Patient, carer and health professional experiences of end-of-life care services in chronic obstructive pulmonary disease: an interpretive synthesis of qualitative studies

Amanda Landers,1 Johanna Margaretha de Koning Gans,1 Suzanne Pitama,2 Suetonia Palmer,1, Lutz Beckert1

ABSTRACT
The objective of this systematic literature review is to identify patients’, carers’ and health professionals’ reported perspectives of end-of-life care services for severe chronic obstructive pulmonary diseases (COPD) and explore whether services are person-centred and integrated according to WHO definitions. The systematic review was qualitative with interpretive synthesis. The data sources included MEDLINE, CINAHL, Embase, Cochrane (CENTRAL), Joanna Briggs Institute and PsycINFO databases from inception to 23 May 2022 limited to the English language. Qualitative studies were eligible if they reported open-ended patients’, carers’ or healthcare professionals’ experiences of end-of-life care for severe COPD. Qualitative data were categorised according to healthcare stakeholder groups and conceptualised within a health services network using the Actor-Network Theory. Eighty-seven studies proved eligible. Eleven stakeholder groups constituted the healthcare services network for severe COPD (in order of frequency of interactions with other stakeholders): secondary care, primary care, community services, acute care, palliative care, carer, healthcare environment, patient, government, social supports and research. When evaluating the network for evidence of patient-centred care, patients and carers received input from all stakeholder groups. The relationship between stakeholder groups and patients was largely unidirectional (stakeholders towards patients) with low influence of patients towards all stakeholder groups. There was limited interaction between specific healthcare services, suggesting low network integration. Government services, research and social supports had few connections with other services in the healthcare network. Multiple intersecting health, community and government services acted on patients, rather than providing patient-informed care. Health services provided poorly integrated services for end-of-life care for severe COPD. PROSPERO registration number CRD42020168733.

INTRODUCTION
Chronic obstructive lung diseases were the third most frequent global cause of death in 2019 (6%).1 Almost four million people died from chronic obstructive pulmonary diseases (COPD), representing an increase of 18% since 1990.2 In 2016, the Lancet Respiratory Medicine Commission reported on the challenge of COPD care in the USA highlighting that patients who have severe respiratory diseases are required to negotiate complex healthcare systems with low adherence to best practice guidelines.3 In response to these findings, the commission aimed ‘to engage the COPD community in a dialogue’ to achieve more closely coordinated healthcare services in partnership with patients and their carers.
The WHO has articulated a strategy to adopt people-centred and integrated health systems to increase care quality and safety. Using this strategy, people-centred care intentionally embraces individual, family and community perspectives as participants in, and users of, the healthcare system. Central to this approach is providing education and support to consumers to enable meaningful participation in care. Integration of health services, according to the WHO definition, depends on supportive leadership, systems of communication and strong governance. Without continuity and co-ordination, patients and carers and health professionals experience fragmentation of care. High-performing healthcare networks deliver services through integrating disease prevention, disease modification, rehabilitation and palliative care. Healthcare system design may be particularly relevant in advanced COPD, a complex and unpredictable illness that involves primary care, secondary and hospital services and non-government organisations.

The aim of this systematic review with interpretive synthesis was to explore the perceptions and experiences of patients, carers and health professionals related to healthcare services for end-of-life COPD, and explore whether healthcare services are person-centred and integrated care according to WHO definitions.

METHODS
Design and registration
The protocol was prospectively registered with PROSPERO CRD420920168733 prior to data collection. We used the Enhancing Transparency in Reporting the Synthesis of Qualitative Research to guide reporting.

Study selection
Studies were eligible if they were qualitative and reported experiences and perspectives on end-of-life care involving adults diagnosed with severe COPD (forced expiratory volume in 1 second <40% or Global Initiative for Chronic Obstructive Lung Disease Group D), their carers and healthcare professionals providing end-of-life care for advanced COPD. We included home-based, hospital-based and community-based care. Studies reporting only quantitative data and closed question surveys were ineligible. Studies that used structured questionnaires, observational epidemiological studies, editorials, reviews, non-research articles, anecdotal reports and letters were also ineligible. Studies involving patients with lung cancer were excluded. Due to resource constraints, we restricted studies to those published in English.

