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# BMJ Open What patients with lung cancer with comorbidity tell us about interprofessional collaborative care across healthcare sectors: qualitative interview study

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**To cite:** Bossert J, Forstner J, Villalobos M, *et al*. What patients with lung cancer with comorbidity tell us about interprofessional collaborative care across healthcare sectors: qualitative interview study. *BMJ Open* 2020;**10**:e036495. doi:10.1136/bmjopen-2019-036495

► Prepublication history and additional material for this paper are available online. To view these files, please visit the journal online (<http://dx.doi.org/10.1136/bmjopen-2019-036495>).

Received 18 December 2019  
Revised 30 April 2020  
Accepted 29 May 2020



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## ABSTRACT

**Background** Patients with lung cancer with comorbidity often require treatment and care by different health professionals, in different settings and at different points in time during the course of the disease. In order to organise and coordinate healthcare efficiently, effective information exchange and collaboration between all involved care providers are required. The aim of this study was to assess the views of patients with advanced lung cancer with comorbidity regarding coordination of treatment and care across healthcare sectors.

**Methods** This qualitative study, as part of the main study, The Heidelberg Milestones Communication Approach, used face-to-face guide-based semistructured interviews with patients with advanced lung cancer and their informal caregivers to explore cross-sectoral information exchange and collaboration in Germany. All generated data were audio-recorded, pseudonymised and transcribed verbatim. Data analysis was performed using qualitative content analysis to structure data into themes and subthemes. All data were managed and organised in MAXQDA.

**Results** In 15 interviews, participants reported that cross-sectoral collaboration functioned well, if treatments occurred as planned. However, treatment gaps were experienced, especially regarding medication and regimen. As a result, participants felt insecure and obliged to take responsibility for the coordination of healthcare. Patients reported to be in favour of an active patient role but felt that healthcare coordination should still be a responsibility of a care provider. A more intensive information exchange, potentially by using an electronic platform, was expected to strengthen cross-sectoral collaboration.

**Conclusion** Patients with lung cancer are uncertain about their role in the coordination of treatment and care across healthcare sectors. Healthcare providers should be more aware of care recipients' willingness of taking on a more active role in healthcare coordination.

**Trial registration number** DRKS00013469.

## Strengths and limitations of this study

- Due to the qualitative character, a deep insight into the perspective of a special group contributing to the development of cross-sectoral collaboration.
- The methodological approach contributes to the minimisation of a recall bias, as patients were interviewed directly during their treatment process.
- Interviewing was carried out by a researcher who did not know the patients, thereby reducing social desirability.
- The interviews were evaluated by two researchers according to a coding system, which provides clear definitions of the individual categories.
- Generalisation of findings to other types of cancers is difficult due to the qualitative character of the study.

## BACKGROUND

Lung cancer remains the leading cause of cancer-related deaths worldwide.<sup>1</sup> The majority of patients with lung cancer are diagnosed at an advanced stage, with a mean age of 70 years at diagnosis. As the prevalence of comorbidity increases with age, older patients with lung cancer have a particularly high risk of being affected with comorbid conditions.<sup>2</sup> Therefore, patients with lung cancer with comorbidity often require multimodal treatment and care by different health professionals, in different settings and at different points in time over the course of the disease. In order to coordinate healthcare across sectors, effective information exchange and collaboration between all involved care providers are required. However, studies show that despite several efforts, provision of optimal cancer care for patients with comorbid conditions still remains a major challenge.<sup>3</sup> Unclear responsibilities and incomplete information transfer across sectors can impede the coordination of

