European Journal of Oncology Nursing 70 (2024) 102564

Contents lists available at ScienceDirect

European Journal of Oncology Nursing

journal homepage: www.elsevier.com/locate/ejon

A systematic review of the barriers and facilitators impacting patient enrolment in clinical trials for lung cancer

Benjamin Lond [a,*], Christopher Dodd [a], Zoe Davey [a], Liz Darlison [b], John McPhelim [c], Janette Rawlinson [d,e], Iain Williamson [f], Clair Merriman [a,g], Francesca Waddington [h], Dominic Bagnallainslie [h], Balaji Rajendran [h], Jesse Usman [h], Catherine Henshall [a,h]

[a] Oxford Institute of Applied Health Research, Oxford Brookes University, Oxford, United Kingdom
[b] University Hospitals of Leicester, The Glenfield Hospital, Leicester, United Kingdom
[c] University Hospital Hairmyres, NHS Lanarkshire, East Kilbride, United Kingdom
[d] Lung Cancer Patient Advisory Group, European Lung Foundation, Sheffield, United Kingdom
[e] British Thoracic Oncology Group Steering Committee, Leicester, United Kingdom
[f] Division of Psychology, De Montfort University, Leicester, United Kingdom
[g] Oxford University Hospital Foundation Trust, Oxford, United Kingdom
[h] Oxford Health NHS Foundation Trust, The Warneford Hospital, Oxford, United Kingdom

ARTICLE INFO

Keywords:
Lung cancer
Clinical trials
Recruitment
Systematic review

ABSTRACT

Purpose: Clinical research trials are needed to enhance the medical care and treatment for lung cancer, which remains the leading cause of cancer-related deaths worldwide. While clinical trials allow for the development of novel therapies to treat cancer, the recruitment of lung cancer patients to trials is low. This review aimed to identify and synthesise the available literature concerning barriers and facilitators affecting lung cancer patients' decisions to enrol in clinical trials to guide future cancer research efforts.

Methods: Four databases were systematically searched: Academic Search Complete, CINHAL, PubMed, and PsycINFO in August 2023. A supplemental grey literature search was also conducted alongside this. Articles were quality appraised using CASP and JMI checklists, and results were narratively synthesised.

Results: Eighteen articles of varied design met the inclusion criteria, and results were mapped onto the Capability, Opportunity, and Motivation Behaviour (COM-B) Model to help structure and conceptualise review findings. Evidence suggests that the decision to enrol in a trial is multifaceted and informed by: when and how study information is presented, travel and trial eligibility, and altruistic hopes and fears.

Conclusions: There is need to address the many different concerns that lung cancer patients have about participating in a clinical trial through the supply of accessible and timely trial information, and via the reduction of travel, expansion of study eligibility criteria, and recognition of a person's altruistic wishes, hopes, fears, and family-oriented concerns. Future research should aim to work alongside lung cancer patients, clinicians, and other stakeholders to increase research accessibility.

1. Introduction

Lung cancer is the leading cause of cancer-related deaths across the world for both men and women (World Health Organization, 2023), with evidence indicating that approximately 1.8 million people died due to lung cancer in 2020 (International Agency for Research on Cancer, 2022). Although these figures highlight the severity of lung cancer, they may be greatly improved via current and future clinical trials. Indeed, people who participate in trials generally have better clinical outcomes (Ozdemir et al., 2015), and experiences of care (Morris et al., 2014). Potential benefits may also include access to novel drugs, better disease control, improved survival, enhanced quality of life, improved symptom management, better follow-up and monitoring, and increased patient empowerment (McPhelim, 2015). Lung cancer trials are therefore vitally important to improving clinical knowledge and outcomes, and to enhancing patient quality of life and care.

Despite this, the enrolment of lung cancer patients to clinical trials is low (Cancer Research UK, 2022). About 8% of lung cancer patients are

* Corresponding author.
E-mail address: blond@brookes.ac.uk (B. Lond).

https://doi.org/10.1016/j.ejon.2024.102564
Received 27 December 2023; Received in revised form 6 March 2024; Accepted 11 March 2024
Available online 19 March 2024

recruited to trials (National Institute for Health Research, 2022), which is below the 11% participation rate for all cancer trials (The Institute of Cancer Research, 2021). In addition, while there is a strong link between lung cancer incidence and socioeconomic deprivation, wherein the most deprived areas have the highest rates of lung cancer incidence and mortality burden (O'Leary et al., 2016), those on lower incomes are also significantly less likely to enrol and benefit from clinical trials (Unger et al., 2016). Furthermore, people who live further from major cancer centres are less likely to be presented the option to enrol in a clinical trial (The Institute of Cancer Research, 2021). Other factors inhibiting clinical trial participation also include poor prognosis, higher comorbidity, and increasing patient age (McPhelim, 2015; Prewett et al., 2012), as well as poor literacy, feelings of stigma and lack of confidence to talk about treatment options with healthcare staff (Macmillan, 2015).

Healthcare professionals are well-placed to support and increase the recruitment of patients to trials. Clinical lung cancer nurse specialists are associated with better experiences of care (Alessy et al., 2021), and nurse-patient interactions are also important to the trial recruitment and decision-making process (Gregersen et al., 2019). However, lung cancer nurses often feel ill-equipped to talk about clinical trials with individuals due to a lack of knowledge, confidence, time, expertise and training (McPhelim, 2015). Research staff involved in trials are also often beset by the complexities of screening and terminology, scarcity of staff resources, perceived administrative burden, concern regarding patient suitability, and limited information supplied to staff and patients (The Institute of Cancer Research, 2021).

Although clinical trials can improve the outcomes of people living with lung cancer, and enhance their quality of life, and care experiences more generally, the enrolment of individuals to trials remains low and uneven across socioeconomic and geographical strata. In addition, research staff often feel unable to effectively support the trial recruitment and decision-making process for various structural reasons. While this research elucidates several issues that underpin the low recruitment of lung cancer patients to trials, there is also a need to address the barriers and enablers to lung cancer clinical trials from the patient perspective. This review thus seeks to identify and synthesise the available literature regarding the barriers and facilitators that impact individuals' decisions to enrol in lung cancer trials. Moreover, the current review aims to better understand why individuals choose to participate, or not participate, in clinical research in order to guide future trial policies and practices.

2. Methods

This review was conducted in accordance with the recommendations of the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA, 2020) statement (see Page et al., 2021). The protocol for this review was registered on PROSPERO International Prospective Register of Systematic Reviews (CRD42023449523).

2.1. Search strategy

A combination of keywords, Medical Subject Heading (MeSH) terms, and Boolean operators were used to form the search command; via words and phrases relevant to the population (lung cancer patients), issue (barriers and enablers), context (respiratory cancer care), and outcomes (clinical trial enrolment). The complete search strategy can be viewed in Supplementary File 1. This command was put into four databases: Academic Search Complete, CINHAL, PubMed, and PsycINFO. The search was restricted to records published between 2006 and July 2023, and was conducted over a two-week period between August 1 and August 15, 2023.