Data sources and searches
Electronic searches were conducted in MEDLINE, CINAHL, Emcare, Embase, Cochrane (CENTRAL), Joanna Briggs Institute and PsycINFO databases from inception to 23 May 2022, using a highly sensitive search strategy (online supplemental appendix A). We also searched the reference lists of relevant articles and reviews to identify additional eligible studies. Two reviewers (AL and JMdKG) independently screened the title and abstract of retrieved records and retained all potentially eligible records. These were read in full text independently by the same two reviewers to adjudicate eligibility. Consensus was reached through discussion and included a third reviewer (LB) if required.

Data extraction
Included studies were uploaded into NVivo software (V.12, QSR International, Melbourne, Australia) and the text was extracted from the methods, results and discussion sections of each article. Study characteristics were recorded in a purpose-built Excel (Microsoft Corporation, 2018) database including publication year, study aim, participant characteristics, methods of data collection, analysis and themes (online supplemental appendix B). Data extraction was completed by AL and checked by JMdKG. The research team consisted of two respiratory physicians (JMdKG and LB), a palliative care physician (AL) and two methodologists (SPa and SPI) all working within a high-resource health setting. AL, LB, SPI and SPa have expertise in qualitative synthesis and health systems research. SPI is an Indigenous researcher.

Comprehensiveness of study reporting
We assessed the comprehensiveness of the reporting in each included study using the Consolidated Criteria for Reporting Qualitative research (COREQ) guidelines. One reviewer (AL) assessed all the studies and a second author (JMdKG) evaluated selected articles to ascertain concordance.

Synthesis of findings
We employed actor–network theory (ANT) to categorise healthcare service stakeholder groups that patients, carers, and healthcare professionals reported as present in the care of patients with severe COPD. The ANT is a framework to investigate and theorise about the elements of complex healthcare systems, and assisted the investigator team to identify the human and inanimate ‘actors’ (healthcare services and stakeholders) in the examined healthcare network. We conducted an interpretive synthesis of the data, informed by the ANT, to conceptualise the key stakeholders in the healthcare system providing care for advanced COPD.

We conducted two cycles of coding to synthesise the data. In the first cycle, we used provisional coding to analyse data according to a predetermined list of codes drawn from prior fieldwork. Potential ‘actors’ in the network were listed before coding, which also enabled the research team to identify possible missing actors from the data. Two researchers (AL and JMdKG) formulated the actor list based on their clinical experience of working with patients diagnosed with COPD in hospital and community settings. Two researchers (AL and JMdKG) reviewed each article for the presence or absence of actors within a healthcare network based on
| Stakeholder groups    | Actors                                                                 | Studies | Interactions |
|-----------------------|------------------------------------------------------------------------|---------|--------------|
| **Secondary services** | Pulmonary rehabilitation  
Respiratory clinical nurse specialist  
Respiratory nurses  
Respiratory physicians  
Physicians  
Advance care plans  
Action plans  
Assistive devices  
Health professionals  
Nurses  
Health service provider | Opioids and medications  
Ward nurse  
Ward staff  
Discharge care plan  
Breathlessness service  
Oxygen  
Multi-disciplinary meeting  
Non-pharmacological interventions | 73      | 534          |
| **Primary care**      | General practice  
GP nurse  
General practitioner  
Health service provider  
Respiratory clinical nurse specialist  
Physician  
Health professional  
Nurses | Opioids and medication  
Assistive devices  
Advance care plan  
Action plan  
Care coordinator  
Multi-disciplinary meeting  
Non-pharmacological interventions | 67      | 418          |
| **Community services** | Physiotherapist  
Care coordinator  
Community nurses  
District nurses  
Pulmonary rehabilitation  
Assistive devices  
Health professional  
Pharmacist  
Care worker  
Guidelines  
Nurses | Action plan  
Community services  
Discharge care plan  
Respiratory physician  
Allied Health  
Care Managers  
Complementary therapists  
Multi-disciplinary meeting  
Non-pharmacological interventions | 67      | 352          |
| **Acute care**        | After-hours GP  
Ambulance crews  
Discharge care plan  
Emergency service  
Intensive care nurse  
Intensive care physician  
Health service provider | Opioids and medication  
Health professional  
Nurses  
Assistive devices  
Physicians | 62      | 323          |
| **Palliative care**   | Day hospice  
Hospice  
Palliative care structure  
Palliative care nurse  
Palliative care service  
Palliative care specialist  
Health service provider | Opioids and medication  
Nurses  
Health professionals  
Action plan  
Physicians  
Advance care plan  
Multi-disciplinary meeting  
Occupational therapist | 64      | 304          |
| **Carer**             | Family  
Friends  
Carer | 35      | 203          |
| **Healthcare Environment** | Palliative care structure  
Electronic patient file  
Health policies  
Medical culture  
Model of care | Education  
Guidelines  
Healthcare system  
Health service provider | 37      | 109          |
reported roles and interactions. The actors were then aggregated into stakeholder groups based on roles, work settings, and relationships with other actors. Some actors were categorised into more than one stakeholder group (table 1). The final stakeholder groups were discussed and triangulated among all investigators.