healthcare.<sup>4</sup> In order to close gaps in treatment and care, patients could provide important input in the exchange of information and collaboration between healthcare providers and across different healthcare sectors. Most patients are willing to take on this active role in the care process, and studies also show that an active patient role may have benefits.<sup>5,6</sup> However, little is known about how patients with advanced lung cancer perceive their role in palliative care and how their role affects them.<sup>5</sup> The role of coordinator of their own healthcare may have a negative impact on the quality of life of patients with advanced lung cancer and comorbidity, because they potentially feel overtaxed by it.<sup>7</sup> There is thus a need to define responsibilities for coordination of treatment and care across healthcare sectors. Complete and timely information exchange is an important precondition for collaboration and coordination of healthcare for patients with lung cancer.<sup>8</sup> The perspective of health professionals was examined in a previous study,<sup>9</sup> but the perspective of patients and informal caregivers is still unknown. Due to the severity of the disease, informal caregivers often play an important role in the planning of treatment and care for the patient.<sup>10</sup> The aim of this study was to explore the perspectives and experiences of patients with advanced lung cancer regarding their current role in the coordination of treatment and care across healthcare sectors.

## METHODS

### Study design

A qualitative interview study using a semistructured interview guide explored the information exchange process between inpatient and outpatient care providers from the patient's perspective in the context of palliative care. If patients were accompanied by an informal caregiver, their perspective was also considered.

### Setting

The study was conducted at the chemotherapy outpatient Department of Thoracic Oncology at the University Hospital Heidelberg, Germany. This hospital is a comprehensive cancer centre with a large catchment area and focuses on thoracic diseases, including lung cancer.

### Participants

A consecutive sample of patients with stage IV lung cancer and comorbidity (another chronic disease, chronic obstructive pulmonary disease (COPD), back pain and chronic heart disease) with a limited prognosis (median of <12 months) were personally invited to participate in the present interview study. Only patients who had participated in the control group of the main study, the Heidelberg Milestones Communication Approach (MCA), were included. They met the inclusion criteria defined by the MCA study (newly diagnosed stage IV lung cancer, reasonable mastery of German language, capable to fill in questionnaires of the main study, at least 18 years old).<sup>11</sup> Some of the patients had an informal caregiver

with them during the interview. All patients and informal caregivers gave their written informed consent into study participation.

### Data collection

Data were collected between September 2018 and April 2019. Face-to-face interviews using a semistructured interview guide were conducted in a separate and quiet room on the ward by a healthcare researcher (JB). The interview guide (online supplementary file) was developed based on a literature review and in accordance with the MCA project. Interview questions were oriented towards eliciting open-ended responses to acquire specific information on cross-sectoral information exchange. The interview guide was pretested with one patient to ensure that all questions were comprehensible. All interviews were digitally recorded and transcribed verbatim. The transcripts were compared with the digital recordings to correct any inaccuracies. Data were collected until saturation was reached.

In addition to the interviews, further information such as demographic data and comorbidities were collected from patients' medical records. No demographic data were explicitly assessed for informal caregivers but were retrieved from the interviews if available.

### Data analysis

Data were analysed according to qualitative content analysis<sup>12</sup> to structure collected data into themes and subthemes. Within this approach, a summary of the content was carried out by two female researchers with a background in health services research (MSc) and nursing (JB and JF) deleting all expletives and repetitions. Then, the material was coded line-by-line deductively with an a priori developed system of themes derived from the interview guide and inductively from additional contents of the interviews. In this way, qualitative data were grouped into five main themes containing a different number of subthemes each. All interviews were analysed applying this approach by both researchers to enhance reliability of coding. The analyses were compared and the coded themes were modified when applicable. Moreover, all interviews were expansively discussed between the two researchers in order to ensure validity. All qualitative data were managed and analysed using MAXQDA V.12 (VERBI Software GmbH, Berlin).<sup>13</sup> Quotes presented as examples in this article have been translated from German into English with due diligence and slightly adapted to maintain meaning.

### Patient and public involvement

There was no patients and public involvement in this study.

