of the patients are cancer patients".* [LC nurse_05]	*heart restarting, obviously, he'd signed a 'do not resuscitate' form".* [GP_23]

Figure 1: Initial recruitment plan of clusters showing the order of recruitment for all
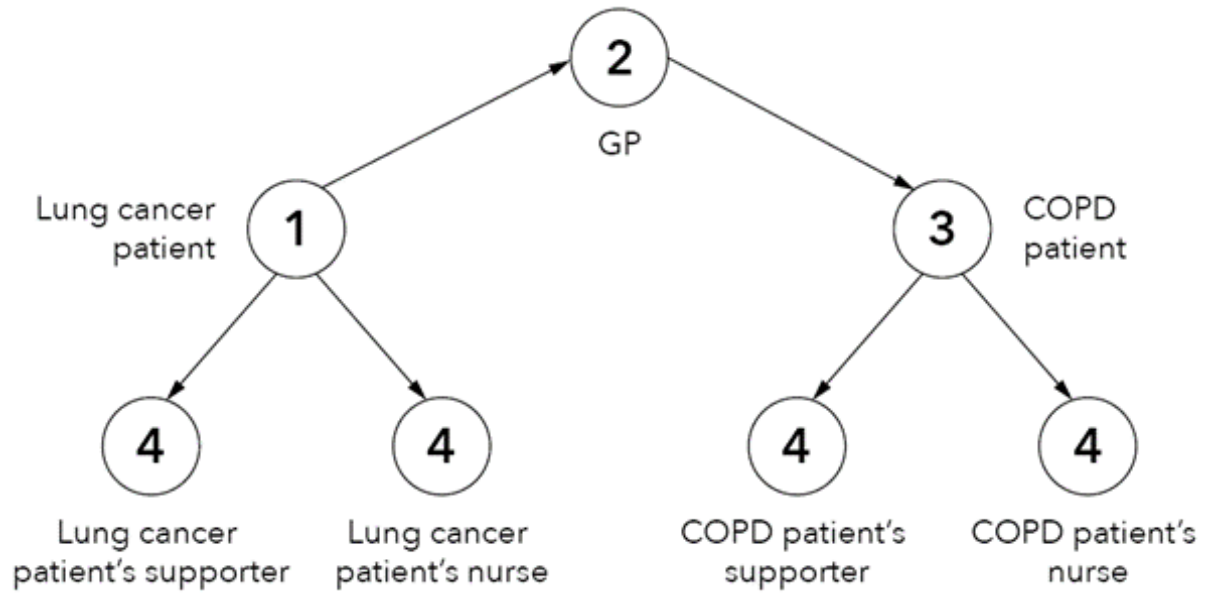
participants