This search was supplemented by reviewing the reference lists of eligible articles for additional papers that may have been missed. A grey literature search was also conducted via the Google search engine, using supported terms and operators: "Lung cancer patient" AND (Recruitment | Access | Awareness) AND "Clinical Trial".

2.2. Eligibility criteria

All primary studies, published between 2006 and July 2023, investigating the barriers and enablers to lung cancer patient enrolment in clinical trials were eligible to be included irrespective of study design, including quantitative, qualitative, and grey literature, but excluding literature reviews and protocols. Moreover, studies of various and mixed design, including survey, intervention, interview, focus group, case study, and retrospective design, were all eligible so long as they presented primary research data addressing why individuals with lung cancer choose to enrol, or not enrol, in trials. No geographical or language restrictions were applied.

Eligible participants included individuals diagnosed with lung cancer, irrespective of lung cancer stage, treatment received, or stage on the care pathway. The family members and caregivers of people living with lung cancer were also eligible, in addition to healthcare professionals who work with lung cancer patients as all these groups may have potential insights and impact on the trial enrolment process.

2.3. Study selection

Records were managed using the web-based systematic review platform Rayyan (Ouzzani et al., 2016). After importing references to Rayyan, duplicate articles from across the four databases were removed. Titles and abstracts of remaining records were then independently screened by at least two reviewers using the eligibility criteria, with any discrepancies resolved via discussion with the wider review team. The remaining records were then subject to full-text screening by at least two reviewers in view of the eligibility criteria, with any discrepancies also resolved through discussion with the wider review team. Supplemental papers identified through hand searching and grey literature searches were also subject to independent screening by two reviewers. The study selection process is illustrated via PRISMA flow diagram in Fig. 1.

2.4. Quality assessment

Appraisal tools were used to help understand the various elements and methodological quality across the literature. The Qualitative Studies Checklist (Critical Appraisal Skills Programme, 2018) was utilised to help structure the review of qualitative articles; and includes 10 questions that invite consideration of different issues, such as the handling of ethics and rigour of the analysis. An adopted version of the Checklist for Analytical Cross-Sectional Studies (JBI, 2020) was utilised to help structure the review of quantitative articles and was adapted by removing a question about the measure of variable exposure. The adapted tool includes seven questions that invite consideration of various issues, such as whether the sample inclusion criteria was clearly defined and whether appropriate statistical analysis was used.

2.5. Data extraction and synthesis

To cross-check for accuracy and completeness, the data extraction of each article was done in duplicate by two reviewers working separately. Information was extracted using a purpose-built extraction table, to promote the consistent and organised collation of research data, including the article title, author(s), year of publication, conflicts of interest, data collection period, study aims, variables, research design, method of analysis, number of participants, lung cancer type, sampling method, recruitment method, key findings, and conclusions. A copy of the extraction table can be viewed in Supplementary File 2.

A meta-analysis was not carried out on the quantitative data due to the diversity of outcome measures and variable data across the different studies. Instead a narrative summary was conducted by carefully tabulating the findings of each article into a shared file, and arranging the

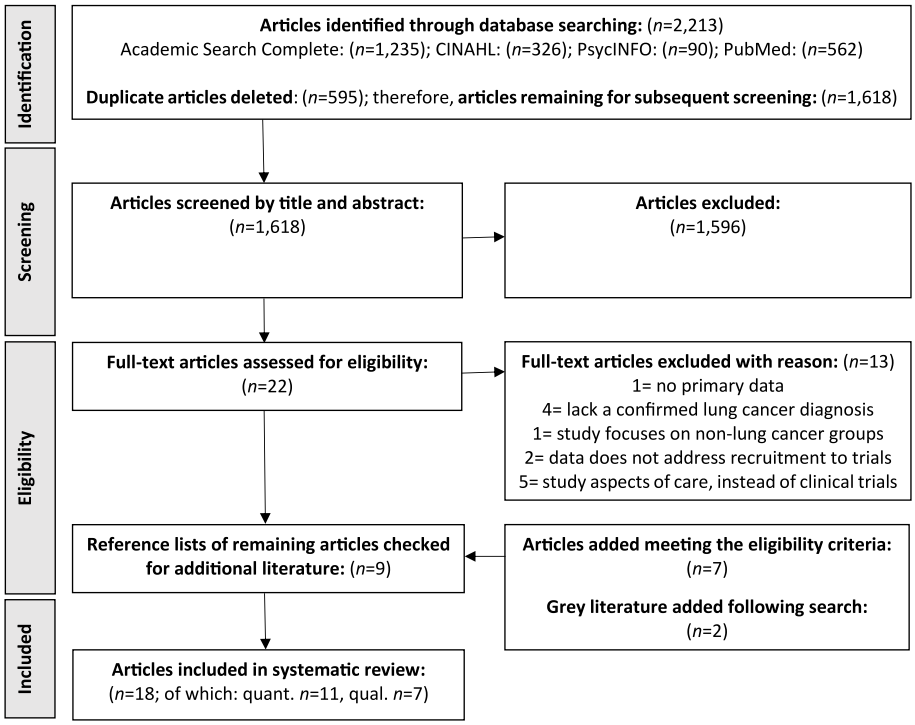

Fig. 1. PRISMA flow diagram.

findings in view of similarity; for example, grouping together the findings of several articles relating to the effect of lung cancer type on an individual's ability to join a clinical trial. This table facilitated the review of similar and dissimilar findings, and was co-produced by authors: BL, CD, CM, FW, DB, BR, JU, and CH.

To help organise and theorise the reporting of findings from across the literature, the grouped findings were reviewed and mapped on the Capability, Opportunity, and Motivation Behaviour (COM-B) Model (Michie et al., 2011). The COM-B model theorises behaviour as part of a system of interacting factors, namely: *Capability*, *Opportunity*, and *Motivation*; with higher Capability, Opportunity, and Motivation increasing the likelihood of behaviour. Capability refers to a person's psychological and physical ability to perform a behaviour; Opportunity refers to the external factors that exist outside of the individual; and Motivation refers to the mental processes, beliefs and goals of the person to perform a behaviour. By applying this model to the structuring and reporting of study findings, the narrative summary below aims to further our understanding of the issues which impact peoples' capabilities, opportunities, and motivations to take part in clinical lung cancer trials.

3. Results

3.1. Study selection

A total of 2213 papers were identified in the database search. This decreased to 1618 papers following the removal of 595 duplicates. Screening by title and abstract saw the further removal of 1596 papers. The remaining 22 papers were subject to full-text review which resulted in the removal of 13 papers. Seven articles were added after checking reference lists of included papers, and two additional articles were included following the search for grey literature. This left 18 articles for inclusion in this review. The study selection process is illustrated via the PRISMA flow diagram in Fig. 1.