In the second cycle of coding, the research team used pattern coding to generate a network of interactions between stakeholder groups in the health system. Each interaction reported between stakeholder groups in the health system network was coded as an actual interaction. Actual interactions were reported when two stakeholder groups had interacted with each other. At completion of the second cycle of coding, interactions between the groups were conceptualised as a health services network that described patients’ experiences of end-of-life COPD care.

The research team discussed the frequency and strength of the interactions in the formulated network. One researcher (AL) presented the initial network diagram to local healthcare providers to seek feedback. The research team subsequently revised the network model, via an iterative process including triangulating the results of provider consultation.

The network was analysed by the research team to explore the extent and nature of people-centred care and health service integration as recommended by the WHO framework for high-performing healthcare systems. In this analysis, people-centred care was defined as bidirectional interactions between stakeholder groups, and health service integration was described as connections between stakeholder groups in the formulated network.

### Patient and public involvement

No consumer or public engagement occurred in setting the research question or study conduct.

### RESULTS

Eighty-seven studies involving 2290 participants proved eligible (figure 1 and online supplemental appendix B). Studies evaluated healthcare in three WHO regions: the Americas (n=14), Europe (n=64), and the Western Pacific (n=9). No studies included participants in African, South-East Asia or Eastern Mediterranean regions. Sixty-four of the studies had been published since 2010 and 36 studies were published within the nursing discipline. Fifty studies focused on patients’ perspectives. Twenty-seven studies evaluated health professional perspectives, and 22 reported carers’ experiences.

### Completeness of reporting

Based on the COREQ checklist, most studies reported the personal characteristics and positioning of the interviewer/facilitator and methods related to study design, sample size and population, and data collection (online supplemental appendix C). Seventy studies reported the number of coders and 79 studies reported how themes were derived. All studies reported participant quotations. Ten studies reported the interviewers’ characteristics. Seven studies returned the transcripts to participants for member checking.

### Interpretive synthesis

Sixty-six actors were identified in the healthcare network for end-of-life COPD. These were categorised into 11 stakeholder groups.

| Stakeholder groups | Actors                                                                 | Studies | Interactions |
|--------------------|----------------------------------------------------------------------|---------|--------------|
| Patient            | Patient, Finance, Cultural background                                  | 31      | 60           |
| Government         | Health policies, Ministries, Model of care, Education, Guidelines, Public Insurance | 20      | 39           |
| Social supports    | Lawyer, Psychologist/counsellor, Spiritual support, Social networks, Social worker, Transport, Support groups, Voluntary organisations | 16      | 23           |
| Research           | Scientific research                                                    | 17      | 22           |

COPD, chronic obstructive pulmonary diseases; GP, general practitioner.
stakeholder groups (in order of frequency of interactions with other stakeholders): secondary care, primary care, community services, acute care, palliative care, carer, healthcare system, patient, government, social supports and research (table 1, figure 2). We did not identify reporting of Indigenous community services, aged residential care providers, internal medicine or geriatric medicine.

According to the WHO recommendations related to people-centred care, the interpretive synthesis demonstrated areas of high connectivity in the healthcare network from all stakeholder groups towards patients and carers (figure 2). The stakeholder group with the most frequently reported activity towards patients was secondary care. The next most frequently reported active stakeholder groups towards patients were (in decreasing frequency) primary care, community services, carer, and palliative care. (figures 2 and 3).

In contrast, the network showed most activity from patient groups to four stakeholder groups: carer, primary and secondary care, and community services. Studies reported little activity from patient stakeholder groups towards acute care, government, the healthcare environment, palliative care, research or social supports. Similarly, all stakeholder groups in the network connected with the carer groups. No studies reported activity of

**Figure 1** Summary of the systematic literature search and review process.
carer groups towards the government, palliative care or research stakeholder groups (figure 3).

