Utilization of Lung Cancer Registries in Learning Health Systems for Health Care Improvement

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ABSTRACT

PURPOSE Lung cancer is the leading global cause of cancer mortality with substantial evidence of inequity, disparity in process and outcomes, and unwarranted clinical variation. Over the last decades, there has been major evolution and discovery in best evidence-based practice (EBP), enhancing diagnostics, management, and the delivery of precision medicine. However, questions remain about the completeness of translation of best EBP into delivered care.

DESIGN Learning health systems (LHSs) have been defined as improvement environments where knowledge generation processes are embedded into daily clinical practice to continually improve the quality, safety, and outcomes of health care delivery. Lung cancer clinical quality registries (CQRs) provide a rigorous infrastructure supporting LHS function through the collection, analysis, and reporting of care process and outcome information delivered by health service organizations. CQRs measure the appropriateness and effectiveness of delivered care and report on the degree of best EBP delivery by stakeholder providers. The provision of risk-adjusted, benchmark reporting to stakeholders describes equity, disparity, and unwarranted clinical variation and is a fundamental driver of improvement in the safety and quality of care provided to consumers.

RESULTS There is mounting international evidence of the positive impacts of CQR reporting on management processes, health care infrastructure, survival, quality improvement, and education within lung cancer communities. The use of implementation science approaches including the Knowledge to Action framework targets bridging the gaps between evidence-based knowledge and practice.

CONCLUSION Registry evolution is exampled by the Danish Lung Cancer Registry, National Lung Cancer Audit (United Kingdom), Dutch Lung Cancer Audit, and Victorian Lung Cancer Registry (Australia), which identify innovation opportunities to close the evidence-practice gap, overcome service deficits, and lead to better decision making for health care improvement.

ACCOMPANYING CONTENT

Appendix

Data Supplement

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PROBLEM STATEMENT: PERSISTING EVIDENCE OF FAILURE OF EFFECTIVE KNOWLEDGE TRANSLATION

Decision makers in health care struggle with the efficient uptake and translation of rapidly evolving scientific knowledge into policy, organizational process, and health care practice.[1] Health services research suggests that care in line with best evidence-based practice (EBP) guidelines is just 60%, whereas 30% of care is wasteful, duplicative, or of low value, and 10% of care results in adverse events or patient harm, described as the 60:30:10 challenge.[2-5]

These numbers are reflected in contemporary lung cancer reports. Best EBP reveals low levels of testing for actionable biomarkers for patients with advanced or metastatic non–small cell lung cancer (NSCLC),[6] missed diagnostic opportunities leading to diagnostic delay,[7] and patients insufficiently presented to lung cancer multidisciplinary meetings (MDMs).[8] Low value care is reflected by high levels of ineligible patients referred for lung cancer screening,[9] higher chemotherapy cycle numbers providing limited or no additional survival benefit,[10] and limited benefit of erythropoietin-stimulating agents in chemotherapy-induced anemia.[11] Harm delivered in treatment is suggested by 10% of patients treated with checkpoint inhibitors[12] and chemotherapy[13] experiencing severe or life-threatening adverse events.

Observational studies confirm substantial gaps in delay of translation of evidence-based innovations to clinical practice, taking up to 17 years, with fewer than half of clinical innovations translated into general usage.[14,15] These gaps threaten the overuse, underuse, or misuse of medical treatments when the care provided is not evidence-based and may adversely affect health care quality, safety, and cost. A recent lung cancer review confirms significant delay in best evidence implementation, affecting timely diagnosis and referral of lung cancer; underutilization of curative and palliative treatments, psychosocial support, and palliative care; and significant variations in treatment utilization associated with patient characteristics, provider practices, and the organization of health care services.[16,17]

DISPARITY, INEQUITY, AND UNWARRANTED CLINICAL VARIATION IN BEST EBP

Disparity and inequity have been widely identified in the delivery of lung cancer care to disadvantaged groups characterized by age,[18] sex,[19] regionality,[20] socioeconomic disadvantage,[21] educational status,[22] indigenous status,[23] and racial, cultural, and ethnic diversity.[24,25]

EBP in lung cancer management is defined in clinical practice guidelines, and the measure of stage-specific, guideline-concordant treatment (GCT) provides one potential measure of population-based delivery of best evidence-based management practice. The delivery of GCT is associated with significant survival benefits, making assessment of barriers and enablers to GCT an important best practice measure.[25-27]

Study of delivery of GCT in lung cancer populations reveals wide variation in receipt of GCT (48%-77%), with 16%-33% receiving less intense treatment (non-GCT) and 15%-33% receiving no active treatment.[26-30] A US study of 377,370 patients with NSCLC identified substantial and significant variation in receipt of surgery, GCT initial treatment, and survival between racial subgroups.[25] Factors associated with non-GCT have been identified, including poor performance status, advanced clinical stages, NSCLC subtypes, race, ethnicity, public hospital insurance, geography, area-level deprivation, and comorbidities.