3.2. Overview of included studies

The 18 papers included in this review were published between 2006 and 2023: American Lung Association, 2023; Baggstrom et al. (2011); Du et al. (2006); Fouad et al. (2013); Gonzalez et al., 2013; Harrop et al. (2016); Horn et al. (2013); Islam et al. (2014); Kehl et al. (2014); Lim et al. (2016); LUNGevity, 2017; Mudaranthakam et al. (2022); Quinn et al. (2007), 2008, 2011; Schoenau et al. (2020); Spiegel et al. (2017); Tanai et al. (2009). Studies were undertaken in the United States (n = 14), Canada (n = 1), Denmark (n = 1), Japan (n = 1), and the United Kingdom (n = 1). Nine papers studied demographic variables of patients to assess their impact on clinical trial enrolment using quantitative, retrospective chart review methods (Baggstrom et al., 2011; Du et al., 2006; Fouad et al., 2013; Gonzalez et al., 2013; Horn et al., 2013; Lim et al., 2016; Mudaranthakam et al., 2022; Spiegel et al., 2017; Tanai et al., 2009). One paper used quantitative surveys to examine patient decision-making for clinical trial enrolment (Kehl et al., 2014), and one paper used quantitative surveys to gather patient and carers' views of the barriers that inhibit clinical trial enrolment (LUNGevity, 2017). Six papers used qualitative interviews to explore patient, carer, and/or clinician views regarding patient decisions to participate in trials, attitudes towards trials, and/or experiences of trials (American Lung Association, 2023; Harrop et al., 2016; Quinn et al., 2007, 2008, 2011; Schoenau et al., 2020). One paper used qualitative focus groups to explore patient, caregiver, and care provider views about incorporating patient centred outcomes as part of lung cancer trials (Islam et al., 2014). The study characteristics for the 18 included papers are shown in Table 1.

3.3. Quality appraisal of included studies

Regarding the quantitative studies, all the papers clearly defined the eligibility criteria for participation, with the exception of LUNGevity (2017) which did not clearly define the participant eligibility criteria. All studies suitably described the participants and study setting. Eight studies used objective, standard criteria to collect data, while papers by Baggstrom et al. (2011), Lim et al. (2016), and LUNGevity (2017) did not give ample detail to assess this. Four studies by Du et al. (2006), Fouad et al. (2013), Kehl et al. (2014) and Tanai et al. (2009) identified and outlined strategies to manage various confounding factors. Nine

Table 1
Summary of included studies (n = 18).

Author(s) and Year	Country	Study Aims	Study Design	Participants	Method of Analysis
1. American Lung Association (2023)	United States of America	Inform future communications around clinical trials and health inequities in lung cancer among Black communities.	Qualitative Interviews	Lung Cancer Patients, Advocates, Clinicians, Trial Coordinator n = 10	Content Analysis
2. Baggstrom et al. (2011)	United States of America	Evaluate barriers to enrolment in non-small cell lung cancer clinical trials in a tertiary care centre.	Quantitative Retrospective Chart Review	Lung Cancer Patients *n* = 183	Kruskall-Wallis rank sum test and Fisher's exact test
3. Du et al. (2006)	United States of America	To assess enrolment rates and factors that are predictive of enrolment onto lung cancer clinical trials.	Quantitative Retrospective Chart Review	Lung Cancer Patients n = 427	Chi-square, T-test, Logistical Regression
4. Fouad et al. (2013)	United States of America	To understand how patient and provider characteristics impact clinical trial participation.	Quantitative Retrospective Chart Review	Lung Cancer Patients *n* = 5244	Logistical Regression
5. Gonzalez et al. (2013)	United States of America	Study clinical trial offers and identifies if patient or physician demographics effect the offer of a trial and why patients decline participation.	Quantitative Retrospective Chart Review	Lung Cancer Patients *n* = 300	Descriptive summary, Test of Difference (Unspecified)
6. Harrop et al. (2016)	United Kingdom	Explore the psychological impact of participation in a clinical trial for patients with advanced lung cancer in intervention and control arms.	Qualitative Interviews	Lung Cancer Patients *n* = 10	Interpretative Phenomenological Analysis
7. Horn et al. (2013)	United States of America	To assess study enrolment of patients with lung cancer into clinical trials and define barriers to enrolment.	Quantitative Retrospective Chart Review	Lung Cancer Patients *n* = 1043	Chi-squared Test and Logistical Regression
8. Islam et al. (2014)	United States of America	To explore the views of patients, caregivers, and providers on lung cancer treatment success, and patient centred outcomes research.	Qualitative Focus Groups	Lung Cancer Patients *n* = 7; Family *n* = 6; Advocates *n* = 3; Nurses *n* = 10; Doctors *n* = 10	Thematic Analysis
9. Kehl et al. (2014)	United States of America	To better understand how patients with newly diagnosed lung or colorectal cancer decide whether to participate in clinical trials.	Quantitative Survey	Lung Cancer Patients *n* = 4089	Logistical Regression
Author(s) and Year	Country	Study Aims	Study Design	Participants	Method of Analysis
10. Lim et al. (2016)	Canada	Study effect of performance of research biopsies on the enrolment of patients with advanced non-small cell lung cancer in clinical trials.	Quantitative Retrospective Chart Review	Lung Cancer Patients *n=636*	Kruskall-Wallis test, Fisher's exact test, Mann-Whitney test
11. LUNGevity (2017)	United States of America	To understand patient and carer perspectives of barriers prevent patients from taking part in lung cancer clinical trials.	Quantitative Survey	Lung Cancer Patients *n=170,* Caregivers n = 49	Descriptive Summary
12 Mudaranthakam et al. (2022)	United States of America	To study screening logs and determine factors that act as barriers to the accrual of rural residents in clinical trials.	Quantitative Retrospective Chart Review	Lung Cancer Patients *n=1347*	Analysis of Effect Size via Cohen's D
13. Quinn et al. (2007)	United States of America	Study lung cancer patient attitudes and behaviours towards clinical trials and develop an intervention to increase patient knowledge	Qualitative Interviews	Lung Cancer Patients *n=43*	Content Analysis
14. Quinn et al. (2008)	United States of America	Introduce the Faces of Lung Cancer project: to increase awareness of and humanise clinical trials.	Qualitative Interviews	Lung Cancer Patients n = 12; Caregivers n = 4; Thoracic Clinicians n = 4	Content Analysis
15. Quinn et al. (2011)	United States of America	To explore the application of the Theory of Planned Behaviour to patient's decisions about participating in a clinical trial.	Qualitative Interviews	Lung Cancer Patients *n=21*	Content Analysis
16. Schoenau et al. (2020)	Denmark	To explore the experiences of individuals who declined participation in a randomized clinical exercise rehabilitation trial.	Qualitative Interviews	Lung Cancer Patients *n=15*	Interpretative Phenomenology
17. Spiegel et al. (2017)	United States of America	To explore impact of requiring biopsies as part of screening for clinical trials on duration of screening, screening failure and enrolment.	Quantitative Retrospective Chart Review	Lung Cancer Patients *n=311*	Chi-Square, Logistical Regression, T-tests, Log-rank test
18. Tanai et al. (2009)	Japan	Study characteristics and outcomes of eligible patients who decline to participate in trials compared to patients who enrol in clinical trials.	Quantitative Retrospective Chart Review	Lung Cancer Patients n = 272	Logistical Regression and Multivariate Analysis

papers explained how trial enrolment was measured while studies by Baggstrom et al. (2011) and LUNGevity (2017) did not clearly describe this process. All studies used appropriate statistical analysis, except Gonzalez et al. (2013) which is unclear; instead stating that two-sided statistical tests were used. Table 2 tabulates the quality appraisal of the quantitative studies.