The WHO recommendation related to integrated care ensures people receive a continuum of healthcare at different levels and sites of care within the health system. The interpretive synthesis demonstrated infrequent connectivity among the identified stakeholder groups, indicating poor health services integration for advanced COPD (figure 2). Palliative care, the healthcare environment, secondary care and primary care stakeholder groups were the most active within the network, demonstrating integration with multiple other stakeholder groups. In contrast, studies reported limited integration among government, research and social support with all stakeholder groups (figure 2).
**DISCUSSION**

**Summary of main findings**

Our systematic review collated data related to patient, carer and health professional experiences to formulate a network describing healthcare systems for patients in end-of-life care for severe COPD and evaluated for evidence of person-centredness and integration. The network showed limited person-centred characteristics as interactions between patients and health service stakeholders tended to be unidirectional towards patients, with low connectivity and limited influence from patients and carers towards the healthcare services they use. Connectivity between stakeholders to assess the level of health services integration in the developed network showed that healthcare services integration was heterogeneous. The most integrated stakeholder groups were palliative care, healthcare environment, and secondary and primary care, connecting across multiple external stakeholders. The government, research and social support had few or no connections with the network suggesting low integration. Stakeholder groups absent from the network included aged residential care, internal medicine, geriatric medicine, and cultural and spiritual support.

### Interactions towards stakeholder groups

|                      | Acute care | Community services | Government | Healthcare environment | Carer | Palliative care | Patient | Primary care | Research | Secondary care | Social supports |
|----------------------|------------|--------------------|------------|------------------------|-------|-----------------|---------|--------------|----------|---------------|-----------------|
| Acute care           | 8          | 0                  | 4          | 46                     | 5     | 128             | 4       | 0            | 0        | 0             | 0               |
| Community Services   | 0          | 0                  | 7          | 48                     | 9     | 167             | 3       | 0            | 5        | 2             |                 |
| Government           | 0          | 0                  | 4          | 1                      | 1     | 6               | 1       | 0            | 0        | 0             | 0               |
| Healthcare environment| 7          | 25                 | 0          | 11                     | 6     | 16              | 12      | 0            | 11       | 1             |                 |
| Carer                | 25         | 18                 | 0          | 1                      | 0     | 151             | 19      | 0            | 23       | 1             |                 |
| Palliative Care      | 1          | 27                 | 0          | 6                      | 49    | 133             | 13      | 0            | 11       | 2             |                 |
| Patient              | 2          | 7                  | 2          | 0                      | 19    | 3               | 14      | 1            | 13       | 0             |                 |
| Primary care         | 0          | 6                  | 0          | 4                      | 51    | 11              | 224     | 0            | 8        | 2             |                 |
| Research             | 2          | 3                  | 0          | 0                      | 1     | 0               | 2       | 2            | 2        | 0             |                 |
| Secondary care       | 2          | 10                 | 0          | 6                      | 83    | 21              | 323     | 9            | 0        | 0             |                 |
| Social supports      | 0          | 0                  | 0          | 0                      | 5     | 0               | 11      | 0            | 0        | 0             |                 |