A recent global survey assessed the degree of uptake of best EBP practice in molecular testing in lung cancer across 102 countries, suggesting <50% of patients with lung cancer receive molecular testing, with barriers including cost, access, quality, turnaround time, and lack of awareness.[31]

OPPORTUNITIES FOR IMPROVEMENT: IS AND LHSs

Research on how to improve health care has been variably described using terms including quality improvement, dissemination and implementation science (IS), learning health systems (LHSs), and knowledge translation, with substantial overlap within objectives and definitions. Prominent researchers have identified an important focus in the testing, refinement, and integration of these theories rather than further framework proliferation.[1] Better understanding of these definitions and implementation strategies may provide major opportunities for knowledge translation and health care improvement.

IS AND THE KNOWLEDGE TO ACTION FRAMEWORK

IS has been defined as the "scientific study of methods to promote the systematic uptake of research findings and other EBP into routine practice, and, hence, to improve the quality and effectiveness of health services and care."[32] IS seeks to systematically close the gap between what we know and what we do, referred to as the evidence-practice gap, by identifying and addressing the barriers and facilitators of practical uptake of effective health interventions and best EBPs.[33] IS aims to develop, implement, and sustain strategies designed to enhance awareness, promote behavioral change, and seek alignment by practitioners and policymakers with best evidence-based information.[34] Reports call for increasing alignment between quality improvement practice and IS by (1) strengthening research/practice partnerships, (2) fostering local ownership of implementation, (3) generating practice-based evidence, (4) developing context-specific implementation strategies, and (5) building practice-level capacity to implement interventions and improve care.[35]

The Knowledge to Action framework is a cognitive construct used in IS that helps connect knowledge creation and implementation[36,37] (Appendix Figure A1). Knowledge synthesis is the first step in this process, aggregating and interpreting research findings within the broader context of existing knowledge. This transformation of large volumes of research knowledge into concise and actionable forms leads to the development of knowledge tools and products. The second element is the iterative practical utilization of this knowledge using the seven steps of the action cycle in the framework.[37] This framework provides a process with the potential to inform and map the dissemination and implementation of innovation strategies for health care improvement.[34]

Improvement in the effective dissemination of quality improvement interventions facilitates knowledge sharing, enabling peer teams to rapidly identify tangible improvement tools and methodologies and to engage the stakeholders necessary to ensure the effective implementation of improvement plans for health care improvement.[38,39] Investment in quality improvement provides additional financial and sustainability benefits to organizations, benefiting hospital networks and ultimately the patients.[40]

DEVELOPMENT OF A CONSENSUS IS TAXONOMY

Inconsistent terminology for core concepts in IS has been widely noted as an obstacle to effective IS research.[41] Such inconsistencies potentially inhibited those developing and planning implementation initiatives and limit the effective dissemination of successful strategies between jurisdictions and health services.[42]

A Delphi-confirmed consensus taxonomy of IS strategies has recently provided a cognitive infrastructure to this process.[41,43] The Expert Recommendations for Implementing Change (ERIC) study addressed terminological inconsistency by creating an expert consensus agreement on discrete implementation strategies involving processes or actions used to support practice improvement[41] (Fig 1 and Data Supplement, Table 1). Cluster analyses defined nine concept groupings: use evaluative and iterative strategies, provide interactive assistance, adapt and tailor to context, develop stakeholder interrelationships, train and educate stakeholders, support clinicians, engage consumers, use financial strategies, and change infrastructure. This led to a further subcategorization of 73 agreed implementation strategies (Data Supplement, Table 1).

LHSs

"In a learning healthcare system, science, informatics, incentives and culture are aligned for continuous improvement and innovation, with best practices seamlessly embedded in the delivery process, with patients and families active participants in all elements, and new knowledge captured as an integral by-product of the delivery experience."[44] An LHS aims to combine different types of knowledge, including health services and systems research, population health analytics, patient-centered engagement and codesign, evidence syntheses, implementation and behavioral science, equity, health economics, community engagement, and community participatory action research, enabling improvement collaboratives to find strategies to integrate and apply knowledge to enable better decision making and create better outcomes for their patients.[45-47]

The LHS incorporates three important information sources (Fig 2): first, the capture of data that describe what we are actually doing, that is, clinical performance quality determined by adherence to agreed quality indicator standards, defined as Performance to Data (P2D); second, a process of discovery engaging health care data review, evaluation, and analysis, enabling us to plan, innovate, and implement for better outcomes, defined as Data to Knowledge (D2K); and third, the interpretation of findings that facilitates the design of new interventions and strategies for implementation, defined as Knowledge to Performance (K2P).[48,49]

The LHS, however, is differentiated by three important factors[50]: first, establishing a multistakeholder learning community focused on the problem and the collaborative