Regarding the qualitative studies, all papers clearly outlined their aims, appropriately used a qualitative methodology, and used a suitable research design to address the aims of the research. Four studies by Quinn et al. (2007, 2008, 2011) and Schoenau et al. (2020) used an appropriate recruitment strategy, though three papers by American Lung Association (2023), Harrop et al. (2016), and Islam et al. (2014) did not give enough detail to assess this. All studies collected data in a way that addressed the research topic with the exception of American Lung Association (2023) where this is unclear. Two studies by Harrop et al. (2016) and Schoenau et al. (2020) considered the researcher-participant relationship and its possible influence on the participants' accounts and analysis. Five studies adequately addressed the relevant ethical issues of research, while the American Lung Association (2023) and Islam et al. (2014) did not discuss ethical issues. All studies demonstrated sufficient analytical rigor with the exception of Harrop et al. (2016) where this is unclear due to lack of information. All

Table 2
Appraisal of included quantitative studies using criteria adapted from the JBI Critical Appraisal Checklist for Analytical Cross-Sectional Studies.

Author(s) and Year	**Q.1** Were the criteria for inclusion in the sample clearly defined?	**Q.2** Were the study subjects and the setting described in detail?	**Q.3** Was the exposure measured in a valid and reliable way?	**Q.4** Were objective, standard criteria used for the measurement of the condition?	**Q.5** Were confounding factors identified?	**Q.6** Were strategies to deal with confounding factors stated?	**Q.7** Were the outcomes measured in a valid and reliable way?	**Q.8** Was appropriate statistical analysis used?	Total Criteria Fulfilled* By Study
Baggstrom et al. (2011)	Yes	Yes	N/A	Unclear	Unclear	No	Unclear	Yes	3
Du et al. (2006)	Yes	Yes	N/A	Yes	Yes	Yes	Yes	Yes	7
Fouad et al. (2013)	Yes	Yes	N/A	Yes	Yes	Yes	Yes	Yes	7
Gonzalez et al. (2013)	Yes	Yes	N/A	Yes	Unclear	No	Yes	Unclear	4
Horn et al. (2103)	Yes	Yes	N/A	Yes	Unclear	No	Yes	Yes	5
Kehl et al. (2014)	Yes	Yes	N/A	Yes	Yes	Yes	Yes	Yes	7
Lim et al. (2016)	Yes	Yes	N/A	Unclear	Unclear	No	Yes	Yes	4
LUNGevity (2017)	No	Yes	N/A	Unclear	No	No	Unclear	Yes	2
Mudaranthakam et al. (2022)	Yes	Yes	N/A	Yes	Unclear	No	Yes	Yes	5
Spiegel et al. (2017)	Yes	Yes	N/A	Yes	Unclear	No	Yes	Yes	5
Tanai et al. (2009)	Yes	Yes	N/A	Yes	Yes	Yes	Yes	Yes	7
Number of Times Citeria Fulfilled Across All Studies	10	11	N/A	8	4	4	9	10	

* **Criteria fulfilled** if reviewer answered 'Yes' to a question presented by appraisal tool (e.g. were confounding factors identified?). Score range: 0–7 with a higher score denoting higher research quality and a green cell denoting all criteria being met.

the studies presented a clear statement of findings. Table 3 tabulates the quality appraisal of the qualitative studies.

3.4. Population

Together, studies analysed the data of 14,226 individuals, the large majority of whom were lung cancer patients ($n = 14{,}130$). These totals exclude colorectal cancer patients who were included in two studies (Fouad et al., 2013; Kehl et al., 2014). Of the studies employing retrospective chart review methods, individual data was derived via the collection and analysis of existing medical records which accounted for 9763 lung cancer patients; the survey, interview, and focus group studies recruited the remaining 4463 individuals as participants. Regarding non-patient participants: 59 family members and/or carers were recruited in addition to three lung cancer patient advocates, 10 nurses, 10 doctors, and a further four clinicians whose medical roles were not specified. A further 10 participants were recruited by the American Lung Association (2023), including lung cancer patients, advocates, and clinicians, however, the exact number of patients, advocates, and clinicians in the sample is unspecified. Reflecting the mix of quantitative and qualitative methodologies, the sample sizes varied considerably between studies: ranging from 5244 (Fouad et al., 2013) to 10 (American Lung Association, 2023; Harrop et al., 2016).

3.5. Narrative summary of findings

The systematic extraction and comparison of study results allowed the identification of similar findings across the literature. These findings are presented below to give an overview of what we know to date regarding issues impacting lung cancer patients' decisions to enrol in clinical trials. As stated previously, (see *Data extraction and synthesis*) the summarised findings are presented under the headings of the COM-B Model in order to better conceptualise and structure the reporting, and this is illustrated below by overlaying the summarised findings onto the COM-B Model in Fig. 2.

3.5.1. Capability

In terms of issues impacting patients' knowledge and abilities to enrol in clinical trials, multiple studies highlighted the need for healthcare professionals to provide clear and concise trial information to help make patients aware of current trials and suitably informed to make decisions about trial participation (American Lung Association, 2023; Harrop et al., 2016; Islam et al., 2014; Quinn et al., 2007). These studies also reported that lung cancer patients and carers voiced a desire for comprehensive and plain information to clarify what participation would entail; in terms of frequency of treatment, potential side-effects, and the broader history of clinical trials to better equip patients to understand the research process and feel suitably prepared to take part. Some studies also addressed the timing of the information provided, observing that trial information is normally shared with new patients who are still processing their diagnosis and may therefore feel overloaded and unable to properly consider whether to take part (American Lung Association, 2023; Harrop et al., 2016; Islam et al., 2014).

Multiple studies also found that the way in which information was presented and by whom influenced patient decision-making around trial participation. Many former trial participants stated they were attracted by particular words or phrases that suggested a strong or more '*aggressive*' approach to cancer treatment, and by clinicians saying '*we*' in

Table 3
Appraisal of included qualitative studies using the 'CASP Qualitative Studies Checklist'.

Author(s) and Year	**Q.1** Was there a clear statement of the aims of the research?	**Q.2** Is a qualitative methodology appropriate?	**Q.3** Was the research design appropriate to address the aims of the research?	**Q.4** Was the recruitment strategy appropriate to the aims of the research?	**Q.5** Was the data collected in a way that addressed the research issue?	**Q.6** Has the relationship between researcher and participants been adequately considered?	**Q.7** Have ethical issues been taken into consideration?	**Q.8** Was the data analysis sufficiently rigorous?	**Q.9** Is there a clear statement of findings?	Total Criteria Fulfilled* By Study
American Lung Association (2023)	Yes	Yes	Yes	Unclear	Unclear	No	No	Yes	Yes	5
Harrop et al. (2016)	Yes	Yes	Yes	Unclear	Yes	Yes	Yes	Unclear	Yes	7
Islam et al. (2014)	Yes	Yes	Yes	Unclear	Yes	No	No	Yes	Yes	6
Quinn et al. (2007)	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	8
Quinn et al. (2008)	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	8
Quinn et al. (2011)	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	8
Schoenau et al. (2020)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	9
Number of Times Citeria Fulfilled Across All Studies	7	7	7	4	6	2	5	6	7	

* **Criteria fulfilled** if reviewer answered 'Yes' to the question presented by CASP (e.g., 'Was there a clear statement of the aims of the research?'). Score range: 0–9 with a higher score denoting higher research quality and a green cell denoting all criteria being met.

