2023

Supporting the implementation of lung cancer screening: **a focus on data management and programme evaluation**

Policy brief

LUNG CANCER POLICY NETWORK

This policy brief was written by the Lung Cancer Policy Network Secretariat and co-authored by members of the Lung Cancer Policy Network.

For a full list of members, please see: https://www.lungcancerpolicynetwork.com/members/

We would like to thank the following experts for sharing their knowledge with us in interviews:

- Professor Mariusz Adamek, Medical University of Silesia, Medical University of Gdańsk
- Professor David Baldwin, University of Nottingham
- Dr Joanna Bidzińska, Medical University of Gdańsk
- Professor Kate Brain, Cardiff University
- Angela Criswell, GO2 Foundation
- Dr Joelle Fathi, GO2 Foundation
- Professor Sam Janes, Lungs for Living Centre, University College London
- Professor Ella Kazerooni, University of Michigan
- Professor Stephen Lam, University of British Columbia
- Dr Andrea McKee, Lahey Hospital & Medical Center and Tufts University School of Medicine
- Dr Samantha Quaife, Queen Mary University of London
- Professor Witold Rzyman, Medical University of Gdańsk
- Dr Edyta Szurowska, Medical University of Gdańsk
- Professor Emeritus Martin Tammemägi, Brock University
- Dr Carey Thomson, Mount Auburn Hospital/Beth Israel Lahey Health, Harvard Medical School
- Douglas E. Wood, MD, University of Washington

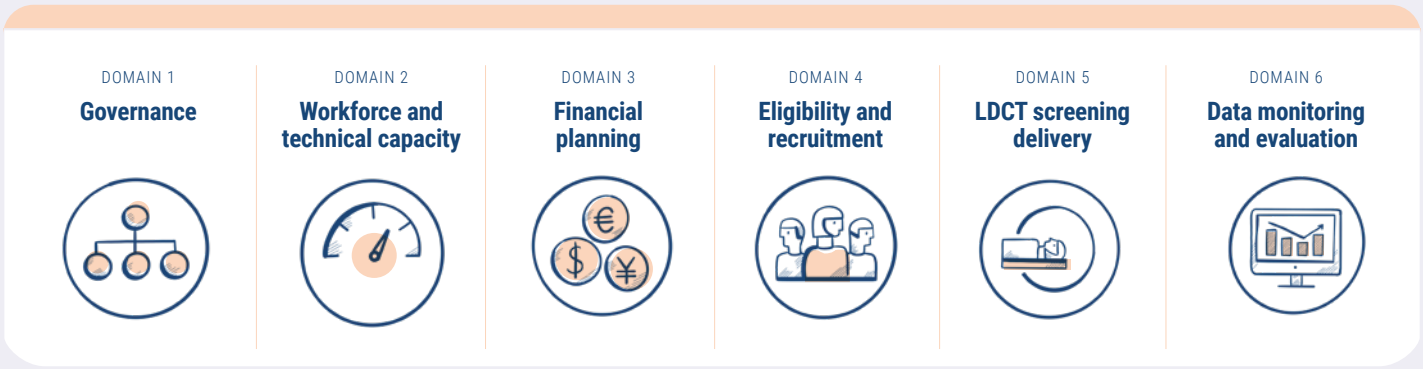
Please cite as: Lung Cancer Policy Network. 2023. *Supporting the implementation of lung cancer screening: a focus on data management and programme evaluation. Policy brief*. London: The Health Policy Partnership.

INTRODUCTION

The momentum for implementing targeted low-dose computed tomography (LDCT) screening programmes for lung cancer has gained pace over recent years, calling for careful consideration of how to optimise these programmes in terms of feasibility and public health impact. Setting up a lung cancer screening programme is complex, but a wealth of implementation research and a growing number of large-scale programmes continue to provide important lessons on how to optimise design and implementation.[1]

The Lung Cancer Policy Network has developed an implementation toolkit, which includes a framework to support those involved in the planning and delivery of lung cancer screening programmes. The framework follows a health systems approach and is organised into six domains, each consisting of a series of metrics. The metrics help users assess whether key requirements for screening are in place and identify gaps that may need addressing (*Figure 1*).