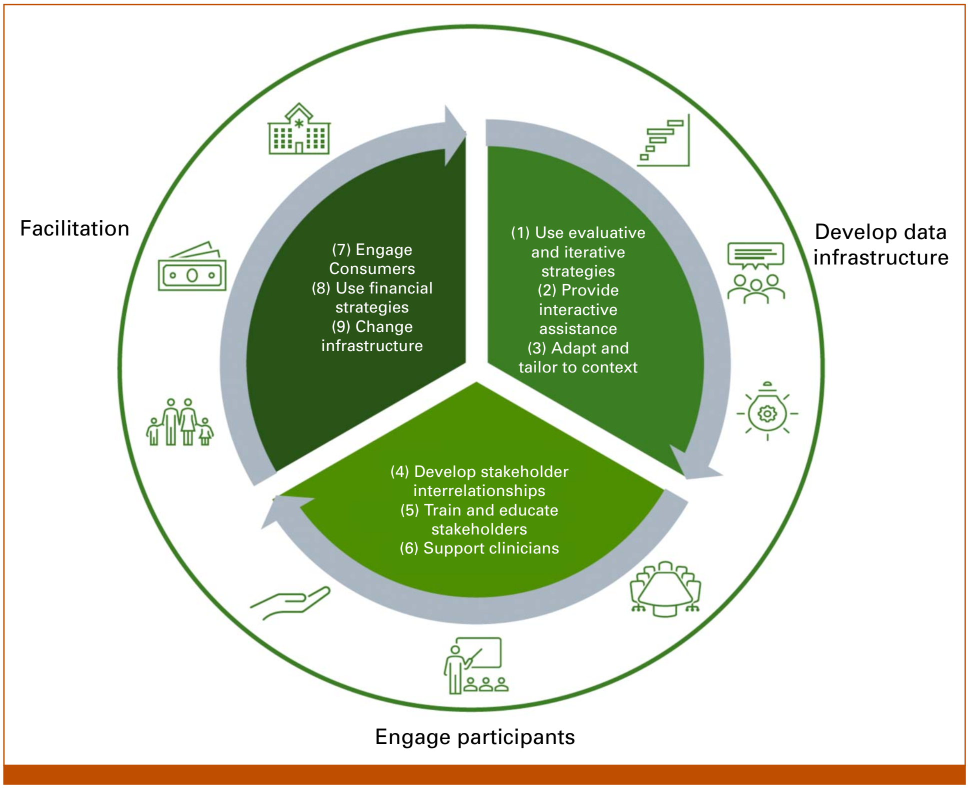

FIG 1. The ERIC framework is a compilation of 73 discrete implementation strategies, grouped into nine categories by cluster analysis, developed within the field of IS to address the challenge of translating research findings into real-world practice.[41,43] ERIC, Expert Recommendations for Implementing Change; IS, implementation science.

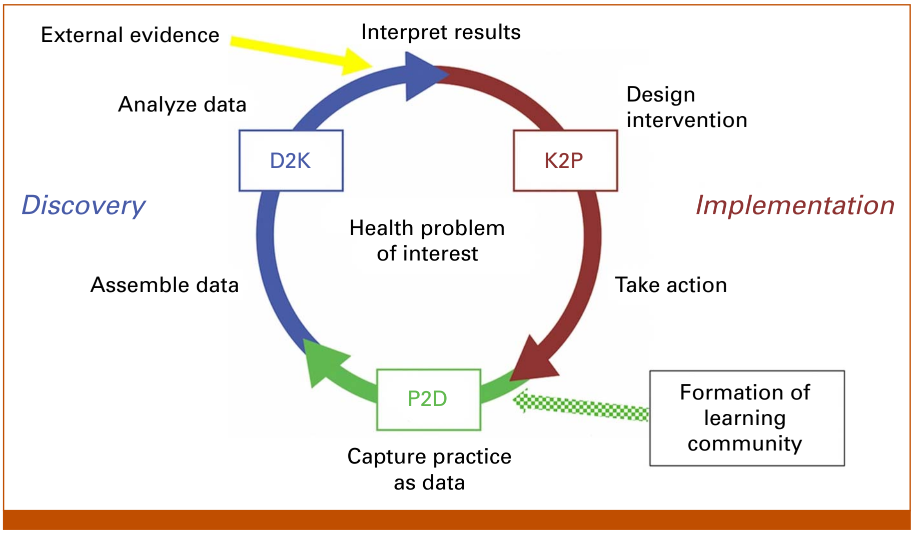

FIG 2. The LHS links discovery to implementation.[33,50] The cycle commences with the formation of a learning community and proceeds with collection of data to capture what is happening in clinical practice. Analysis of this information enables understanding of how improvement might be affected, followed by innovation and implementation of strategies to drive health care improvement. From there, the learning cycle repeats iteratively. D2K, Data to Knowledge; K2P, Knowledge to Performance; LHS, learning health system; P2D, Performance to Data.

execution of the whole cycle; second, embracing the uncertainty of improvement processes by undertaking a rigorous discovery process before any implementation takes place; and third, supporting multiple co-occurring cyclic improvement initiatives including the Plan Do Study Act processes within the sociotechnical improvement infrastructure.[51]

MICRO, MESO, AND MACRO OPPORTUNITIES FOR HEALTH CARE IMPROVEMENT

The LHS provides opportunities for health care improvement at multiple levels. At the micro-level, registries can inform individual patient and clinician communication based on patient-specific characteristics, responding to the question, what happens in patients like me? At the meso-level, the provision of benchmarked feedback allows hospitals, local health care networks, and clinicians to monitor and evaluate care delivery, process and outcomes, and impacts of quality improvement initiatives. At the macro-level, knowledge from population-wide data confirms evidence in real-world patient cohorts of efficacy and adverse events unrestricted by the strict inclusion criteria of randomized controlled trials.[52]