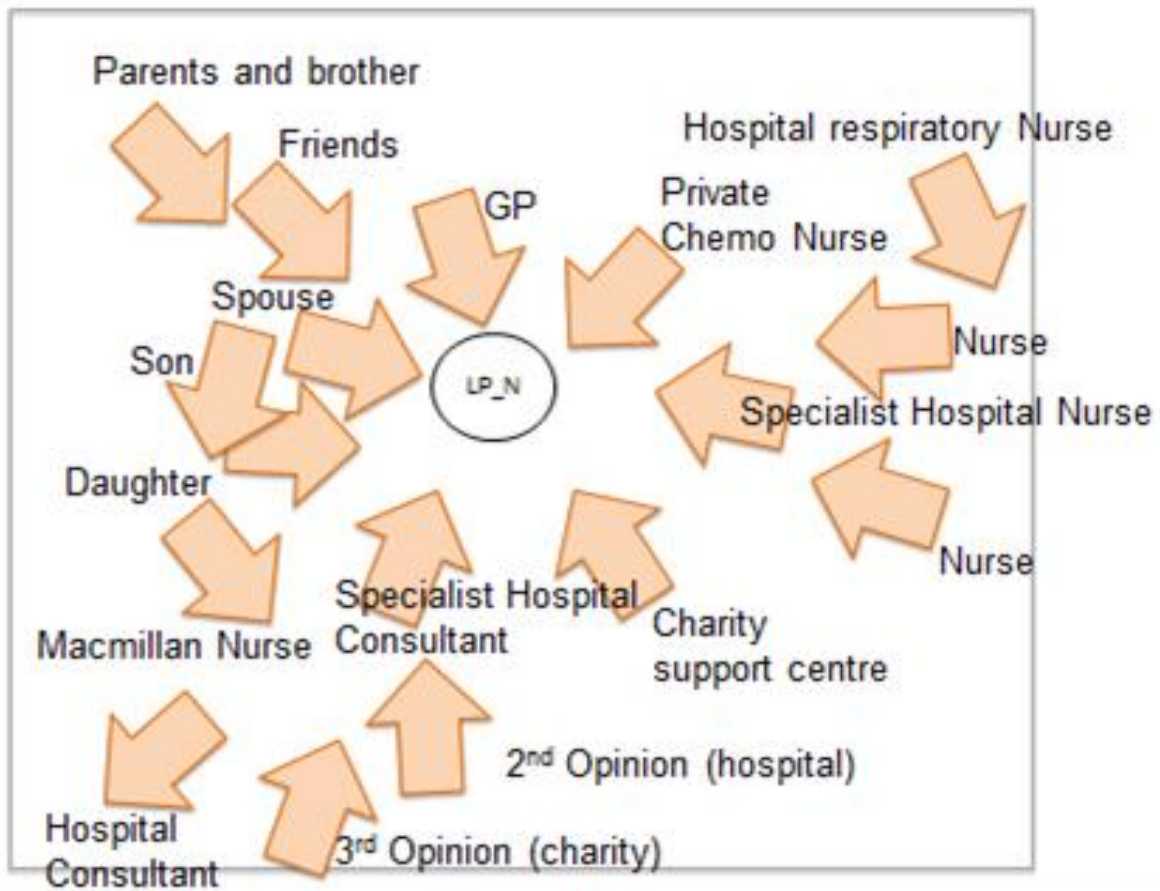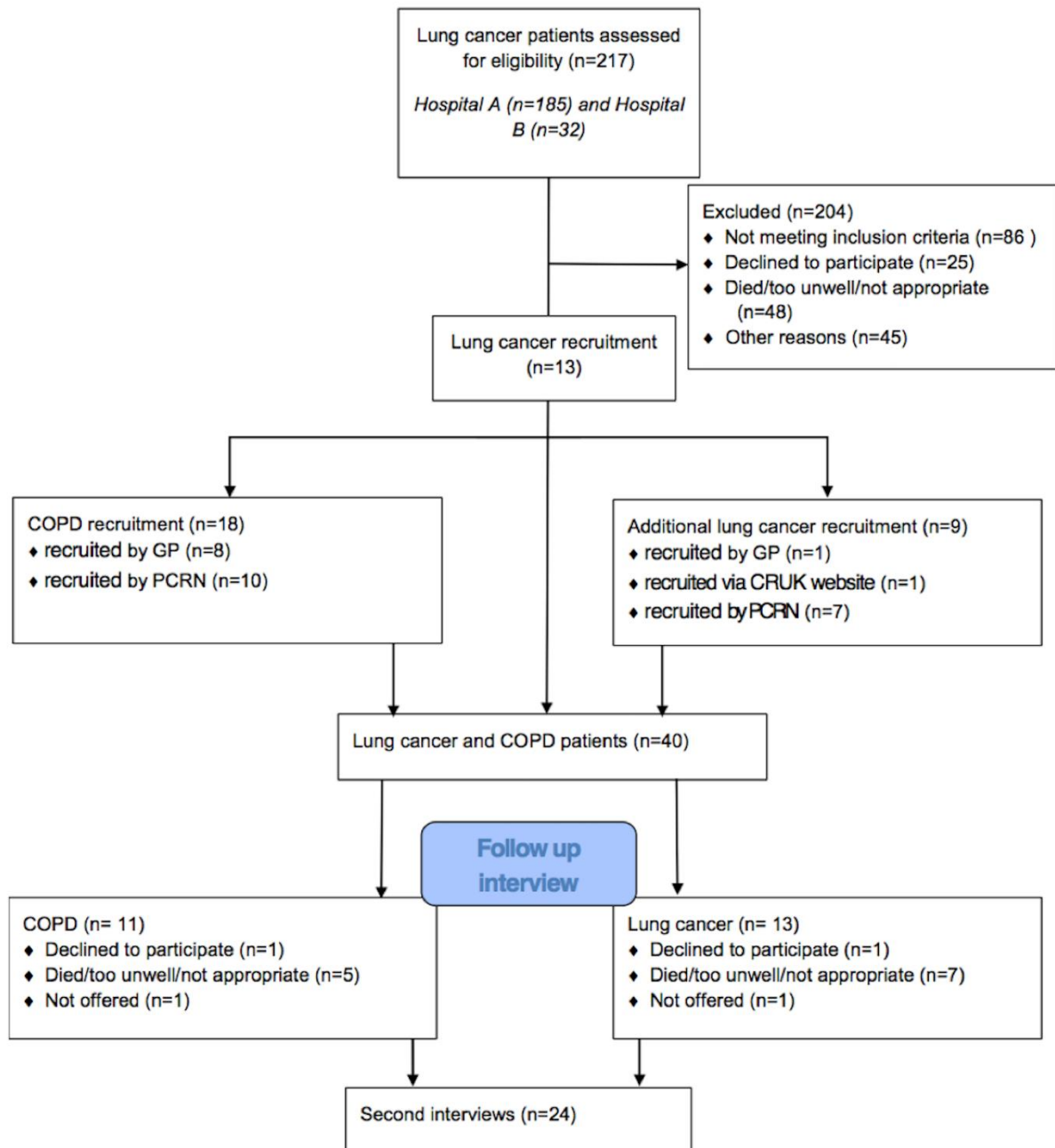Figure 2: An example of a Pictor chart from a lung cancer patient

Figure 3: Diagram showing the recruitment process of lung cancer and COPD patients in the East of England, UK (2010-2012).

Supplementary document
Interview guide

Background (past)

This is a research study, so I don't have access to your medical notes.

Can you tell me about your **illness**, how it has developed and the services you were offered?

Prompts: What did you find helpful (good quality care)? What did you find less helpful?

GP (GP practice, or individual GP) community nurse / specialist nurse hospital consultant

What **information** have you been given about your illness?

Prompts: What did you find helpful?

What did you find less helpful? Do you use the internet?

Have you looked on the internet about your illness?

Pictor (present)

Explain and show example - Who is 'here' for you?

Participant places post-its on the chart - Discuss

Prompts: What do you find helpful (good quality care)?

What do you find less helpful?

Prompts: GP (GP practice, or individual GP), how often and where? community nurse / specialist nurse, how often and where? hospital consultant and how often? key worker

What information would you like to have?

Future

For some people in the study we are coming back again in 3 [6] months. Do you think anything might change between now and then?

Is there anything else you would like to talk about? Wrapping up

Thank you

Arrange next phone call / visit Switch off recorder