Figure 1. Six domains for assessing health system readiness for the implementation of lung cancer screening



This series of policy briefs explores the six core domains underpinning the implementation framework, with this brief focused on data management and programme evaluation. This brief provides key insights on requirements for data management, monitoring and evaluation of lung cancer screening programmes, presenting case studies from countries where implementation is underway. It also offers recommendations on how stakeholders and policymakers can support successful implementation.

ENSURING ROBUST DATA MANAGEMENT AND EVALUATION OF LDCT LUNG CANCER SCREENING: WHY IS THIS IMPORTANT?

Screening programmes are complex, requiring comprehensive and well-organised data management systems to encompass all aspects of a care pathway. Robust data are key to evaluating the success of the programme, assessing any risks, and determining the true impact of screening on population health.

This policy brief highlights some of the key considerations for health system leaders around monitoring and evaluating the quality and impact of lung cancer screening programmes.

Health system decision-makers must:

- **establish what data are important to capture** – to inform the development and governance of data management systems
- **ensure that data collected and systems used for screening are compatible** – to effectively monitor the programme and deliver consistently high-quality screening
- **plan how the screening programme will be evaluated** – to assess the impact of screening on population health.

Establish what data are important to capture

Health system leaders need to establish what types of data will be relevant across the screening programme and how they will be collected and managed effectively. Securing access to a range of different types of data is essential to facilitate the set-up of a screening programme;[2] for example, electronic health records will be required to identify people at high risk of lung cancer to enable recruitment for screening.[a 3 4] As a result, the volume and complexity of data collected can quickly become unmanageable, even for smaller screening programmes. Therefore, selecting or developing a robust data management system that can securely hold all personal and medical data for each participant will be a critical part of implementation.

Data management systems should facilitate the long-term follow-up of people participating in LDCT lung cancer screening programmes. Databases should notify staff and participants when appointments are due, and provide feedback to the healthcare professional who made the referral for screening.[3] They enable staff to monitor longer-term follow-up; for example, by tracking referrals for diagnostic workup for lung cancer or other conditions detected incidentally during screening. Ideally, they should also incorporate a way to reach people who do not attend (e.g. automated notification letters), which would support staff in managing capacity.[5]

Once the programme is underway, one of the biggest challenges is ensuring appropriate data governance and security. As different stakeholders will be involved in delivering screening, a process must be in place to govern how data collected can be standardised, securely managed and shared.[5] This may require agreements and processes to be established or expanded to integrate the screening programme and external data management systems (e.g. electronic health records in primary care).[4 6]

a. For other examples of relevant data, please see implementation resources for Domain 6 on the Lung Cancer Policy Network website.[2]

Ensure that data collected and systems used for screening are compatible

Screening programmes must establish mechanisms that will link different data management systems to facilitate effective monitoring of screening and clinical decision-making. The periodic reporting of data to an external body is often mandatory for the continual monitoring and evaluation of the programme.[7] To facilitate this, systems must be able to synchronise data captured by all sites that offer screening with records stored on a central network (*Case study 2*).[5] Exchange of data within programmes can also be an opportunity for multidisciplinary teams to provide virtual support for the clinical evaluation of results.[8] Finally, staff may need to access information stored in other hospital systems to monitor participant outcomes from screening, including incidental findings.[4]

Monitoring the quality of data collected is critical to ensuring that the screening programme is safe, effective and of consistent quality. High-quality data collection makes it possible to compare screening outcomes and draw reliable conclusions. Planning for quality assurance should take place early so that measures to help maintain agreed standards are fully integrated throughout the delivery of screening.[9-11] For example, using common templates to capture data from electronic health records (e.g. smoking history) may help improve the validity and completeness of information stored on each participant,[6] and ensure that screening is only offered to people at high risk of lung cancer.[4] Data collection in an LDCT screening programme can also be standardised by using a structured reporting system (*Case study 1*).

Establishing a common data management system across the screening programme can also be an opportunity to embed digital tools to guide clinical decision-making. Digital resources, such as decision aids or risk calculators, could be accessed by healthcare professionals during appointments and used to support participants in making an informed decision on whether to undergo screening.[4] Data management systems can also be used to facilitate virtual training for programme staff, while digital memos that summarise a participant's appointment history or the availability of services may help streamline

the onward referral process. There are numerous other benefits of having a shared data management system in place, such as the potential use of artificial intelligence (AI) to promote greater efficiency of screening.[12-14]

Case study 1

A structured reporting system for monitoring and evaluating LDCT screening results