DEVELOPMENT OF AN IMPROVEMENT INFRASTRUCTURE

The successful development of an LHS and quality improvement infrastructure requires the alignment of people, technologies, policies, and processes—brought together by shared needs and a culture of continuous quality improvement.[53] The elements of this infrastructure include people within a trained workforce to conduct the work; technologies that support data collection, analysis, evaluation, reporting, and dissemination; policies that shape and frame targeted domains and improvement activities; and processes that support workplace routines, efficiency, and sustainability.[54] These infrastructural pillars are strongly represented within the objectives, governance, data capture, analysis, and reporting frameworks provided by clinical quality registries (CQRs). The creation of such learning infrastructures has the additional capacity to inform, facilitate, and support multiple cross-sectoral improvement initiatives within health care networks, supporting complex improvement initiatives within other cancer improvement initiatives such as breast, prostate, and colorectal cancers.

LUNG CANCER REGISTRY FUNCTION FOR HEALTH CARE IMPROVEMENT

Lung cancer registries have the potential to play key and central roles in the reporting, evaluating, and disseminating quality improvement initiatives for health care performance in LHS[48] (Fig 3). The intention of lung cancer registries has been to address high disease burden, poor survival, inequity, disparity, and unwarranted clinical variation in diagnostic and management pathways and to assess the effectiveness and appropriateness of delivered care.[55-58]

Registry processes achieve these outcomes by the delivery of risk-adjusted, benchmarked reports to stakeholder clinicians and health systems, providing a rigorous quality improvement infrastructure designed to stimulate service improvement activity. CQRs provide diverse opportunities including deeper understanding of epidemiological changes in populations over time, associations between clinical characteristics, and an understanding of the linkage between

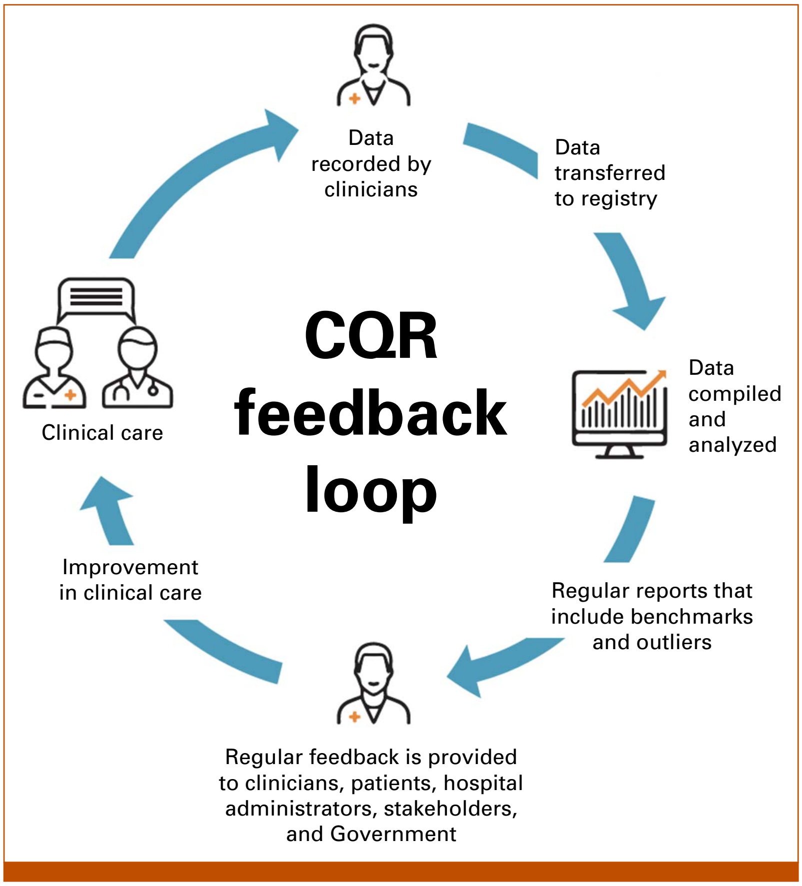

FIG 3. CQRs collect, analyze, and report information about the care and outcomes being delivered by health service organizations and serve as a fundamental driver of ongoing improvements in the safety and quality of the care provided to consumers.[109,110] CQR, clinical quality registry.

management processes and health outcomes. They also develop and provide evidence for advocacy, policy development, and resource distribution within the lung cancer community.

Registry processes also report on patient groups underrepresented in clinical trials, such as the elderly, comorbid, and socially disadvantaged populations, and assess their adherence to clinical practice guideline changes and novel EBP uptake over time. Registry data are used regularly to build systems-oriented approaches to quality improvement, data transparency, and encouragement of patient, family, and career-centered engagement aimed at ensuring the best outcomes and care practices for people at local, national, and international levels.[56-59]

A recent systematic review assessed the effectiveness of strategies designed to support the use of clinical practice guidelines and CQR data to identify gaps in best practice care and to inform and improve health service delivery.[60] Five complementary strategies were identified to maximize the likelihood of best practice health service delivery: (1) feedback and transparency, (2) intervention sustainability, (3) clinical practice guideline adherence, (4) productive partnerships, and (5) whole-of-team approach.