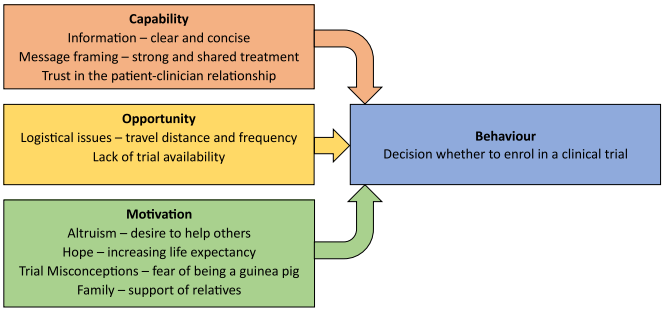

Fig. 2. Issues affecting lung cancer patient choice to enrol in a trial, mapped onto the COM-B Model.

reference to *our* need to treat the cancer—implying a shared effort by the patient and clinician to fight the cancer which left patients feeling less isolated (Quinn et al., 2007). Both patients and carers stressed the importance of trust in the patient-clinician relationship; some patients stated that trust in their clinician alone was reason enough for them to take part in a trial (American Lung Association, 2023; Islam et al., 2014; Quinn et al., 2007, 2011).

Some quantitative studies reported significantly higher participation rates if the clinician offering a trial was an oncologist (Kehl et al., 2014), was based at a centre of clinical excellence (Fouad et al., 2013), or had many years of clinical experience (Tanai et al., 2009).

3.5.2. *Opportunity*

Regarding opportunities for patients to enrol in clinical trials, a number of studies reported that patients, carers, and clinicians identified that travel to and from medical centres was a major reason for patients declining to take part in trials; due to the amount of time involved in long-distance travel, in addition to the associated financial costs and perceived vulnerability of patients (Islam et al., 2014; LUNGevity, 2017). These qualitative findings are in line with some of the included quantitative studies showing that long-distance travel was the most common reason patients declined to take part in a trial (Baggstrom et al., 2011; Gonzalez et al., 2013; Horn et al., 2013).

Several studies also found significant disparity in the availability of various lung cancer trials to patients due to highly specified eligibility criteria that reduced opportunities for patients to participate. Patients were often ineligible to enrol if they evidenced a reduced ability to manage daily activities—typically determined using performance status scales (Baggstrom et al., 2011; Gonzalez et al., 2013; Horn et al., 2013; Lim et al., 2016; Mudaranthakam et al., 2022; Spiegel et al., 2017). There were also significantly more trials available for advanced stage IV lung cancer and for patients with non-small cell lung cancer, as compared to other lung cancer stages and types (Gonzalez et al., 2013; Horn et al., 2013). However, Du et al. (2006) found no significant difference between trial enrolees and non-enrolees according to performance status or lung cancer stage.

3.5.3. *Motivation*

Regarding the psychosocial motivations and concerns of individuals to participate in clinical trials, both patients and carers in several qualitative studies voiced altruistic desires as a key reason for opting to

join a trial; with many such individuals expressing hope that their involvement may benefit future lung cancer patients through the scientific advancement of medical knowledge (American Lung Association, 2023; Harrop et al., 2016; Islam et al., 2014; LUNGevity, 2017; Quinn et al., 2007, 2008). These individuals hoped that their participation could help others, and so have a positive long-term outcome, regardless of whether the trial was able to improve the patient's individual prognosis.

In addition to them wanting to help others, four studies reported that many patients and carers stated that the opportunity to enrol in a trial engendered feelings of hope that new experimental treatments might increase their life expectancy (Harrop et al., 2016; LUNGevity, 2017; Quinn et al., 2007, 2008). This was reported to be especially salient for patients who had already seen other physicians and received standard treatment which was no longer effective. These patients regarded more novel trial treatment options as rays of hope and powerful motivations to enrol in clinical trials (LUNGevity, 2017; Quinn et al., 2007). Conversely, more fatalistic patients -who were more likely to doubt the potential benefits of experimental therapies-were reported to be significantly less likely to enrol in clinical trials (Kehl et al., 2014).

Although altruistic and hopeful beliefs may motivate lung cancer patients to participate in clinical trials, some studies also reported trial related fears and misconceptions that can deter research participation. Two studies found that patients may fear being treated as a 'guinea pig'—that is subject to volatile and risky treatments that prioritise a researcher's career advancement before patient health and wellbeing (American Lung Association, 2023; Quinn et al., 2007). Some care providers also reported that patients of African American backgrounds may refuse to take part in a trial because they see it as a 'lesser' form of treatment and care, compared to more standard treatment (American Lung Association, 2023). Du et al. (2006) also found African American individuals were significantly less likely to enrol in a trial, relative to other racial groups, but Fouad et al. (2013) found no significant racial disparity in enrolment after controlling for physician characteristics. One study also found fear was an emotional barrier to potential participation; as individuals reported fear of a novel treatment not working would discourage their taking part (LUNGevity, 2017).

A number of studies identified that lung cancer patients further credited the decision to enrol in a clinical trial to family members—either because relatives supported and encouraged their taking part, or because patients viewed their participation as the best way of ensuring that they could continue to be present and provide for family members, particularly younger children (American Lung Association, 2023; Quinn et al., 2007, 2011). Conversely, the input of family members was highlighted in one study as influencing individuals to not take part in a trial—either because patients feared participation would inconvenience relatives, or because family members had voiced a preference for standard treatment and had discouraged trial participation as a first line treatment (Quinn et al., 2011).

4. Discussion

This review has collated the findings of 18 articles exploring lung cancer patients' decisions to enrol in clinical trials and used the COM-B model to theoretically underpin the review findings. This has allowed us to better understand individuals' perceived capabilities, opportunities, and motivations to take part in lung cancer research; and how this is impacted by factors such as the availability, presentation, and awareness of trial information, travel and other logistical issues, in addition to the attitudes and beliefs for entering clinical trials which include altruism, hope, trial misconceptions, and familial support.

Regarding individuals' perceived capabilities to take part in clinical research, several studies evidenced the value to patients of having a trusted healthcare clinician provide clear and concise trial information. This highlights the value of healthcare professionals in the recruitment and consent process and the need for lung cancer nurses and other allied health professionals to tailor the accessibility, volume, and timing of the information provided to patients. Lung cancer nurses are routinely tasked with presenting trial information to patients, thus providing valuable recruitment support to research teams (Gregersen et al., 2019; Hauck et al., 2021; McPhelim, 2015). However, lung cancer nurses often report feeling that they lack the knowledge, confidence, time, and training required to perform this vital task (McPhelim, 2015). This may be compounded by perceived administrative burden, extensive screening, and technical complexities associated with modern trials (The Institute of Cancer Research, 2021). Consequently, tensions may exist for lung cancer nurses, in terms of balancing their responsibilities to provide patients with the latest information to make choices about their care and treatment pathways, and their professional role boundaries. Focusing more attention on the needs and capabilities of patients and clinicians may be an effective way to maximise clinical trial recruitment prospects.