## RESULTS

Fifteen interviews were conducted with patients. In five interviews, an informal caregiver was also present due to patient's wish or their physical condition. All informal caregivers were the partner or spouse of the patient. **Table 1** shows the sociodemographic characteristics of

**Table 1** Sociodemographic characteristics of the patients participating in this study (n=15)

	n		n (%)		
	Total	Mean (range)	Total	Female	Male
Age (years)	15	67.3 (43–89)			
Gender	15		15 (100)	5 (33.3)	10 (66.7)
Exposure to hazardous substances in the past*	15		6 (40)	1 (16.7)	5 (83.3)
Past employed	15		11 (73.3)	2 (18.2)	9 (81.8)
Comorbidity documented in medical records (≥5)	15		5 (33.3)	2 (40)	3 (60)
Hypertension	15		6 (40%)		
COPD	15		5 (33%)		
Vascular diseases	15		4 (27%)		
Living with partner	15		14 (93.3)	5 (35.7)	9 (64.3)

\*Includes all substances that lead to a toxic effect on organisms. The toxicity of a substance is divided into acute toxicity, subacute toxicity and subchronic toxicity of chronic toxicity.<sup>30</sup>  
COPD, chronic obstructive pulmonary disease.

the patient sample. The mean number of comorbidities was three (range 2–11). The mean interview duration was 24.5 min (range 5.4–43.4).

The analysis highlighted five interdependent main themes regarding the coordination of treatment and care across healthcare sectors: (1) setting, (2) tasks, (3) experiences, (4) impact and (5) ideas on optimisation. All themes included subthemes.

### Theme 1: setting of cross-sectoral collaboration

This main theme represented the current situation of cross-sectoral collaboration and could be seen as an inventory. This included all participating institutions, care providers and patients' characteristics. Each individual component had an overall influence on cross-sectoral collaboration. This theme comprised specialist groups, inpatient institutions, outpatient institutions and comorbidities. From the patients' perspective, the groups mostly involved in cross-sectoral collaboration were general practitioners and lung specialists, other hospitals and outpatient palliative care. Most common comorbidities mentioned by patients were type 2 diabetes mellitus, hypertension, coronary heart disease and other oncological diseases (ie, oesophagus carcinoma and urothelial carcinoma), for which the patients also consulted specialists. The three most common comorbidities taken from medical records were hypertension, COPD and vascular diseases.

### Theme 2: tasks of cross-sectoral collaboration

This main theme comprised task areas performed by care providers in the outpatient and inpatient sectors, patients and informal caregivers. Four subthemes were contained: tasks of the outpatient sector, tasks of the inpatient sector, patients' tasks and informal caregivers' tasks. Tasks of the outpatient and inpatient sector reflected cross-sectoral cooperation and were additionally subdivided into 'organisational tasks', 'preventive tasks', 'diagnostic tasks', 'therapeutic tasks' and

'rehabilitative tasks'. In this context, only organisational aspects were dealt with, as these were relevant for cross-sector collaboration.

### Cross-sectoral organisational tasks

The interviews revealed that many organisational tasks seemed to be assigned to the outpatient sector. A frequently mentioned aspect was the referral, which the lung specialist must issue for inpatient admission to the thoracic clinic (legally required in Germany).<sup>14</sup> Patients and informal caregivers reflected critically on this aspect because they could not understand the necessity of including outpatient lung specialists in the treatment:

The strange thing is that I always have to bring a referral from the lung specialist - I went there every time, the lung specialist doesn't know me, but I have the referral. Patient 013

Although it's not quite clear to me what I should do with her [the patient] at the lung specialist. Informal caregiver 004

Patients had the impression that the lung specialists themselves were not aware of their role in cross-sectoral collaboration. They also thought the specialists did not see any added value.

(...) the lung specialist said [to the medical assistant]: "He's [treated] in the Thoracic Clinic, then I don't have to do anything; that's okay, give him the referral" (...). Patient 013

Patients also stated that they were not informed about the necessity of a referral issued by a lung specialist at the beginning of their treatment. This resulted in an additional organisational effort. Another inconvenience was seen in the fact that every quarter a new referral was needed.