**Figure 3** Heat map of the 11 stakeholder groups involved in the COPD end-of-life network. This map shows the interactions between the groups from the perspective of those listed on the y-axis. The red colour highlights the frequency of the interactions between those two stakeholder groups. For example, the palliative care stakeholder group interacted towards community services in the network 27 times, however, community services interacted towards palliative care providers nine times. COPD, chronic obstructive pulmonary diseases.
This evidence synthesis showed high connectivity of end-of-life COPD services with patients and carers. However, the review also highlighted a lack of patient engagement from and influence on the healthcare network by patients, falling short of the Lancet Respiratory Commission recommendations that services need to meet the requirements of patients and their families. Without substantial bidirectional communication and engagement between patients and healthcare services, key priorities for care may differ between patients with severe COPD and the services offered within the healthcare network. Potential disparities may include the communication and delivery of expectations, shared decision-making, health education and referrals to additional services such as pulmonary rehabilitation or palliative care. Other researchers have similarly reported on the effects of insufficient bidirectional interactions between patients and healthcare providers. Hallding et al reported that a lack of follow-up and flexibility within their services negatively affected trust and collaboration between patients and health providers. Ek et al reported that a lack of information about patients’ perceptions concerning their healthcare correlated with limited psychosocial and emotional support. It has been recommended that people with severe COPD and their families who live with constant uncertainty require adequate bidirectional interaction with health services, to enable high quality, efficient and cost-effective services. This systematic review has documented evidence of low integration between stakeholder groups. Stakeholder groups who had particularly constrained connections within the network included acute care, social supports, government and research. Other authors have highlighted that this lack of integration hinders the patient from accessing the correct care for advanced COPD in a timely manner and leads to unmet needs. One of our key findings was the absence of reports of the government functioning within the health network, despite the centrality of governments in funding, leadership and governance in many national healthcare networks. It has been noted that government funding does not incentivise this aspect of integration. Without rigorous review of government influences on the healthcare network, strategies to strengthen health provider governance, reorientation of models of care, effective co-ordination of services, breaking down of siloes and workforce reform may not occur. In addition to the lack of government integration, several other stakeholder groups worked in isolation. Consequences of low co-ordination included reliance on patients for information transfer and wasted resources, for example, by doubling up investigations. Low connectivity of the healthcare network for people with severe COPD has been directly correlated with a lack of referral to services such as palliative care and pulmonary rehabilitation. Fragmented health networks may contribute to poor communication between hospital to community services, leading to further losses of information and care co-ordination. When health professionals from varying disciplines come together for a common goal, improvements can be made in communication and task integration leading to more holistic care. The lack of cultural support stakeholder groups in our review ignores the value of these social networks that allows productive health promotion and engagement with their communities. The potential consequence of this missing stakeholder includes exposure to racism in the health system, dislocation from cultural support systems, lack of culturally appropriate educational material, communication barriers and inequitable distribution of resources. Aged residential care was also absent from the healthcare network in this review, despite the rising number of people receiving this type of care. Moving into long-term care is a critical transition for people with chronic conditions. Fragmented integration between key stakeholder groups during the shift to residential care may lead to lack of quality care co-ordination and clarity as to the roles of the healthcare team.

Strengths and limitations of the study
The strengths of this systematic review include the comprehensive synthesis of qualitative data from patient, carer and health professional experiences of the network of end-of-life care in advanced COPD. Healthcare model evaluations are scarce in the literature, particularly in palliative care. The ANT enabled us to identify the stakeholders, human and inanimate in the current network. We followed a predefined approach, which included a published protocol (PROSPERO CRD42020168733), a comprehensive literature search, critical appraisal and two cycles of qualitative coding by multiple reviewers. This systematic review has limitations which may have influenced the interpretation of findings. First, we identified a lack of published evidence of cultural diversity potentially leading to a Eurocentric viewpoint. Healthcare settings were principally higher income. An absence of evidence from settings in Africa, South-East Asia and the Middle East reduces the potential generalisability of the findings among these populations. This impact may have been amplified by the restriction of studies to those published in English. Second, we did not include grey literature or governmental or non-governmental reports which may have led to publication bias. The systematic literature review was limited to the data provided in the publications which may have accounted for the observed disconnection of research and government stakeholder groups from the rest of the network. Finally, studies used different ways of data collection and the way the data was obtained was not always clear (eg, lack of interview guides).
Implications for clinicians and policy-makers

From a clinical perspective, qualitative research is important in highlighting the experience of service users. Gathering information from healthcare providers and from those that use those services help guide more efficient and effective care. The integration of stakeholders in end-of-life COPD care is inconsistent leading to an unstable network. Integrated care challenges are most intense at the intersections between healthcare settings, and between stakeholder groups. Clinicians and policy-makers need to find innovative ways of connecting and maintaining strong links to sustain efficient and effective healthcare for their populations. Key stakeholders may be missing and therefore are not contributing to better health outcomes. Shifting the focus from short-term political goals to a committed longitudinal change, including meaningful community engagement, is necessary to fulfil the WHO’s people-centred and integrated health systems recommendations.

Unanswered questions and future research

This review discusses the current global healthcare network for those diagnosed with severe COPD and the other major stakeholders involved in their care. On a local level, it is important to understand the integration of stakeholders; what is working, what is not, and why this is the case. In Canterbury, New Zealand, we have been working for many years on improving relationships between secondary, primary and community care for people with long-term conditions. A local study is planned to explore the experiences of patients with advanced COPD, their carers and health professionals against the global network outlined in this study. This will highlight aspects of the network that are working and may provide lessons for other health system networks to follow.

