



# **Lung Cancer Policy Network**

Terms of Reference

October 2024

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# 1 The Lung Cancer Policy Network: overview

The Lung Cancer Policy Network (the Network) was initiated in 2021 by the <u>Lung Ambition Alliance</u> (LAA), a global coalition aiming to eliminate lung cancer as a cause of death around the world.

The aim of the Network is to create a lasting, international, multidisciplinary alliance of stakeholders who are engaged in making lung cancer a policy priority worldwide, helping drive meaningful change for people with lung cancer.

The Network is global in scope and includes patient and industry representatives, as well as representatives from ongoing lung cancer screening programmes, lung cancer coalitions, professional associations, public health and screening experts, and thought leaders on early detection and lung cancer epidemiology.

The Network contributes to the LAA's ambition of doubling lung cancer survival by advocating for the earlier detection of lung cancer and the optimisation of lung cancer care pathways.

#### 1.1 Mission and aims

The vision and mission of the Network can be summarised as follows:

- Vision. The Network is a global, multidisciplinary network of experts from across
  the lung cancer community that provides consensus-driven insights to accelerate
  policy engagement around the world, with the aim of driving efforts to increase
  survival from lung cancer.
- Mission. The Network drives political engagement to advance early detection, accelerate the implementation of successful lung cancer screening programmes and improve lung cancer care and survival for all patients.

The Network is intended to be a multi-year initiative with an ambition to continue to grow its membership, bringing together experts from around the world. Our aim is to support shared learning and promotion of best practice, and share insights to drive policy engagement.

#### 1.1.1 Core Network objectives

The objectives related to the Network's vision and mission are to:

- Create a unique, global multi-stakeholder alliance advocating for greater
  political awareness and action on lung cancer as a key opportunity to reduce
  mortality from lung cancer. This alliance aims to involve a wide range of
  healthcare professionals and public health experts engaged in cancer prevention
  and care, along with the research community, patient groups, insurers and
  industry.
- Create an independent, international learning community focused on generating evidence-based commentary, sharing lessons and building these into policy engagement.
- Help generate momentum around the implementation of lung cancer screening and earlier detection through ongoing communication and dissemination. The Network will specifically work to produce resources that

support countries in developing new approaches and materials. These include clear pathways to early detection and robust implementation plans that take a system readiness approach to assessing the resources required at country level.

- Support the development of optimal lung cancer care pathways, and further grow Network expertise, generating a strong evidence base to identify key gaps in lung cancer care and provide policy recommendations for addressing these.
- Help advance the overarching goals of the lung cancer community to gain political traction on lung cancer. The Network will feed into, and seek synergies with, other policy platforms. Together, they will help create political will to invest in early detection of lung cancer. This will contribute to national commitments to reduce mortality from non-communicable diseases (NCDs), enhance early detection of cancer and meet the United Nations' Sustainable Development Goals focused on NCDs.

# 2 Membership

### 2.1 Composition of the Network

Membership of the Network comprises those with an interest or expertise in lung cancer. The Network provides for the following categories of membership (for full details, see *Appendix, Table A*):

- Major/Minor Funders: include for-profit companies that contribute to the activities of the Network or make financial contributions, as either Major or Minor Funders; each funder is invited to nominate two representatives
- Patient Representatives: either as an individual representative or advocate, or as a representative of a patient organisation; organisations are invited to nominate two representatives
- Scientific Advisers, either as an individual or as a representative of a professional scientific organisation: organisations are invited to nominate two representatives
- Professional Organisations and Networks: these organisations are invited to nominate two representatives
- Clinicians with interest or expertise in lung cancer
- Other members: refers to all other Members of the Network.

No Network Members of any category are remunerated for their role in the Network (*Table 1*). Secretariat for the Network is provided by The Health Policy Partnership (HPP), an independent health policy research organisation.

# 2.2 Process for Network membership

Membership of the Network is open to individuals and organisations from around the world with an interest or expertise in lung cancer. Initial invitations to Members were made based on recommendations from the LAA partners and HPP's own stakeholder mapping.

Any existing Member can recommend further Members. Recommendations for additional Members, and applications from prospective Members, will be reviewed by the Network Steering Committee on a quarterly basis. The Secretariat will conduct the outreach to, and onboarding of, any new Members.