### Patients' tasks

Patients took on an active participation in cross-sectoral collaboration by acting as messengers between physicians. They perceived their role as securing the care process and thought there would be less information for care providers if they did not do so. However, some informal caregivers associated the active patient role with too much responsibility and pressure.

I pass the documents on to the different doctors so they can at least have everything [available] to themselves. At least, the general practitioner (...), that he is informed about the state of progress and I also do that with the diabetologist, because if we are honest, they are all so overworked. Patient 010

Because he always has to tell the doctor everything that has been done, and until he gets to the doctor, (...) it's ticking up there [in the mind]: "I have to remember it, and I have to remember it. Informal caregiver 016

### Informal caregivers' task

As the active patient role was perceived as carrying a lot of responsibility, informal caregivers tried to support patients by taking care of organisational aspects, such as making appointments and the transmission of clinical information to the general practitioner.

I have to manage everything, (...) he can't do anything at all. Informal caregiver 019

### Theme 3: experiences with cross-sectoral collaboration

This main theme included positive and negative experiences of patients and their informal caregivers in the treatment process. These related both to a single sector and to exchanges between healthcare sectors, since processes and structures within a sector were seen as the basis for cross-sectoral exchange. This was a subjective assessment of the actual condition from the patient's and informal caregivers' point of view.

### Patients' positive cross-sectoral experiences

The collaboration between the inpatient and outpatient sectors was evaluated controversially. Some patients experienced the collaboration positively and considered the exchange by means of a doctor's letter to be successful, extensive and timely. The care providers were equally informed, which led to satisfaction with care.

I have to compliment the clinic very much; the doctor's letter is very detailed and another doctor can do something with it and that's why I think you don't need personal exchange. Patient 019

Here, they also do it in such a way that they forward the reports immediately if something is wrong, and I think it's a good thing that you don't have to start all over again. Informal caregiver 026

### Patients' negative cross-sectoral experiences

Negative experiences referred to different information levels among providers, especially on medication and treatment regimen. Patients reported that their general practitioner often was not informed about their current status. One negative experience related to unmatched information levels of care providers, reflected by the provision of incorrect information to the patient.

The clinic prescribes a medication, about which my general practitioner does not know anything and he prescribes drugs, which do not fit together (...) I felt quite bad and a half a year later the same happened again (...) that annoyed me. Patient 013

We got a doctor's letter from the former clinic, the tumour would have grown - and then we came here and nothing had grown, it had shrunk (...) I had already gotten a chemotherapy and that was the information from the initial CT (...) so we were shocked (...) everything went a little bit confused in our case. Patient 014

### Theme 4: impact of cross-sectoral collaboration

This theme covered the effect of current cross-sectoral collaboration on patients and their informal caregiver. Indicators for this were the level of knowledge regarding cross-sectoral collaboration and the impact of cross-sectoral collaboration on quality of life. This theme was also a subjective representation of the current state of cross-sectoral collaboration. Furthermore, insight into the extent to which information was available and accessible to patients and their informal caregivers was provided. The theme was divided into the subthemes 'awareness on cross-sectoral collaboration' ('informed' vs 'not informed') and 'patients' quality of life' from both patient and informal caregiver perspectives.

#### Awareness: informed

Patients reported that they often did not pay a lot of attention to cross-sectoral exchange as long as they were satisfied with treatment processes. However, if there were shortcomings or gaps in care delivery, patients felt increasingly aware of its relevance. Yet, in general, patients mentioned that the doctor's letter was used as the communication tool of choice.

All I know is that the lung specialist gets the clinical results and the general practitioner gets a copy, but I don't know if he gets it sent. Patient 015

#### Awareness: not informed

Patients perceived little information exchange across healthcare sectors. This was reflected when patients were actively asked by their general practitioner what the hospital doctor had requested or said.