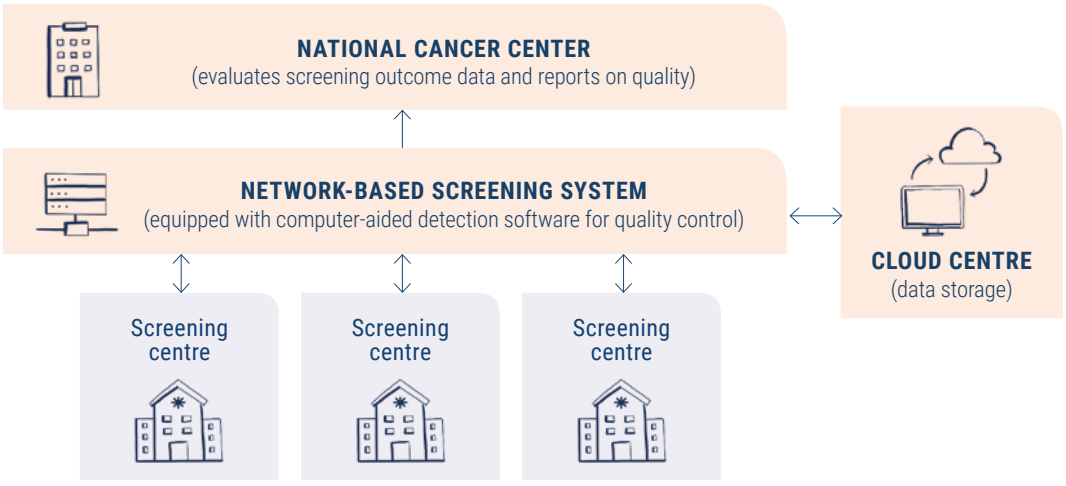
First developed in 2014 by the American College of Radiology, the Lung Imaging Reporting and Data System (Lung-RADS) is a standardised reporting system for the evaluation of lung nodules detected during LDCT screening.[15] The system comprises a structured framework that radiologists can use to determine and communicate the likelihood of any lung nodules detected on a computed tomography (CT) scan being lung cancer based on their size and position.[16]

The use of Lung-RADS has helped establish a uniform way of reporting the results from LDCT screening, facilitating comparisons across different programmes and promoting a more robust approach to evaluating outcomes from screening.[16] Some countries require programme sites that offer LDCT screening to use Lung-RADS to maintain their accreditation.[17] As a result, the system has been widely adopted by LDCT screening pilots and programmes across the world.[18]

Case study 2

Example of how data flow across a centralised network for LDCT screening[19]

In South Korea, LDCT scan data are exchanged with a centralised hub dedicated to quality control, which submits reports on programme performance to the National Cancer Center.[19-21]



Adapted from the system used for the Korean Lung Cancer Screening Project (K-LUCAS) national pilot in Lee *et al.* (2019).[19] Copyright © 2019 by the Korean Cancer Association.

Plan how the screening programme will be evaluated

Assessing whether screening is delivering its intended impact on population health requires appropriate measures for programme evaluation being in place. Examples of key measures for evaluating the short-term success of a screening programme include the participation rate and the proportion of lung cancers diagnosed at an early stage. Numerous other measures are also useful for identifying the areas of a programme that require periodic adjustments for quality improvement (*Table 1*).[9 20 22] However, it can take several years for the long-term impact on population health to become evident in population-based cancer registry data, such as a shift in the stage at which lung cancer is diagnosed and resulting improvements in lung cancer survival.[23-25] Benchmarks from other cancer screening programmes and establishing links to LDCT screening registries may provide helpful reference points for defining such indicators (*Case study 3*).[26-28]

The active participation of all stakeholders relevant to lung cancer screening in evaluation processes will make it easier to derive comprehensive and meaningful insights. Healthcare professionals involved in the delivery of screening can regularly work with a multidisciplinary steering committee to identify areas of the programme for quality improvement. Qualitative research involving both programme staff and participants can also provide useful insights on how to optimise the delivery of LDCT screening, including the recruitment process.[29-31] It is important that these evaluations include representatives from groups that may experience barriers to accessing lung cancer screening.[32-34] There are many examples of how this has been approached, such as co-producing evaluations with patient groups or community leaders.[b 35-39]

b. For other examples of community engagement, please see the policy briefs for Domains 1 and 4 on the Lung Cancer Policy Network website.