The Secretariat will provide a short application form to anyone interested in applying for membership. Applicants are asked to outline their preferred membership type, their areas of interest in the Network and their preferred affiliation.

#### 2.3 Role of Network Members

#### 2.3.1 Strategic direction

The Secretariat will work to ensure that all Members are involved in discussions and decisions linked to: strategic plans for the Network; the scope of Network activities; and governance of the Network.

#### 2.3.2 Network meetings

All Network Members are invited to quarterly Network meetings in which Network activities, strategy and direction will be discussed.

All Network Members will be invited to project-specific meetings, as required, to inform the scope and direction of key project activities and deliverables.

#### 2.4 Workstreams

As the activities of the Network evolve, its programmes of work will develop into multiple workstreams. The Network's first workstream focused on early detection with lung cancer screening at its core. The second workstream was developed in 2023 with a focus on optimising the entire lung cancer care pathway. Both workstreams will continue to be developed in 2025 and beyond.

The Secretariat will also conduct additional stakeholder mapping and outreach to ensure that these workstreams and associated outputs are informed by relevant expertise.

All Network Members are welcome to suggest activities that could be built into Network workstreams or other projects that the Network could contribute to, at any point during the year. A decision about whether to progress these activities will be based on review by the Steering Committee with consideration given to the alignment of the proposed activity to the Network strategy and the financial capacity of the Network.

# 3 Funding

# 3.1 Multiple company funding

Support from a broad range of companies is critical to ensure that the Network has strong external credibility as well as a sustainable funding base over several years.

The Secretariat leads engagement efforts to seek Funders for the Network. All Funders are asked to contribute to the core activities of the Network in the first instance and to contribute to supplementary activities based on the amount of overall funding available. As such, all Network outputs are considered to be co-funded equally by all Funders.

The sequence of supplementary activities to be undertaken will be discussed by the Steering Committee as new funding is secured and presented to all Members for approval.

All Funders are asked to sign a funding agreement with the Secretariat, which respects these Terms of Reference. They will also need to agree to the Memorandum of Understanding between Funders.

### 3.2 Funding tiers

Funders are listed transparently on Network outputs. Major Funders are currently defined as companies that provide at least £75,000 per year to the Network, while Minor Funders are defined as those providing up to £75,000 per year with a minimum commitment of £25,000 per year.

As of 2024, Major Funders are eligible to join the Network Steering Committee. Minor funders are ineligible to join the Network Steering Committee but are invited to join quarterly Network member meetings.

Funders may change tier each year, depending on their level of funding.

The funding level that constitutes the specific funding tiers is subject to change. The Secretariat will notify existing funders with at least 3 months' notice if funding requirements change.

#### 3.3 Member consultation on Funders

The Secretariat will inform all Members of any discussion with potential Funders at the quarterly Network meetings to ensure that there are no conflicts of interest.

#### 4 Governance

The Network is an independent, multi-stakeholder and non-promotional initiative, with its Members leading the scope and direction of its activities.

The Network Secretariat coordinates all activities, engages Members and new Funders, delivers Network activities and provides operational support for the Network. HPP will uphold the Terms of Reference and present to the Steering Committee a summary account of how funding for the Network is being spent (see *section 4.1*).

The Network's mandate and governance structure are reviewed on an annual basis.

At the beginning of each calendar year, the Network Members agree on and deliver activities in accordance with an annual workplan, which is presented by the Secretariat to the Steering Committee for initial approval. The workplan is then shared with all Members for their comments, input and final approval.

# **4.1 Expectations of Network Members**

#### 4.1.1 Terms of Reference

By agreeing to be Members of the Network, all Members, regardless of their membership type, agree to work with the Secretariat to achieve the Network's aims.

All Network Members, and the Network Secretariat, agree to abide by the Terms of Reference.

#### 4.1.2 Secretariat communications

Network Members grant permission to the Secretariat for routine correspondence and for notification of their endorsement and membership of the Network to be announced publicly.

Network Members grant permission for their email address to be added to the Network Newsletter database and to the virtual Member Hub so that they can receive Network communications.

#### 4.1.3 Network promotion

Network Members agree to promote awareness of and engagement with the Network to external stakeholders, wherever it is possible and appropriate to do so, with due consideration of the need to balance their other work and professional duties.