Collaboration (...) between my GP's practice and the clinic - (...) I have the feeling that there is very little communication between them (...) because I didn't

really notice anything, and because the general practitioner always asked me ‘How does the clinic want it (to be arranged) with the blood sample? Patient 016

#### Patients’ quality of life

Cross-sectoral collaboration was reported to have an effect on patients’ quality of life. In order to achieve an improvement, optimisations of the collaboration were seen as preferable. Patients currently saw legal requirements as the cause of deficits in collaboration.

A good collaboration has a 100% effect on the quality of life (...) it's simply the most important thing (...) but the context and the rules force the doctors to act in the way they do. This leads to a lack of quality that affects the patient. Patient 016

#### Informal caregivers’ quality of life

Informal caregivers also saw successful cross-sectoral collaboration as essential for quality of life, both for the patient and for themselves. This was due to the impression of an effective cross-sectoral collaboration leading to a higher level of patient safety.

An optimised collaboration would change the quality of life, because you would feel to be in good hands (...) Yes, then I would feel more light-hearted. I want to know who I can call if there's anything (...) These are things that could go a little better. Informal caregiver 019

#### Theme 5: optimal cross-sectoral collaboration

This main theme describes tasks related to the healthcare sector and care providers that should be carried out in order to achieve optimal cross-sectoral cooperation. The theme was split into three subthemes: descriptions of optimal cross-sectoral collaboration, patients’ and caregivers’ view on the relevance of cross-sectoral collaboration, and suggestions for improvement of cross-sectoral collaboration.

#### Description of optimal cross-sectoral collaboration

From the participants’ point of view, as a result of good collaboration, all care providers should have the same level of information and answer questions uniformly and independently.

I would like to go to my general practitioner and ask the same questions as here (thoracic clinic) and he could give me the same answers as the doctor here. Patient 024

Patients expressed that good collaboration was also characterised by one person acting as a manager and being responsible for coordination and prioritisation in the treatment process.

A person should determine where things are heading to and how they should be done and then it is good. Patient 014

It's good for the well-being to have another watchful hand over me. People who know [about the procedures]. Patient 024

The general practitioner was considered to take on this role, as he usually had an intensive relationship with the patient and was seen as a confidant. Therefore, good collaboration was characterised by the general practitioner staying in close contact with the inpatient sector and taking on the role of a care manager.

The general practitioner knows everything about my situation and I think that's good for a patient and that's why he should stay in touch with the clinic. Patient 027

#### Relevance of cross-sectoral collaboration

Patients stated successful cross-sectoral collaboration as relevant, because it allowed optimal results to be achieved in all aspects of the treatment process. In addition, they felt relieved and enabled to communicate with a doctor on the same level. Effective cross-sectoral collaboration was considered to also bring advantages for care providers as treatment processes could be better planned. This was reflected in well-coordinated processes.

Then I could have a better conversation with my general practitioner, in the same way I communicate with the doctor here. Patient 022

The more consistently [all doctors] are informed, the easier it is for them to drive a machine. Patient 026

#### Suggestions for improvement of cross-sectoral collaboration

Patients and their informal caregivers saw more intensive exchange between care providers as a relevant suggestion for optimisation. For a more intensive exchange, the doctors’ interest in the patient was seen as a prerequisite.

(...) as a doctor you take care of your patients and then also inform the others or request results. Patient 008

(...) the general practitioner should be interested in what is actually planned as the next steps (...) A doctor must actually be a confidant (...). Informal caregiver 004

Concrete measures of optimisation were seen in the way of communication and the electronic transmission of information was mentioned. Another suggestion regarding improved cross-sectoral exchange was seen in the personal communication that could take place, for example, by telephone.

(...) that everyone had access to the patient's data, so they could do it over the internet (...) the letter form is okay, but direct access from one to the other would be better. Patient 024

(...) they should talk more to each other (...) I would like to receive a note with the words about this and what they have prescribed. It should also say what was



done and what the result was (...), that the general practitioner doesn't have to ask me because I often don't understand everything myself. Informal caregiver 018

In the context of the suggestion for optimisation, the referral by the lung specialist again was discussed. In patients and informal caregivers' opinions, this should no longer be necessary for patients with lung cancer. An improved definition of tasks was also seen as a measure for improved cross-sectoral collaboration.