In terms of the perceived opportunities available to patients when considering clinical trial entry, our review indicates that patients often view the distance and frequency of travel as significant barriers to enrolment; this is due to the time and associated costs of long-distance travel, and related medical concerns of vulnerable patients in transit. This barrier may disproportionately impact individuals from lower socioeconomic backgrounds, in view of travel costs and need to take time off work; and this may partly explain why people from higher socioeconomic backgrounds are frequently over-represented in clinical studies (Nipp et al., 2019).

The review findings found significant disparities in the availability of lung cancer trials to patients, with substantially more trials available for individuals with advanced stage lung cancer and/or non-small cell lung cancer than other lung cancer types. Likewise, patients were far less likely to be eligible if they had a poor performance status—in line with findings that trial entry is undermined by poor prognosis, increasing age and comorbidity (Prewett et al., 2012). Though clinical justification may be provided for trial eligibility criteria favouring the inclusion of healthier individuals, this can restrict opportunities for many patients who do not fit this profile and further reduce overall trial participation numbers.

Regarding patients' motivations to enrol in clinical trials, multiple studies found that altruism and hope were key reasons for people choosing to take part; either out of a desire to advance medical research, or to improve their own clinical prognosis. Conversely, some studies found that individuals decline to take part due to historical beliefs and mistrust regarding the nature of trials, particularly among certain minority ethnic groups (American Lung Association, 2023). Family members' support or lack of support for clinical trial entry also had a substantive impact on patients' decision-making regarding enrolment. This underlines the need for clinicians to be mindful of a person's beliefs and the impact of these beliefs on recruitment. While supporting particular hope related beliefs may increase enrolment, for example, by acknowledgment that trial participants tend to have better clinical outcomes (Ozdemir et al., 2015), and experiences of care (Morris et al., 2014), such measures should be careful to avoid overstating the potential benefits of participation and endeavour to represent research accurately and clearly.

4.1. Implications for practice

Findings can help researchers and clinicians consider the various issues that affect lung cancer patients' decisions to participate in clinical trials, so as to inform and enhance the ways that trials are presented. Study information should be clear and address relevant patient concerns such as the likely implications of taking part including the frequency of treatment, potential treatment side-effects, and trial location. Further thought should be given to when and how often information is presented to patients to reduce information overload especially in newly diagnosed patients. The repeated drip-feeding of information at follow-up

appointments may be a way to reach the right patients at the right time. Effort should also be made to build rapport between healthcare staff and patients, to promote trusting relationships and transparency when discussing clinical research. Nursing staff are well-suited to this due to their patient facing roles and increased opportunities to build effective rapport in their relationship with patients.

Addressing patient travel to trials can increase enrolment opportunities and can be achieved either by providing material support to offset travel and accommodation costs, or by reducing the distance and frequency of travel; this could be accomplished via the increased setup of trials in non-tertiary centres. Further expanding the variety of clinical trials and related eligibility criteria would allow more people -with different forms and stages of lung cancer-the opportunity to participate in clinical research.

Researchers and clinicians should be aware of an individual's motivations to take part in research and recognise altruism, hope, and family as salient reasons for decisions around participation; they should also be careful to acknowledge the individual's motivations and concerns, and further outline research accurately and transparently.

4.2. Strengths and limitations

This review has summarised the findings of several studies to provide a more complete understanding of issues impacting peoples' decisions to enrol in lung cancer trials. However, this review does not offer a conclusive framework or model to fully explain why individuals decide to take part in clinical research. Moreover, while this review benefits by using the COM-B Model to help organise and theorise findings, it cannot fully systematise human behaviour and variability (Ogden, 2016), and readers are encouraged to use this text as part of a patient-focused approach to clinical trial consultations and recruitment.

Most of the studies were also conducted in the United States, and only one study by Tanai et al. (2009) was done in a non-Western country (Japan); which is likely to implicate the generalisability of findings. The current literature and review is therefore likely to better highlight the clinical trial decision-making processes of lung cancer patients living in Western settings, and the United States especially; however, this leaves the socioeconomic and structural concerns of lung cancer patients in non-Western settings comparatively unexplored.

4.3. Future research

This review highlights multiple issues that are pertinent to our understanding of why individuals decide to enrol in clinical trials. Although this offers a rich insight of the decision-making process, much of the literature to-date is retrospective or descriptive and is therefore unable to evaluate potential strategies for improving trial consultations. In addition, the percentage of lung cancer patients enrolling in clinical trials remains low (Cancer Research UK, 2022; National Institute for Health Research, 2022). Therefore, future research should try to proactively engage with lung cancer professionals, patients, and relatives to identify and pilot strategie s to improve trial discussions and increase the accessibility of research.

The current findings may also be used to guide the future development and testing of clinical resources to support nurses and other clinicians who are otherwise hesitant to discuss clinical trials with patients (McPhelim, 2015). This review presents a summary of previous research findings which can inform the design of novel tools to help healthcare staff navigate conversations about clinical trials; for example: by encouraging staff to signpost support for travel, and to further explore a person's motivations and fears regarding participation.

5. Conclusion

This review provides a comprehensive overview of the literature regarding issues affecting lung cancer patients' decisions to take part in clinical trials. Informed by the COM-B Model, the findings have been organised in relation to peoples' capabilities, opportunities, and motivations to participate in research. Findings suggest that trial enrolment is a multifaceted decision which comprises several interpersonal, logistical, and psychosocial factors. Researchers and clinicians should attempt to address these via the supply of accessible trial information, prioritisation of patient welfare and trust, travel-related support, expansion of clinical trials and eligibility criteria, as well as acknowledgment of individuals' altruistic wishes, hopes, fears, and familial concerns. Future research should seek to work with key stakeholders, such as lung cancer nurse specialists, patients, and family members, to proactively explore initiatives to increase the accessibility of clinical trials, and further develop clinical tools to help research staff support and engage patients at the outset of the clinical care process and beyond.

Funding

This article has been produced as part of the 'Improving Access to Lung Cancer Clinical Trials' (Lung I-ACT) project, funded by the Roy Castle Lung Cancer Foundation. The Roy Castle Lung Cancer Foundation did not contribute to the conducting, writing, editing, or any other part of this review.