CONCLUSIONS

End-of-life services for patients with severe COPD involve multiple intersecting health, community, and government services that are reported as acting on, rather than demonstrating people-centred care. The health services network is poorly integrated in the service delivery for patients with COPD and their end-of-life care needs.

Acknowledgements  We thank our Research Advisory Group based throughout New Zealand. Dr Maira Patu- Senior Clinical Lecturer, Ministry of Indigenous Health Institute, University of Otago, Christchurch. General Practitioner (Pegasus PHO), Ngai Tahu, Te Arawa. Dr Ben Hudson, Senior Lecturer and Head of Department General Practice, University of Otago, Christchurch. General Practitioner (Pegasus PHO). Dr Melissa Kerdemelidis- Public Health Physician, Planning and Funding and the Canterbury Initiative, Canterbury and West Coast District Health Boards. Robin Rutter-Baumann- Service Manager, Christchurch Hospital, Canterbury District Health Board. Doana Fatulei. Fanau Ola Service Manager, Pacific Health Development, Counties Manukau Health, Auckland. Registered nurse.

Contributors  AL, LB and SPI have been researching in this area together for several years. SPi joined the group and together helped AL obtain a Health Research Council grant. AL, LB, SPI and SPa formulated the research question and designed the study. AL completed the search and data extraction with JMDK. The protocol and manuscript were drafted by AL with review comments and edits from all the other authors. The entire team was responsible for interpreting the findings. AL created the figures and schema. All authors have read and given final approval for the manuscript. The corresponding author (AL) confirms that all listed authors meet the criteria for authorship, and no-one has been omitted. AL is the guarantor.

Funding  This study is funded by the Health Research Council (HRC) of New Zealand. The research team are independent of the HRC except for SGP who sits on the Health Research Council of New Zealand Board and Miain Health Committee but was exempt from the funding discussion. The views outlined in this manuscript are those of the authors and not necessarily the HRC who had no role in design and conduct of the research.

Competing interests  None declared.

Patient consent for publication  Not applicable.

Provenance and peer review  Not commissioned; externally peer reviewed.

Supplemental material  This content has been supplied by the author(s). It has not been vetted by BMJ Publishing Group Limited (BMJ) and may not have been peer-reviewed. Any opinions or recommendations discussed are solely those of the author(s) and are not endorsed by BMJ. BMJ disclaims all liability and responsibility arising from any reliance placed on the content. Where the content includes any translated material, BMJ does not warrant the accuracy and reliability of the translations (including but not limited to local regulations, clinical guidelines, terminology, drug names and drug dosages), and is not responsible for any error and/or omissions arising from translation and adaptation or otherwise.

Open access  This is an open access article distributed in accordance with the Creative Commons Attribution Non Commercial (CC BY-NC 4.0) license, which permits others to distribute, remix, adapt, build upon this work non-commercially, and license their derivative works on different methodological approaches could also influence how the authors processed and presented their data.

REFERENCES

1 World Health Organisation. The top 10 causes of death, 2019. Available: https://www.who.int/news-room/fact-sheets/detail/the-top-10-causes-of-death [Accessed Aug 2021].

2 Soriano JB, Kendrick PJ, Paulson KR, et al. Prevalence and attributable health burden of chronic respiratory diseases, 1990-2017: a systematic analysis for the global burden of disease study 2017. Lancet Respir Med 2020;8:585–96.

3 Han MK, Martinez CH, Au DH, et al. Meeting the challenge of COPD care delivery in the USA: a multiprovder perspective. Lancet Respir Med 2016;4:473–526.

4 World Health Organization. WHO global strategy on people-centred and integrated health services: interim report World Health Organization; 2015.

5 World Health Organisation. WHO global strategy on integrated people-centred health services 2016-2026; 2015.

6 World Health Organisation. Continuity and coordination of care: a practice brief to support implementation of the who framework on integrated people-centred health services; 2018.

7 Timmins N, Ham C. The quest for integrated health and social care: a case study in Canterbury, New Zealand: Kings Fund London, 2013.

8 Cramm JM, Nieboer AP. The changing nature of chronic care and coproduction of care between primary care professionals and patients with COPD and their informal carers. Int J Chron Obstruct Pulmon Dis 2016;11:175.