(...) if it would be possible with the health insurance card to come here and the referral wouldn't longer be needed (...) in the sense that the general practitioner can store the data there. Informal caregiver 014

(...) the problem is that there is no good division (who does what when), (...) if you say you do more here now, and you there, and you there, then everything is more distributed. Patient 016

## DISCUSSION

This study explored perspectives and experiences from patients with lung cancer with comorbidity and their informal caregivers to generate an understanding of current perceptions of cross-sectoral healthcare coordination. Patients reported to be in favour of an active patient role, but they would still prefer that coordination is done by a health professional. The study indicates that general practitioners may take this role. At the same time, it showed that patients may be involved more actively in healthcare coordination. A more intensive exchange, potentially via an electronic platform, was perceived to support such active patient engagement.

It became clear that patients report on positive experiences with cross-sectoral collaboration, if treatment and care take place as planned. In this case, patients find communication through the doctor's letter, as customary in the German healthcare system, sufficient, as it is extensive and detailed. Factors that support a successful cross-sectoral collaboration are diverse and include aspects such as personal attitudes of care providers and the course of illness associated with unplanned events.<sup>15</sup> A further influential aspect is the patient's level of prognostic awareness.<sup>16</sup> Informing patients about the current status of their treatment has an effect on information flow between all involved care providers. This, in turn, leads to a higher level of patients' and informal caregivers' satisfaction with treatment and care.<sup>17</sup>

However, if there were shortcomings or gaps in treatment and care, patients in this study became increasingly aware of the relevance of the coordination across healthcare sectors. Negative events referred to different information levels among providers related to medication and treatment regimen. If such incidents occurred, patients felt insecure and had the feeling that they had to take

responsibility for the healthcare coordination. In view of the severity of the disease, this can lead to overstraining and additional burden for patients and informal caregivers. Studies show that severely ill patients, in particular, often need a high level of support in order to cope with their situation.<sup>18</sup> A functioning cross-sectoral collaboration can contribute to the relief of these patients and lead to an active patient, who is neither overburdened by decisions nor over-ruled by care providers.<sup>19</sup>

A challenge to cross-sectoral collaboration is seen in the necessity of a quarterly referral from the lung specialist that is needed for the clinical treatment. This represents a major organisational challenge which, moreover, has no discernible benefit from their perspectives. The requirement of referral is legally determined by the National Association of Statutory Health Insurance Physicians for financial accounting reasons.<sup>14</sup> This implies that changes in the necessity of referral would require by an adaptation of the healthcare system. Since such a change could be expected to be time-consuming and extended, alternatives are needed to support patients and informal caregivers. One option is seen in the use of an electronic referral system. Studies analysed changes in the referral process regarding workflow, waiting times and clinical care.<sup>20</sup> Nevertheless, the use of electronic referrals is not common in Germany. Partly responsible for the difficulties in implementing telemedicine are the rather restrictive data protection laws in Germany. German data protection laws guarantee a high degree of data security for patients but leave little room for innovations.<sup>21</sup>

Not only electronic systems can provide coordinated care but also a professional coordinator. Coordinated care has been shown to have positive effects. Especially quality of life can be influenced by coordination of care since patients experience continuity of care, defined responsibilities and therewith less burden related to multiple diagnostics and organisational efforts in combination with a challenging end-of-life situation.<sup>22</sup>