Table 1. Examples of types of outcomes that can be monitored and evaluated for lung cancer screening programmes

Types of data	Implementation outcomes	Service outcomes*	Participant outcomes	Population outcomes
Examples	Acceptability Adoption (and uptake) Appropriateness Cost-effectiveness Feasibility Fidelity (adherence to protocol) Sustainability	Effectiveness Efficiency Equity Person-centredness Safety Timeliness	Participation rate Stage distribution Mortality rate	Stage distribution Survival rate Demand for treatment Quality of life
Types of evaluation	Process evaluation (monitoring), operations research		Outcome evaluation	Impact evaluation

*Outcomes listed by the US Institute of Medicine's Standards of Care,[40] as examples.

Adapted from Proctor *et al.* (2011)[41] to provide examples that may be relevant to the evaluation of lung cancer screening programmes. Copyright © The Authors 2010.

Case study 3

Summary comparison of evaluation approaches

England

Targeted Lung Health Check (TLHC) pilot programme

TLHC pilot sites in England are organised by local integrated care boards (ICBs) that oversee primary care practices participating in the programme.[42] ICBs collect and submit data from screening to NHS England, which conducts a national evaluation of the TLHC programme.

At the population level, data from TLHC sites are submitted to the National Cancer Registration and Analysis Service, which registers all cases of cancer diagnosed and treated in the public health system in England.[31 43] The National Lung Cancer Audit uses this cancer registry data to assess how effectively lung cancer is being diagnosed (including cases detected through screening) and treated in hospitals across the country.[8 44]

USA

Lung Cancer Screening Program at the Lahey Hospital & Medical Center

Programme evaluation is carried out by a multidisciplinary steering committee.[45] Quality metrics are collected by the patient navigators, stored in a dedicated database and reported to the committee on a weekly basis. Data are reviewed by the steering committee every other month.

Patient navigators also oversee the submission of a range of programme data to the American College of Radiology Lung Cancer Screening Registry,[27] a registry that has been approved for the reimbursement of screening by insurance providers.[45]

KEY CONSIDERATIONS

to optimise data management and programme evaluation for lung cancer screening

Establish what data are important to capture

- Identify what data are required for each component of a screening programme to be fulfilled
- Establish data-sharing agreements and digital infrastructure to promote better access to the data needed for effective implementation

Ensure that data collected and systems used for screening are compatible

- Build in checks on the quality of data collected to ensure consistency throughout the screening programme
- Promote communication between different systems and providers to facilitate seamless data exchange
- Enable opportunities to leverage data management systems to guide clinical decision-making and optimise the efficiency of screening

Plan how the screening programme will be evaluated

- Establish benchmarks for monitoring and evaluating the performance of a screening programme
- Adhere to best practice when setting up, maintaining and reporting findings from a cancer screening registry
- Encourage the active participation of all relevant stakeholders in evaluation processes to derive comprehensive and meaningful insights

REFERENCES

1. Lung Cancer Policy Network. 2022. *Lung cancer screening: learning from implementation.* London: The Health Policy Partnership

2. Lung Cancer Policy Network. 2023. Domain 6: Types of data and potential requirements for setting up a screening programme. [Updated 31/03/23]. Available from: https://www.lungcancerpolicynetwork.com/app/uploads/Types-of-data-and-requirements-for-setting-up-screening-programme.pdf [Accessed 28/06/23]

3. McKee BJ, McKee AB, Kitts AB, *et al.* 2015. Low-dose computed tomography screening for lung cancer in a clinical setting: essential elements of a screening program. *J Thorac Imaging* 30(2): 115-29

4. Fathi JT, White CS, Greenberg GM, *et al.* 2020. The integral role of the electronic health record and tracking software in the implementation of lung cancer screening - a call to action to developers: a white paper from the national lung cancer roundtable. *Chest* 157(6): 1674-79

5. The UK National Screening Committee M, A. The screening in healthcare manual. [Updated 10/10/23]. Available from: https://nationalscreening.blog.gov.uk/2022/10/10/uk-nsc-screening-manual-describes-best-practice-for-national-screening-programmes/ [Accessed 24/01/23]

6. Modin HE, Fathi JT, Gilbert CR, *et al.* 2017. Pack-year cigarette smoking history for determination of lung cancer screening eligibility: Comparison of the electronic medical record versus a shared decision-making conversation. *Annals of the American Thoracic Society* 14(8): 1320-25