REAL-WORLD LUNG CANCER REGISTRY/LHS OUTCOMES

The DLCR

The Danish Lung Cancer Registry (DLCR) was formed following the identification of concerns in survival and the clinical management of Danish patients with lung cancer and to produce a platform for lung cancer research.[61] The DLCR commenced data collection in 2000 as a quality management system reflecting national guideline recommendations, a database with high data quality, frequent reporting, auditing of key indicators of best practice, and commitment from all stakeholders.[56] Substantial organizational changes have ensued following national reporting, including centralization of lung cancer services, reducing from 90 to 28 centers and four surgical centers.[62]

Clinical indicators reflecting the outcomes of quality improvement work focused on four topics including survival, stage, surgical resection rate, and oncological cure rate with statistically significant improvements in all documented indicators including 1-, 2-, and 5-year survival.[56] DLCR registry process has been associated with enhanced diagnostic accuracy, more timely access to surgery, increased surgical resection rates, increased lobectomy and reduced pneumonectomy rates, lowered postoperative complications, and increased clinical and pathological stage concordance.[63] One-year survival in the period 2001-2020 has increased from 32.2% to 52.0%, and 5-year survival from 9.0% to 23.8%.[64] An assessment of health-related quality-of-life patient-reported outcomes between surgical centers identified significant differences reflecting varied patient experience independent of clinical measures, demanding further evaluation of surgical process and quality outcomes.[62]

The NLCA-UK

The National Lung Cancer Audit (NLCA)-UK was established in 2004 to identify possible inequities within the National Health Service (NHS) and to highlight the potential for service improvements.[65] The NLCA aims to help NHS organizations to benchmark their lung cancer care against measurable standards, to identify unwarranted variation in care, and to provide tools to help services improve quality of care for people with lung cancer. NLCA improvement goals were developed in consultation with patient and professional representatives, reporting 11 clinical quality indicators describing diagnosis, treatment planning, patterns of care, and survival outcomes.[66]

The NLCA-UK has helped to drive up lung cancer surgical resection rates and, in turn, the number of thoracic surgeons within the NHS, and has documented a sustained improvement in survival rates after surgery and a national transition to minimally invasive surgery as the predominant approach used.[59,67] The NLCA has further documented a national increase in proportion of patients with histologically confirmed lung cancer, early-stage disease, number undergoing surgery with curative intent, NSCLC anticancer treatment, MDM assessment, and patients seen by a lung cancer nurse specialist, thereby improving patient experience.[68,69] This has resulted in a significant improvement in 1-year survival rates for all patients reported by the NLCA (41% in 2019 to 50% in 2023).

Research using the NLCA has shown the extent of unwarranted variation in clinical practice and highlighted the disparity between main cancer centers and peripheral hospitals.[70-72] The NLCA-UK provides defined quality improvement models to stakeholder institutions describing implementation opportunities for health care improvement,[73] including a quality improvement resource page, local action plan templates, negative outlier management plans, online webinars, patient and public involvement, communication and dissemination strategies, and coordination between professional bodies and colleges.[73]

The DLCA

The Dutch Lung Surgery Audit commenced in 2012, initially comprising surgical patients only. The audit was expanded in 2016 to include lung oncology and a radiotherapy audit. Hence, it was renamed the Dutch Lung Cancer Audit (DLCA), which consists of the DLCA-L (lung oncology), DLCA-R (radiotherapy), and the DLCA-S (surgery).[57] The DLCA is a multidisciplinary lung cancer registry that transparently evaluates performance of health care for patients with lung cancer and reports on quality indicators of structure, processes, and outcomes.[74]

The DLCA is implemented on a nationwide level with mandatory participation and enables participating health care providers transparent insight into their performance. The audit currently gives feedback on 17 publicly available quality indicators, some of which are available for external stakeholders such as the government or health care insurance companies. Annually, outliers are evaluated and negative outlier institutions are directed to make an improvement plan to minimize hospital variation. Nationally, improvements have been seen in a wide range of lung cancer–related outcomes, including increased patient registration, increased brain imaging, better mediastinal staging, increased receipt of immunotherapy and chemoimmunotherapy in stage IV NSCLC, reduced levels of chemotherapy-induced toxicity, enhanced use of minimally invasive surgery, enhanced treatment timeliness, and increased molecular diagnostics in stage IV NSCLC.[57] In addition, practice variation in the treatment of persistent air leak after lung cancer resections has been investigated with recommendations provided to reduce this common complication.[75]