Patients and their informal caregivers declared that they wished to have a coordinator in the treatment process. Some patients stated that this role should be taken over by the general practitioner, although he or she currently might not be involved in treatment and care of lung cancer. Nevertheless, the suggestion corresponds with the definition of the German College of General Practitioners and Family Physicians, where a general practitioner is defined as the first point of access to medical care as well as the health professional who provides most continuous and comprehensive medical care.<sup>23</sup> Studies already show that general practitioners express a desire and commitment to participate in the planning and coordination of healthcare, but they argue that the role as coordinator needs to be officially recognised and financially reimbursed in order to fulfil it.<sup>24</sup> Also, they may feel uncertain about their involvement in cancer care.<sup>25</sup> Managing comorbidities in patients with lung cancer involves the cooperation not only between general practitioners and lung cancer specialists but also with other specialists, for

example, internists and neurologists. In several studies, specialists and general practitioners discussed concepts for better collaboration, focusing on communication, coordination and responsibilities.<sup>26</sup>

According to this study, a more intensive exchange between care providers would improve collaboration. One possibility is seen in the use of an electronic platform, which could place patients in an active role as healthcare coordinator. Despite growing evidence that patient-managed platforms can have positive benefits for healthcare, such concepts are not yet widely adopted in Germany.<sup>27</sup> Patients who transport paper-based doctor's letters and results from one practice to another are still common. Ironically, the letter is often digitalised by the recipient so that it can be available in the practice software.<sup>28</sup> There is a growing pressure to break down barriers for the implementation of digital information transfer in Germany,<sup>29</sup> which could have major implications for the coordination of healthcare across sectors for all patients.

### Strengths and limitations

Our results provide an initial assessment of cross-sectoral collaboration in patients with cancer with comorbidity. Generalisation of findings to other types of cancers is difficult due to the qualitative character of the study. Some of the identified problems are only specific to patients with advanced lung cancer, other aspects, such as the communication structure between service providers, are likely to apply to other patients with cancer with comorbidity. A potential selection bias is that only patients and informal caregivers who were emotionally and psychologically strong enough to express their opinion in an interview participated in the study. Additionally, we did not elicit patient information needs and their association with patients' ability and willingness to actively participate in coordination of care. Thus, patients who are satisfied with the information they received are hardly concerned with cross-sectoral coordination.

The number of informal caregivers was too small to draw separate conclusions on their perspectives and experiences.

### CONCLUSION

This study presents patients' and informal caregivers' perspectives on cross-sectoral coordination for healthcare providers. Patients with advanced lung cancer would wish a coordinating healthcare professional, as well as active engagement in healthcare coordination for themselves and their informal caregivers. Results can be used as a basis for defining responsibilities in tackling challenges in the care of patients with cancer and comorbidities.

Future research should triangulate those findings with service providers perspectives and explore how these different approaches to coordination are best designed and implemented, followed by trials on effects on clinical outcomes.

**Acknowledgements** We gratefully thank all patients and informal caregivers who participated in this study and also Regina Poß-Doering for her support in proofreading and linguistic revision.

**Contributors** JB, MW, MV and KK conceived and designed the study. JB developed the interview guide, carried out data collection, data analysis and wrote a first draft of this paper. JF also analysed and interpreted all interviews. KK was responsible for critical intellectual advice regarding content aspects of the study and supported the finalisation of this manuscript. MT, AS, ND and CJ contributed substantially to the manuscript. All authors have given approval to the final manuscript.

**Funding** This research was funded by the Federal Ministry of Health, Germany (1504–54401) and the National Center for Tumor Diseases (NCT 3.0, G835), Heidelberg, Germany.

**Competing interests** None declared.

**Patient and public involvement** Patients and/or the public were not involved in the design, conduct, reporting or dissemination plans of this research.

**Patient consent for publication** Obtained.

**Ethics approval** This work is part of a larger study, the Heidelberg Milestones Communication Approach. Patients and informal caregiver gave their written informed consent for participation and analysis of all collected data. The study was approved by the ethics committee of the University Hospital Heidelberg, Germany (protocol no. S-561/2017).

**Provenance and peer review** Not commissioned; externally peer reviewed.

**Data availability statement** Data are available upon reasonable request. Pseudonymised interview transcripts are available upon request to the corresponding author.

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