7. Kim HY. 2019. National lung cancer screening in Korea: Introduction and imaging quality control. *Journal of the Korean Society of Radiology* 80(5): 826-36

8. Royal College of Physicians. 2022. *National Lung Cancer Audit annual report (for the audit period 2019 England, Wales and Guernsey and 2020 England only).* London: Royal College of Physicians

9. Duffy SW, Smith RA. 2020. The evaluation of cancer screening: Concepts and outcome measures. *Med Clin North Am* 104(6): 939-53

10. NHS England. 2019. *Targeted screening for lung cancer with low radiation dose computed tomography: Quality assurance standards prepared for the Targeted Lung Health Checks Programme.* London: NHS England

11. National Cancer Center. 2021. *Quality guidelines for lung cancer screening.* Seoul: Ministry of Health and Welfare

12. Majewska M. Can artificial intelligence replace the radiologist? AI in lung cancer screening and teleradiology [Online]. [Updated 15/06/22]. *Puls Medycyny.* Available from: https://pulsmedycyny.pl/czy-sztuczna-inteligencja-moze-zastapic-radiologa-ai-w-skriningu-raka-pluca-i-teleradiologii-1153405 [Accessed 10/10/22]

13. The Health Policy Partnership, The Health Value Alliance. 2021. *Harnessing data for better cancer care: A policy report by All.Can International.* Brussels: All.Can International

14. Voigt W, Prosch H, Silva M. 2023. Clinical scores, biomarkers and IT tools in lung cancer screening: can an integrated approach overcome current challenges? *Cancers (Basel)* 15(4): 1218

15. American College of Radiology. 2022. Lung-RADS 2022. Available from: https://www.acr.org/-/media/ACR/Files/RADS/Lung-RADS/Lung-RADS-2022.pdf [Accessed 16/06/23]

16. Godoy MCB, Odisio E, Erasmus JJ, *et al.* 2018. Understanding Lung-RADS 1.0: A case-based review. *Semin Ultrasound CT MR* 39(3): 260-72

17. American College of Radiology. Lung Cancer Screening Center Designation. [Updated 09/03/23]. Available from: https://accreditationsupport.acr.org/support/solutions/articles/11000061040-lung-cancer-screening-center-designation-revised-11-9-2022- [Accessed 05/06/23]

18. Lung Cancer Policy Network. Interactive map of lung cancer screening (second edition). [Updated 30/06/23]. Available from: https://www.lungcancerpolicynetwork.com/interactive-map-of-lung-cancer-screening/ [Accessed 23/06/22]

19. Lee J, Lim J, Kim Y, *et al.* 2019. Development of protocol for the Korean Lung Cancer Screening Project (K-LUCAS) to evaluate effectiveness and feasibility to implement a national cancer screening program. *Cancer Res Treat* 51(4): 1285-94

20. Lee J, Kim Y, Kim HY, *et al.* 2021. Feasibility of implementing a national lung cancer screening program: Interim results from the Korean Lung Cancer Screening Project (K-LUCAS). *Translational Lung Cancer Research* 10(2): 723-36

21. Goo JM, Kim Y. A cloud-based computerized system for the Korean Lung Cancer Screening Project. [Updated 15/04/20]. Available from: https://www.ilcn.org/a-cloud-based-computerized-system-for-the-korean-lung-cancer-screening-project/ [Accessed 09/01/23]

22. Lewis JA, Spalluto LB, Henschke CI, *et al.* 2021. Protocol to evaluate an enterprise-wide initiative to increase access to lung cancer screening in the Veterans Health Administration. *Clin Imaging* 73: 151-61

23. NHS England, NHS Improvement, Public Health England. 2022. *NHS Cancer Programme: An introduction to approaches to evaluation.* London: NHS England

24. Yang C-Y, Lin Y-T, Lin L-J, *et al.* 2023. Stage shift improves lung cancer survival: real-world evidence. *J Thorac Oncol* 18(1): 47-56

25. Potter AL, Rosenstein AL, Kiang MV, *et al.* 2022. Association of computed tomography screening with lung cancer stage shift and survival in the United States: quasi-experimental study. *BMJ* 376: e069008

26. International Agency for Research on Cancer. 2019. The Cancer Screening in Five Continents (CanScreen5) project. [Updated 01/01/2019]. Available from: https://canscreen5.iarc.fr [Accessed 20/06/23]