VLCR

The Victorian Lung Cancer Registry (VLCR) is an Australian state-based CQR, initiated in 2011 based on reports from Danish and UK registry improvement efforts.[8,58] The VLCR provides annual risk-adjusted quality indicator reports to stakeholder hospitals identifying performance attainment against 20 quality indicators, with persisting evidence of unwarranted clinical variation.[18,27,76-81] Over time there has been significant improvement in clinical documentation of clinical stage, performance status, and MDM presentation, enabling more informed decision making, improved treatment approaches, and survival benefits at stakeholder hospitals.[8] The selection and adaptation of quality indicators have been reviewed, showing substantial and significant survival benefits for populations attaining quality indicator standards.[8]

MULTINATIONAL REGISTRY COLLABORATIONS

Nordic countries (Sweden Finland, Norway, and Denmark) have a strong history of data collection in nationwide cancer registries commencing in the 1940s, with major evolution of lung cancer–specific data capture over the last decades.[82]

Comparison of registry structures has led to learnings in patient, disease, management, and outcome measures, enabling the potential harmonization of indicator measures across national registries. The ADVANCE-1 project reported a multinational quality improvement collaborative examining international registry–reported benchmarking of quality indicators at two European hospitals.[83] Benchmarking reflected structure and processes within lung cancer services and how these processes affect the patient pathway, identifying barriers and enablers to best practice. Practice review enabled the optimization of patient outcomes dependent on multifactorial approaches addressing infrastructure, staff, access to diagnostics, and therapies and trials in specialist centers. Collaboration between the DLCR and VLCR has enabled reassuring international surgical outcome evaluation and benchmarking.[84]

EVIDENCE OF UTILIZATION OF IS STRATEGIES BY CANCER REGISTRIES

As yet there has been limited published evidence of the use of IS strategies by disease registries for health care improvement.[60] A recent systematic review identified just four lung cancer registry–based studies using IS strategies largely based on NLCA process and outcomes, describing both process success factors and significant health care improvements. There is, however, significant evidence from national lung cancer registries of the use of IS strategies largely predating IS and the release of the ERIC IS taxonomy (Table 1). The DLCR, NLCA, DLCA, and VLCR have systematically developed tools for quality monitoring; organized quality monitoring systems; used formal implementation blueprints; engaged patients and consumers, and data experts and warehousing; provided audit and feedback; reminded clinicians; facilitated clinical feedback; developed academic and research partnerships; and encouraged strong stakeholder engagement.[56,85]

European and UK registries have been strongly supported by legislation mandating hospital participation resulting in high levels of stakeholder engagement and strong evidence of knowledge translation of best EBP. The DLCR, NLCA, and DLCA all report very high levels of data registration and completeness and low levels of missing data.[56,57] The DLCR at a national level has remodeled care infrastructure by defining specialist hospital referral patterns, streamlining surgical referral processes.[56] The most commonly used implementation concept clusters included the use of evaluative and iterative strategies for data evaluation, development of stakeholder interrelationships, training and education of stakeholders, and adaptation and tailoring to context.

ASCO developed the Quality Oncology Practice Initiative, which is a data quality registry designed for outpatient-oncology practices, fostering a culture of self-examination and improvement for participating practices.[86] Core data set outcomes were designed to assess adherence to important patient care processes and are distributed to participating practices to stimulate internal evaluation and quality improvement. Participant practices reported the use of evaluative and iterative strategies, rapid Plan Do Study Act cycles of improvement, multidisciplinary team engagement, and clear communication among all stakeholders comprising multiple IS strategies.[87] To date, some 300 international practices have achieved certification following demonstration of high-level quality practice, demonstrating to patients, payors, and the medical community a practice's commitment to quality.[88]

ACTIONABLE RECOMMENDATIONS: ORGANIZATIONAL ADOPTION OF LHSs

To date, there is very limited published evidence of impacts of LHS on clinical outcomes in lung cancer or other sectors. The importance and need for linkage and integration of quality improvement research and health practice, however, have been recognized by governments, commercial health care providers, academic health care centers, and universities. The formation of the National Institute for Health

TABLE 1. Published Citation Examples of the Utilization of IS Strategies by Lung Cancer Registries[41,43]

ERIC IS Categories	Denmark DLCR	UK NLCA	Netherlands DLCA	Australia VLCR
Use evaluative and iterative strategies	56,61,63	65,69	57,74	8,58
Provide interactive assistance	56,61	69	74	85
Adapt and tailor to context	56,61	69	57	85
Develop stakeholder interrelationships	56,63	55,69	57,74	8,85
Train and educate stakeholders	56	69	57	85
Support clinicians	56	69	74	85
Engage consumers		69	74	8,58
Use financial strategies	56	65	57,74	
Change infrastructure	56	111	42,57	112

NOTE. Citations reflect numbered references within reference list.

Abbreviations: DLCA, Dutch Lung Cancer Audit; DLCR, Danish Lung Cancer Registry; ERIC, Expert Recommendations for Implementing Change; IS, implementation science; NLCA, National Lung Cancer Audit; VLCR, Victorian Lung Cancer Registry.

Research in the United Kingdom, the National Institutes of Health in the United States, the Canadian Institutes of Health Research, and Innovationsfonds in Germany provides substantial funding for research integration.