#### 4.1.4 Consent for recording of Network meetings

Network Members consent to the Secretariat recording quarterly Network meetings and working group or project-specific meetings solely for the Secretariat's internal use in drafting summary meeting minutes. The electronic files of these recordings will be the intellectual property of HPP as Network Secretariat. They will be held on a secure server and deleted after two years.

#### 4.1.5 Consent for recording and dissemination of externally facing activities

For externally facing activities, such as webinars or videos, Network Members will be invited to participate on a project-by-project basis and will be advised in advance whether the activity will be recorded and disseminated, to help inform their decision to participate. Consent will be sought for specific activities on a case-by-case basis.

By providing their consent, Members agree to recording and subsequent distribution of recordings and related materials by HPP as Secretariat of the Network.

Such externally facing activities will abide by the principles governing Network activity (see *section 5*).

The original and edited electronic files relating to these recordings will be held on a secure server and stored by HPP as Secretariat for two years. Final, edited recordings or videos may be made available online, in full or in part, on the Network's website, YouTube channel and social media (including, but not limited to, X (Twitter) and LinkedIn) in connection with the Network's activities.

Consent to this usage applies in perpetuity and participants acknowledge any unauthorised use of recordings or video by third parties is beyond HPP's control.

#### 4.2 Network Steering Committee

From 2024, by agreement of Network Members, the Network will work under the guidance of a Steering Committee. The Steering Committee will meet on a quarterly basis, reviewing the budget and providing recommendations on the direction of Network activities prior to the quarterly Network meetings.

To ensure appropriate representation from each category of Members, the Steering Committee is made up of Major Funders, Patient Representatives, Clinicians, and Scientific Advisers (see *Appendix, Table A*). Each Major Funder is invited to nominate two representatives. The Steering Committee should have two representatives from each of the other categories as listed above. The representatives can change on a yearly basis. The appointment term for Steering Committee representatives will be 1 year.

Network Members are invited to self-nominate to join the Network Steering Committee in relevant categories as listed above and in *Appendix, Table A*. Where more than one Network Member applies for a position, a vote will be taken by the Network to agree which member will join the Steering Committee. Where there are not enough nominations to warrant a vote, the appointment of the Steering Committee member will be via approval from the Secretariat. While organisations can have up to two representatives as Network Members, each organisation within the Network can vote once for a Steering Committee nominee.

Although only the Steering Committee is invited to provide regular review of the direction of Network activity, all Network Members are welcome to share Network activity suggestions for review at quarterly Network Member meetings. Network Members will contribute to discussions about the Network's activities and its contribution to and approval of outputs, which will be recorded at Network Member meetings by the Secretariat.

The Network Steering Committee supersedes the former Network Advisory Committee, which began in 2021 and continued to the end of 2023.

# 5 Principles governing Network activities

# 5.1 Objectivity and editorial control

The Secretariat aims to ensure that Network materials represent a consensus view from its Members and will therefore request comments and insight from Members to shape and develop these (for more information, see *Appendix*, *Table B*).

 Materials are defined as any report, publication, presentation, leaflet, social media posting, webpage, policy brief, video, webinar or speech that has been developed for the sole purpose of achieving the aims of the Network.

#### 5.1.1 Editorial control

- The Secretariat acts as independent chief editor, ensuring the highest editorial standards by leading a rigorous and evidence-driven editorial process of research and drafting. This process involves the integration of expert input, including from Network Members, to validate the content.
- Editorial review by Network Members will be invited for all major outputs of the Network (i.e. reports and publications).
- In the event of a disagreement among Network Members concerning the contents of the Network materials, the Secretariat will coordinate with the relevant parties to find a solution. If a solution cannot be reached, the Secretariat will refer the matter to the Steering Committee for a consensus decision.

- In cases where the content relates specifically to a Network Member, editorial input for Network materials related to the Network website or social media activity will be sought from that individual.
- There may be instances where a third party is commissioned or HPP works alongside a third party to deliver specific aspects of Network activity. In such cases, HPP shall retain editorial control across Network outputs and channels though shall not be responsible for materials distributed independently by the third party.

#### 5.1.2 Medical, Legal and Regulatory (MLR) compliance and review

- Editorial control for all Network content rests with the Secretariat.
- For the sake of clarity, no Funder or sponsor (nor their nominated representative)
  will have any right of editorial control over the outputs of the Network, and the
  outputs of the Network will not be subject to legal or scientific review by any
  Funder or sponsor.