27. American College of Radiology. Lung Cancer Screening Registry. Available from: https://www.acr.org/Practice-Management-Quality-Informatics/Registries/Lung-Cancer-Screening-Registry [Accessed 12/06/23]

28. Anttila A, Lönnberg S, Ponti A, *et al.* 2015. Towards better implementation of cancer screening in Europe through improved monitoring and evaluation and greater engagement of cancer registries. *Eur J Cancer* 51(2): 241-51

29. Spalluto LB, Lewis JA, Stolldorf D, *et al.* 2021. Organizational readiness for lung cancer screening: A cross-sectional evaluation at a Veterans Affairs Medical Center. *J Am Coll Radiol* 18(6): 809-19

30. Lewis JA, Chen H, Weaver KE, *et al.* 2019. Low provider knowledge is associated with less evidence-based lung cancer screening. *Journal of the National Cancer Network* 17(4): 339-46

31. NHS England. 2019. *Targeted screening for lung cancer with low radiation dose computed tomography: Standard protocol prepared for the Targeted Lung Health Check programme.* London: NHS England

32. McLeod M, Sandiford P, Kvizhinadze G, *et al.* 2020. Impact of low-dose CT screening for lung cancer on ethnic health inequities in New Zealand: a cost-effectiveness analysis. *BMJ Open* 10(9): e037145

33. International Agency for Research on Cancer. 2019. *Reducing social inequalities in cancer: evidence and priorities for research.* Lyon: IARC

34. Office for Health Improvement & Disparities. Health equity audit guide for screening providers and commissioners. [Updated 24/09/20]. Available from: https://www.gov.uk/government/publications/nhs-population-screening-a-health-equity-audit-guide/health-equity-audit-guide-for-screening-providers-and-commissioners [Accessed 23/06/23]

35. Cancer Australia. 2020. *Report on the lung cancer screening enquiry*. Surry Hills: Cancer Australia

36. Baldwin DR, Brain K, Quaife S. 2021. Participation in lung cancer screening. *Translational Lung Cancer Research* 10(2): 1091-98

37. Bartholomew K, Parker K, Crengle S. 2022. *Lung cancer screening update: April 2021.* Auckland: Waitematā District Health Board

38. Lung Cancer Policy Network. 2023. *Supporting the implementation of lung cancer screening: a focus on governance. Policy brief.* London: The Health Policy Partnership

39. Lung Cancer Policy Network. 2023. *Supporting the implementation of lung cancer screening: a focus on eligibility and recruitment. Policy brief.* London: The Health Policy Partnership

40. Agency for Healthcare Research and Quality. Six domains of healthcare quality. [Updated 01/12/22]. Available from: https://www.ahrq.gov/talkingquality/measures/six-domains.html [Accessed 11/05/23]

41. Proctor E, Silmere H, Raghavan R, *et al.* 2011. Outcomes for implementation research: conceptual distinctions, measurement challenges, and research agenda. *Administration and Policy in Mental Health and Mental Health Services Research* 38(2): 65-76

42. NHS England. Evaluation of the Targeted Lung Health Check programme. Available from: https://www.england.nhs.uk/contact-us/privacy-notice/how-we-use-your-information/our-services/evaluation-of-the-targeted-lung-health-check-programme/ [Accessed 19/12/22]

43. NHS Digital, National Cancer Registration and Analysis Service. CancerData: Staging data in England, 2019. [Updated 04/05/23]. Available from: https://www.cancerdata.nhs.uk/stage_at_diagnosis [Accessed 23/06/23]

44. Royal College of Physicians. National Lung Cancer Audit. [Updated 2022]. Available from: https://www.rcplondon.ac.uk/projects/national-lung-cancer-audit [Accessed 19/12/22]

45. American Thoracic Society, American Lung Association. 2019. *Lung cancer screening implementation guide.* New York: American Thoracic Society, American Lung Association

LUNG CANCER POLICY NETWORK

The Lung Cancer Policy Network is a global multi-stakeholder initiative set up by the Lung Ambition Alliance. The Network is funded by AstraZeneca, Guardant Health, Johnson & Johnson, MSD and Siemens Healthineers. Secretariat is provided by The Health Policy Partnership, an independent health research and policy consultancy. All Network outputs are non-promotional, evidence based and shaped by the members, who provide their time for free.