The uptake of LHS strategies by health care delivery providers including Veterans Health Administration (United States),[89] Kaiser Permanente (United States),[90] and University of Wisconsin[91] evidences strategic initiatives to improve care by integrating research capability, data collection and evaluation, program design and evaluation, and IS into strategic decision making. At the academic level, the emergence of new journals including *BMJ Quality & Safety*, *Implementation Science* ,and *Learning Health Systems* and the expansion of academic programs in IS and quality improvement have been demonstrated.[92]

SUCCESS FACTORS IN TRANSLATION OF IS FOR HEALTH CARE IMPROVEMENT

Successful implementation requires an evidence-based approach to designing implementation strategies and evaluating their effectiveness. Multiple recent literature reviews by quality improvement researchers have proposed implementation of these frameworks and identifying putative implementation success factors.[47,90,91,93-96] Several modeling frameworks have been proposed to increase the facilitation of project success and sustainability over time with success factors focused on expertise, culture, data systems, investment, and supportive culture (Table 2).[47,95,97] Systematic review of effective IS utilization has suggested five priorities to enhance the impact of implementation strategies: (1) enhance methods for designing and tailoring implementation strategies; (2) specify and test mechanisms of change; (3) conduct more effectiveness research on discrete, multifaceted, and tailored implementation strategies; (4) increase economic evaluations of implementation strategies; and (5) improve the tracking and reporting of implementation strategies.[96,98]

FOUNDATIONS FOR LHSs

The synthesis and best practice objectives for LHSs in lung cancer are determined by context-specific factors identified by improvement leaders and cancer communities. The lack of knowledge translation in an LHS may be due to numerous factors which require consideration, including system stagnation, lack of leadership, communication gaps, lack of collaboration, awareness and education, inadequate infrastructure, organizational culture, unavailability of clinical practice quality indicators and performance feedback, the ineffective dissemination of improvement tools, and a lack of funding and resources.

Measurement is a core foundation of quality improvement, which includes description of key structure, process, and outcome data in targeted fields, demanding comprehensive data capture and programmatic analysis.[99] The Institute of Medicine proposed six domains for quality improvement, including health care that should be safe, effective, patient-

TABLE 2. LHS Facilitators[95]

Enabling Conditions of a LHS	Specific Enabling Factors
Expertise	(1) Employees throughout the organization have the skills and knowledge to engage in structured learning, quality improvement, and data analysis
	(2) Organization provides training to employees on LHS competencies (eg, quality improvement, research methods, and analysis of clinical data)
	(3) Governance supports financial, managerial, and daily operational issues
	(4) Ethical oversight to support overlap between quality improvement, clinical care, and research
Data systems and informatics infrastructure	(1) Informatics technology and resources are in place within the organization
	(2) Clinical data systems are designed strategically (anticipating the questions that investigators will bring and the analyses to be conducted)
	(3) Clinical data systems and repositories meet rigorous standards, especially privacy, quality, and reliability
	(4) Real-time data access supports rapid learning cycle activities
Investment of LHS-dedicated resources	(1) Organizational policies incentivize LHS activities
	(2) Funding mechanisms support short-term learning initiatives
	(3) Mechanisms in place for sustainable infrastructure support
Supportive culture	(1) Organizational leaders are active, visible champions of LHS principles and practices
	(2) Patient, family partners, and careers involved in establishing and directing learning activities
	(3) Organization norms that promote transparency, integrity, and trust-building and encourage and support learning and translation of evidence into practice
	(4) Engagement of health care professionals and teams across multidisciplinary health care sectors
	(5) Partnerships with organizations and groups external to the health care system, including civic and voluntary community organizations representing indigenous, culturally and linguistically diverse and equity support groups

Abbreviation: LHS, learning health system.

centered, timely, efficient, and equitable.[100] Population of these domains with quality indicators enables a proactive quality balance across quality domains, which can be shaped to individual community needs and may evolve over time (Table 3).

The election of appropriate quality indicators has the capacity for longitudinal monitoring of key identified quality measures. Beyond these central tasks are the necessary assessments of risk factors (smoking and lung cancer screening), vulnerable populations (age, indigenous populations, cultural and linguistic diversity, socioeconomic status), organizational practice (access and timeliness, multidisciplinary assessment, best practice diagnostics, management and follow-up), and policy implementation.

The availability of expertise in data analysis, IS, and quality improvement is a significant resource concern at outset, but the availability of substantive real-world data sets to a broad range of stakeholders empowers and strengthens communities, governance, and collaboration; builds confidence and capability; and fosters academic output, evidenced by the publication sets from each of the registries.