CRediT authorship contribution statement

Benjamin Lond: Writing – review & editing, Writing – original draft, Validation, Project administration, Methodology, Investigation, Formal analysis, Data curation, Conceptualization. **Christopher Dodd:** Writing – review & editing, Writing – original draft, Project administration. **Zoe Davey:** Writing – review & editing, Writing – original draft, Project administration. **Liz Darlison:** Writing – review & editing, Writing – original draft, Conceptualization. **John McPhelim:** Writing – review & editing, Writing – original draft, Conceptualization. **Janette Rawlinson:** Writing – review & editing, Writing – original draft, Conceptualization. **Iain Williamson:** Writing – review & editing, Writing – original draft, Conceptualization. **Clair Merriman:** Writing – review & editing, Validation, Investigation, Data curation. **Francesca Waddington:** Writing – review & editing, Validation, Investigation, Data curation. **Dominic Bagnallainslie:** Writing – review & editing, Investigation, Data curation. **Balaji Rajendran:** Writing – review & editing, Validation, Investigation, Data curation. **Jesse Usman:** Writing – review & editing, Validation, Investigation, Data curation.

Declaration of competing interest

None declared.

Appendix A. Supplementary data

Supplementary data to this article can be found online at https://doi.org/10.1016/j.ejon.2024.102564.

References

Alessy, S.A., Lüchtenborg, M., Rawlinson, J., Baker, M., Davies, E.A., 2021. Being assigned a clinical nurse specialist is associated with better experiences of cancer care: English population-based study using the linked National Cancer Patient Experience Survey and Cancer Registration Dataset. Eur. J. Cancer Care 30 (6), e13490. https://doi.org/10.1111/ecc.13490.

American Lung Association, 2023. Improving Lung Cancer Clinical Trial Enrollment. https://www.lung.org/getmedia/1f78dc1a-a501-4c0e-8bb8-1467f6392e3d/ala-improving-trial-enrollment-march17b-draft.pdf.

Baggstrom, M.Q., Waqar, S.N., Sezhiyan, A.K., Gilstrap, E., Gao, F., Morgensztern, D., Govindan, R., 2011. Barriers to enrollment in non-small cell lung cancer therapeutic clinical trials. J. Thorac. Oncol. 6 (1), 98–102. https://doi.org/10.1097/JTO.0b013e3181fb50d8.

Cancer Research UK, 2022. Lung cancer statistics. https://www.cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancer-type/lung-cancer#collapseZero.