9 Tong A, Flemming K, McNees E, et al. Enhancing transparency in reporting the synthesis of qualitative research: ENTREQ. BMC Med Res Methodol 2012;12:1–8.

10 Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. Int J Qual Health Care 2007;19:349–57.
Open access

11 Cresswell KM, Worth A, Sheikh A. Actor-network theory and its role in understanding the implementation of information technology developments in healthcare. *BMC Med Inform Decis Mak* 2010;10:1–11.
12 Latour B. On actor-network theory: a few clarifications. *Soziale Welt* 1996;369–81.
13 Saldaña J. The coding manual for qualitative researchers. Sage, 2021.
14 Cooke M, Thackray S. Differences between community professional and patient perceptions of chronic obstructive pulmonary disease treatment outcomes: a qualitative study. *J Clin Nurs* 2012;21:1524–33.
15 Halding A-G, Aarsheim EI, Dolmen NM, et al. Copd transitions in health and self-management: service users’ experiences from everyday life. *Int J Chron Obstruct Pulmon Dis* 2018;13:2075–88.
16 Ek K, Andershed B, Sahlberg-Blom E, et al. “The unpredictable death”-The last year of life for patients with advanced COPD: Relatives’ stories. *Palliat Support Care* 2015;13:1213–22.
17 Elkington H, White P, Addington-Hall J, et al. The last year of life of COPD: a qualitative study of symptoms and services. *Respir Med* 2004;98:439–45.
18 Gysels M, Higginson IJ. Access to services for patients with chronic obstructive pulmonary disease: the invisibility of breathlessness. *J Pain Symptom Manage* 2008;36:451–60.
19 OECD. Health at a glance 2013 OECD Indicators; 2013.
20 Hofmarcher MM, Oxley H, Rusticelli E. Improved health system performance through better care coordination; 2007.
21 Iqbal S, Glogowska M, McLachlan S, et al. Unplanned admissions and the organisational management of heart failure: a multicentre ethnographic, qualitative study. *BMJ Open* 2015;5:e007522.
22 Vermeylen JH, Szmulowicz E, Kalhan R. Palliative care in COPD: an understudied area for quality improvement. *Int J Chron Obstruct Pulmon Dis* 2015;10:1543.
23 Beernaert K, Cohen J, Deliens L, et al. Referral to palliative care in COPD and other chronic diseases: a population-based study. *Respir Med* 2013;107:1731–9.
24 Collins B. Payments and contracting for integrated care. The false promise of the self-improving health system London: The King’s Fund, 2019.
25 Rinne ST, Resnick K, Wiener RS, et al. VA provider perspectives on coordinating COPD care across health systems. *J Gen Intern Med* 2019;34:37–42.
26 Siouta N, Clement P, Aertgeerts B, et al. Professionals’ perceptions and current practices of integrated palliative care in chronic heart failure and chronic obstructive pulmonary disease: a qualitative study in Belgium. *BMC Palliat Care* 2018;17:1–9.
27 Forster AJ, Murti HJ, Peterson JF, et al. The incidence and severity of adverse events affecting patients after discharge from the hospital. *Ann Intern Med* 2003;138:161–7.
28 Moore C, Wsnivesky J, Williams S, et al. Medical errors related to discontinuity of care from an inpatient to an outpatient setting. *J Gen Intern Med* 2003;18:546–51.
29 Cramm JM, Nieboer AP. In the Netherlands, rich interaction among professionals conducting disease management led to better chronic care. *Health Aff* 2012;31:2493–500.
30 Aspin C, Brown N, Jowsey T, et al. Strategic approaches to enhanced health service delivery for Aboriginal and Torres Strait Islander people with chronic illness: a qualitative study. *BMC Health Serv Res* 2012;12:1–9.
31 O’Grady K-AF, Revell A, Maguire GP, et al. Lung health care for Aboriginal and Torres Strait Islander Queenslanders: breathing easy is not so easy, *Aust Health Rev* 2011;35:512–9.
32 Frey R, Foster S, Boyd M, et al. Family experiences of the transition to palliative care in aged residential care (ARC): a qualitative study. *Int J Palliat Nurs* 2017;23:238–47.
33 Toews I, Glenton C, Lewin S, et al. Extent, awareness and perception of dissemination bias in qualitative research: an explorative survey. *PLoS One* 2016;11:e0159290.