The identification of local, context-specific leadership to drive implementation of EBP is a key program success factor. Currently, there is a paucity of implementation, dissemination, and quality improvement leadership teaching in health care training; however, study of training programs reveals significant improvements with increased implementation leadership skills and organizational implementation climate outcomes.[101]

OPERATIONALIZING IS

IS aims to identify and address care gaps, support practice change, and enhance quality, safety, and equity of health care. To date, there is limited evidence of the effective engagement of IS by cancer registries for cancer care improvement.[102] The operationalization of IS efforts for this improvement demands problem definition, evaluation of health care structure, organization and provider-level inputs, specification of implementation interventions, real-world measurement within causal evaluation frameworks and pragmatic trials, and the effective dissemination of successful IS interventions in cancer care outcomes.[103,104]

GENERALIZABILITY

The quality of a registry can be assessed in four different aspects: completeness, timeliness, comparability, and validity.[105] To date, there is limited published comparison of these data outcomes across different lung cancer registries, making international registry comparisons somewhat challenging.[82,106]

The application of IS in low- and middle-income countries and structurally and financially diverse health care systems has been limited to date with barriers including understanding local needs, system readiness, leadership engagement, infrastructural support, readiness for research, and resource limitations in innovation, implementation, and sustainability.[107] Despite these barriers, published examples have demonstrated successful project outcomes and models for application in chronic respiratory disease while noting significant limitations in the availability of researchers to publish and disseminate successful findings.[108]

The understanding of patient preference in lung cancer management is critical to patient-centered care quality. When patients decline guideline-concordant cancer management, this response may not be well recorded in medical records and quality indicator attainment may be adversely affected.

DISCUSSION

In conclusion, the utilization of lung cancer registries provides a sociotechnical infrastructure that enables the

TABLE 3. Potential Quality Improvement Domains and Indicators in a Lung Cancer LHS[100]

Quality Domain	Potential Indicator	Reference
Safety	(1) Mortality within 28 days of commencing chemotherapy	8,61,73
	(2) Mortality within 30 and 90 days of surgery	
Timeliness	(3) Diagnosis achieved within 28 days of community referral	8,57,61,73
	(4) Treatment commenced within 14 days of diagnosis	
Equity	(5) Treatment access for those defined by sex, age, race, and ethnicity	18,57,113
	(6) Treatment access for those defined by socioeconomic disadvantage/regional residence	
Efficiency	(7) Presentation to a multidisciplinary team	8,57,61
	(8) Evidence of documented clinical stage	
Effective	(9) Adenocarcinoma diagnoses undergoing molecular diagnostics	57,61
	(10) Evidence of clinical and pathological stage concordance in surgically resected patients	
Patient centered	(11) Review by a lung cancer nurse specialist	8,73
	(12) Assessment of psychosocial distress undertaken	

Abbreviation: LHS, learning health system.

reporting of evidence of the quality-of-care delivery, equity, and unwarranted clinical variation in clinical practice by stakeholder centers. The evaluation of practice change solutions and the dissemination of innovation and implementation strategies target the evidence-practice gap and support cyclical improvement in performance within LHSs. This knowledge stimulates innovation and directs implementation of quality improvement strategies for knowledge translation and health care improvement.

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APPENDIX

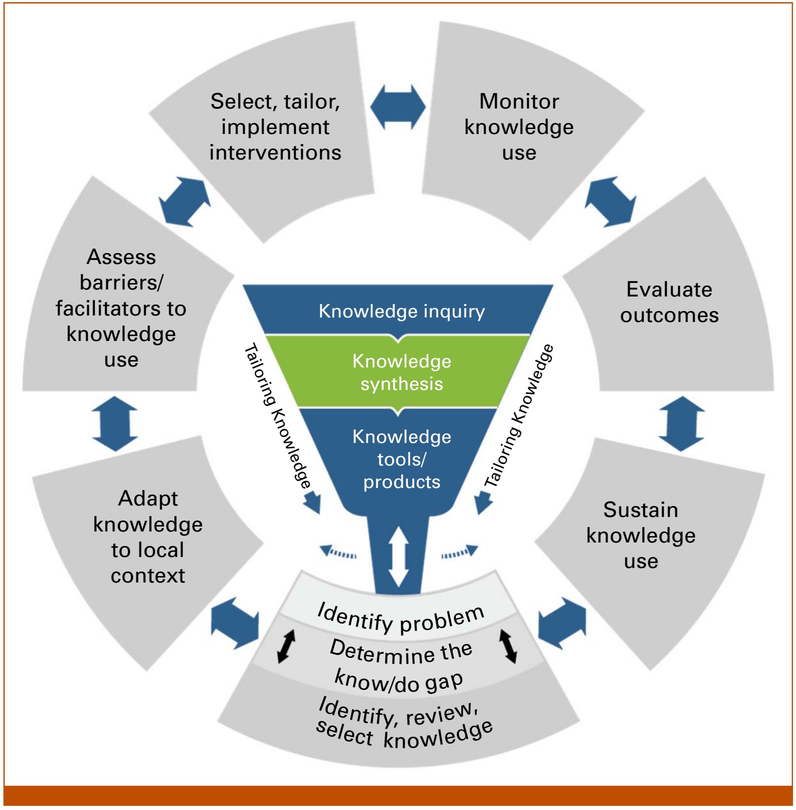

FIG A1. Knowledge to action cycle is composed of two distinct, but related components: (1) knowledge creation (central funnel) broken down into three phases: (a) knowledge inquiry, (b) knowledge synthesis, and (c) the creation of knowledge tools and products, and (2) the action cycle, which is an iterative process and includes the deliberate application of knowledge to enable change in behaviors and/or attitudes.[36]