Critical Appraisal Skills Programme, 2018. CASP Checklists. https://casp-uk.net/casp-tools-checklists/.
Du, W., Gadgeel, S.M., Simon, M.S., 2006. Predictors of enrollment in lung cancer clinical trials. Cancer 106 (2), 420–425. https://doi.org/10.1002/cncr.21638.
Fouad, M.N., Lee, J.Y., Catalano, P.J., Vogt, T.M., Zafar, S.Y., West, D.W., Simon, C., Klabunde, C.N., Kahn, K.L., Weeks, J.C., Kiefe, C.I., 2013. Enrollment of patients with lung and colorectal cancers onto clinical trials. J. Oncol. Pract. 9 (2), e40–e47. https://doi.org/10.1200/JOP.2012.000598.
Gonzalez, L.E., Sutton, S.K., Pratt, C., Gilbertson, M., Antonia, S., Quinn, G.P., 2013. The bottleneck effect in lung cancer clinical trials. J. Cancer Educ. 28 (3), 488–493. https://doi.org/10.1007/s13187-013-0491-z.
Gregersen, T.A., Birkelund, R., Wolderslund, M., Netsey-Afedo, M.L., Steffensen, K.D., Ammentorp, J., 2019. What matters in clinical trial decision-making: a systematic review of interviews exploring cancer patients' experiences. Scand. J. Caring Sci. 33 (2), 266–278. https://doi.org/10.1111/scs.12637.
Harrop, E., Noble, S., Edwards, M., Sivell, S., Moore, B., Nelson, A., FRAGMATIC Trial Management Group (TMG), 2016. "I didn't really understand it, I just thought it'd help": exploring the motivations, understandings and experiences of patients with advanced lung cancer participating in a non-placebo clinical IMP trial. Trials 17 (1), 329. https://doi.org/10.1186/s13063-016-1460-8.
Hauck, C.L., Cartmell, K.B., Mueller, M., Kelechi, T.J., 2021. Scoping review: barriers and facilitators to enrollment in pediatric oncology clinical trials. Pediatr. Nurs. 47 (2), 79–96.
Horn, L., Keedy, V.L., Campbell, N., Garcia, G., Hayes, A., Spencer, B., Carbone, D.P., Sandler, A., Johnson, D.H., 2013. Identifying barriers associated with enrollment of patients with lung cancer into clinical trials. Clin. Lung Cancer 14 (1), 14–18. https://doi.org/10.1016/j.cllc.2012.03.008.
International Agency for Research on Cancer, 2022. Lung cancer awareness month 2022. https://www.iarc.who.int/news-events/lung-cancer-awareness-month-2022/#:~:text=Currently%2C%20IARC%20researchers%20are%20working,being%20treated%20for%20lung%20cancer.
Islam, K.M., Opoku, S.T., Apenteng, B.A., Fetrick, A., Ryan, J., Copur, M., Tolentino, A., Vaziri, I., Ganti, A.K., 2014. Engaging patients and caregivers in patient-centered outcomes research on advanced stage lung cancer: insights from patients, caregivers, and providers. J. Cancer Educ. 29 (4), 796–801. https://doi.org/10.1007/s13187-014-0657-3.
JBI, 2020. Critical appraisal tools. https://jbi.global/critical-appraisal-tools.
Kehl, K.L., Arora, N.K., Schrag, D., Ayanian, J.Z., Clauser, S.B., Klabunde, C.N., Kahn, K. L., Fletcher, R.H., Keating, N.L., 2014. Discussions about clinical trials among patients with newly diagnosed lung and colorectal cancer. J. Natl. Cancer Inst. 106 (10), dju216 https://doi.org/10.1093/jnci/dju216.
Lim, C., Sung, M., Shepherd, F.A., Nouriany, N., Sawczak, M., Paul, T., Perera-Low, N., Foster, A., Zawisza, D., Feld, R., Liu, G., Leighl, N.B., 2016. Patients with advanced non-small cell lung cancer: are research biopsies a barrier to participation in clinical trials? J. Thorac. Oncol. 11 (1), 79–84. https://doi.org/10.1016/j.jtho.2015.09.006.
LUNGevity, 2017. Understanding barriers to participation in clinical trials: the patient and the caregiver perspectives. https://www.lungevity.org/sites/default/files/patient-force/barriers-to-clinical-trial-participation.pdf.
Macmillan, 2015. The Rich Picture: People with Lung Cancer. Macmillan Cancer Support, London, UK.
McPhelim, J., 2015. Role of lung cancer nurse specialists in recruiting patients to clinical trials. Cancer Nurs. Pract. 14 (4), 22. https://doi.org/10.7748/cnp.14.4.22.e1065.
Michie, S., van Stralen, M.M., West, R., 2011. The behaviour change wheel: a new method for characterising and designing behaviour change interventions. Implement. Sci. 6, 42. https://doi.org/10.1186/1748-5908-6-42.
Morris, C., West, R., Stephens, R., Baker, M., Blaveri, E., Brannan, R., Fisher, S., Hanson, J., Inns, K., Pavitt, S., Poole, K., Race, R., 2014. Keeping the customer satisfied: is taking part in research associated with better experience of care? Findings from the National Cancer Patient Experience Survey [Conference presentation]. In: National Cancer Research Institute Cancer Conference, 2014, Liverpool, UK. https://openresearch.surrey.ac.uk/esploro/outputs/conferencePresentation/Keeping-the-customer-satisfied-is-taking-part-in-research-associated-with-better-experience-of-care–Findings-from-the-National-Cancer-Patient-Experience-Survey/99516987002346#details.
Mudaranthakam, D.P., Gajewski, B., Krebill, H., Coulter, J., Springer, M., Calhoun, E., Hughes, D., Mayo, M., Doolittle, G., 2022. Barriers to clinical trial participation: comparative study between rural and urban participants. JMIR Cancer 8 (2), e33240. https://doi.org/10.2196/33240.
National Institute for Health Research, 2022. Open data platform. https://odp.nihr.ac.uk/qlikview/.
Nipp, R.D., Hong, K., Paskett, E.D., 2019. Overcoming barriers to clinical trial enrollment. Am. Soc. Clin. Oncol. Educ. Book. 39, 105–114. https://doi.org/10.1200/EDBK_243729.
O'Leary, E., Cooper, N., Peake, M., Oehler, C., Hounsome, L., Elliss-Brookes, L., Verne, J., White, C., Huws, D.W., Hecht, S., Deas, A., Brewster, D., Donnelly, D., Gavin, A., Deady, S., Comber, H., 2016. Deprivation and cancer: in search of a common measure across england, wales, scotland, northern Ireland and Ireland. National Cancer Registration and Analysis Service. http://www.ncin.org.uk/publications/reports/.
Ogden, J., 2016. Celebrating variability and a call to limit systematisation: the example of the behaviour change technique taxonomy and the behaviour change wheel. Health Psychol. Rev. 10 (3), 245–250. https://doi.org/10.1080/17437199.2016.1190291.
Ouzzani, M., Hammady, H., Fedorowicz, Z., Elmagarmid, A., 2016. Rayyan-a web and mobile app for systematic reviews. Syst. Rev. 5 (1), 210. https://doi.org/10.1186/s13643-016-0384-4.
Ozdemir, B.A., Karthikesalingam, A., Sinha, S., Poloniecki, J.D., Hinchliffe, R.J., Thompson, M.M., Gower, J.D., Boaz, A., Holt, P.J., 2015. Research activity and the association with mortality. PLoS One 10 (2), e0118253. https://doi.org/10.1371/journal.pone.0118253.
Page, M.J., Moher, D., Bossuyt, P.M., Boutron, I., Hoffmann, T.C., Mulrow, C.D., Shamseer, L., Tetzlaff, J.M., Akl, E.A., Brennan, S.E., Chou, R., Glanville, J., Grimshaw, J.M., Hróbjartsson, A., Lalu, M.M., Li, T., Loder, E.W., Mayo-Wilson, E., McDonald, S., McGuinness, L.A., et al., 2021. PRISMA 2020 explanation and elaboration: updated guidance and exemplars for reporting systematic reviews. Br Med J 372, n160. https://doi.org/10.1136/bmj.n160.
Prewett, S.L., Aslam, S., Williams, M.V., Gilligan, D., 2012. The management of lung cancer: a UK survey of oncologists. Clin. Oncol. 24 (6), 402–409. https://doi.org/10.1016/j.clon.2012.03.005.
Quinn, G.P., Bell, B.A., Bell, M.Y., Caraway, V.D., Conforte, D., Graci, L.B., Powell-Stafford, V.L., Sapp, A.L., Shimizu, C.O., Vaughn, E.J., Williams, C., Bepler, G., 2007. The Guinea pig syndrome: improving clinical trial participation among thoracic patients. J. Thorac. Oncol. 2 (3), 191–196. https://doi.org/10.1097/JTO.0b013e318031cdb6.
Quinn, G.P., Bell-Ellison, B.A., Bell, M.Y., Caraway, V.D., Conforte, D., Graci, L.B., Lewandowski, A., Reynolds, B., Shaffer, A., Powell-Stafford, V.L., Sapp, A.L., Shimizu, C.O., Vadaparampil, S., Vaughn, E.J., Williams, C., Bepler, G., 2008. A message of hope: creation of the Faces of Lung Cancer project for increasing awareness of clinical trials. Eur. J. Cancer Care 17 (6), 601–610. https://doi.org/10.1111/j.1365-2354.2007.00919.x.
Quinn, G.P., Pratt, C.L., Bryant-George, K., Caraway, V.D., Paternoster, B., Roldan, T., Shaffer, A., Shimizu, C.O., Vaughn, E.J., Williams, C., Bepler, G., 2011. Lung cancer patients' decisions about clinical trials and the theory of planned behavior. J. Cancer Educ. 26 (4), 641–648. https://doi.org/10.1007/s13187-010-0169-8.
Schoenau, M.N., Hansen, M., Ulvestad, S., Sommer, M.S., Pedersen, J.H., Missel, M., 2020. The lived experiences, perceptions, and considerations of patients after operable lung cancer concerning nonparticipation in a randomized clinical rehabilitation trial. Qual. Health Res. 30 (5), 760–771.
Spiegel, M.L., Goldman, J.W., Wolf, B.R., Nameth, D.J., Grogan, T.R., Lisberg, A.E., Wong, D.J.L., Ledezma, B.A., Mendenhall, M.A., Genshaft, S.J., Gutierrez, A.J., Abtin, F., Wallace, W.D., Adame, C.R., McKenzie, J.R., Abarca, P.A., Li, A.J., Strunck, J.L., Famenini, S., Carroll, J.M., et al., 2017. Non-small cell lung cancer clinical trials requiring biopsies with biomarker-specific results for enrollment provide unique challenges. Cancer 123 (24), 4800–4807. https://doi.org/10.1002/cncr.31056.
Tanai, C., Nokihara, H., Yamamoto, S., Kunitoh, H., Yamamoto, N., Sekine, I., Ohe, Y., Tamura, T., 2009. Characteristics and outcomes of patients with advanced non-small-cell lung cancer who declined to participate in randomised clinical chemotherapy trials. Br. J. Cancer 100 (7), 1037–1042. https://doi.org/10.1038/sj.bjc.6604982.
The Institute of Cancer Research, 2021. Clinical Trials in Cancer. Barriers in Access to Clinical Trials, Especially in Light of the Covid-19 Pandemic. https://www.icr.ac.uk/media/docs/default-source/corporate-docs-accounts-and-annual-reports/policy-statements/clinical-trials-in-cancer.pdf?sfvrsn=d2a92b69_8.
Unger, J.M., Gralow, J.R., Albain, K.S., Ramsey, S.D., Hershman, D.L., 2016. Patient income level and cancer clinical trial participation: a prospective survey study. JAMA Oncol. 2 (1), 137–139. https://doi.org/10.1001/jamaoncol.2015.3924.
World Health Organization, 2023. Lung cancer. https://www.who.int/news-room/fact-sheets/detail/lung-cancer.