### **5.2 Independence and transparency**

#### Independence

- All outputs of the Network will be non-promotional and no specific products or technologies will be listed.
- All Network activities and discussions should further the aim of the Network and comply with applicable laws and regulations.
- The Network will neither promote nor endorse the individual products or services
  of any of its Funders, either directly or indirectly. It will not be biased towards,
  promote or endorse the opinions of any of its Members.
- The Network will not accept funding that comes from individuals or industries that are contradictory to the Network's purpose, including tobacco-related industry funding.
- Network Members provide their time for free. Network Members may be offered reimbursement for reasonable costs incurred (i.e. travel and accommodation).

#### **Transparency**

- All core Network materials (report, publications, policy briefs, Network website)
  will clearly recognise the contributions of Network members and other
  contributing stakeholders.
- All core Network materials (reports, publications, policy briefs, Network website) will have a clear declaration naming all Funders, including Funder logos where appropriate.
  - This declaration will be updated each time a new Funder joins the Network.
     Any funder leaving the Network will be acknowledged as a Funder in public materials for a period of up to 3 months from the end of their involvement.
- As one of the key goals of the Network is to accelerate policymakers' adoption
  of lung cancer screening and early detection, all documents produced by the

Network will be released into the public domain and disseminated as broadly as possible.

## 5.3 Intellectual property

- All intellectual property rights for the work produced during the development, delivery and support of the Network, including but not limited to the Network materials, shall belong to HPP as Network Secretariat.
- All Network Members have the right to use and share Network materials.
  - Members may request permission to adapt materials (e.g. translation).
  - Members may not adapt or modify Network materials (including use of branding) without consent from the Secretariat.
- The Network materials are managed by the Secretariat on behalf of the Network.

#### 6 Contact details

#### **Helena Wilcox**

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# 7 Signatures

SIGNED for and on behalf of The Health Policy Partnership Ltd

Signature

Name: Rhiannon Lavin

Title: Operations Director

Date: 05/11/2024

# **Appendix**

# **Table A: Overview of Network membership categories**

Major/Minor Funders	Funders include for-profit companies that contribute to the activities of the Network or make financial contributions, as either Major or Minor Funders. Major Funders are eligible to join the Network Steering Committee, and are invited to nominate two representatives to the Network. Minor funders are invited to nominate two representatives to the Network but do not sit on the Steering Committee.	
	Patient Representatives can join either as an individual representative or advocate, or as a representative of a patient organisation.	
Patient Representatives	Patient Organisations are not-for-profit organisations which are patient focused. Each organisation is invited to nominate two representatives to the Network.	
	The Steering Committee will aim to ensure two representatives from this membership category.	
Scientific Advisers	Scientific Advisers may join either as an individual or as a representative of a professional scientific organisation. Each organisation is invited to nominate two representatives to the Network.	
	The Steering Committee should include two representatives from this membership category.	
Professional Organisations and Networks	Professional Organisations and Networks include organisational representatives from professional societies, organisations or networks. Each organisation is invited to nominate two representatives to the Network.	
Clinicians	The Steering Committee should include two representatives from this membership category.	
Other members	'Other members' refers to all other Members of the Network.	

**Table B: Review process for Lung Cancer Policy Network outputs** 

R = review requested

	Stakeholders involved in review		
Material	Secretariat	Network Steering Committee	Full Network
Major Network publications (e.g. Network report or policy brief) Network Members will be invited to review draft reports twice, with a week provided for each review		R	R
Core Network documents (e.g. Terms of Reference)	The Secretariat will act as chief editor for all Network materials and will have editorial control over all Network materials	R	R
Network administration materials (quarterly meeting agendas and slides, Network concept notes, quarterly updated slides, individual funding agreements)		N/A	N/A
Secretariat-generated Network website content (e.g. a news item to raise awareness of an upcoming publication or core website page content)		N/A	N/A
Collaborative website content (e.g. Network Member profiles or blogs, including Network Member quotes/insight posts)		R by individual Members	R by individual Members
Secretariat-generated social media content (e.g. X (Twitter) templates for Network Member use)		N/A	N/A
Interactive map (database)		R by individual Members	R by individual Members
Network events (event agendas)		R	R by individual Members
Network events (advertising materials, speaker briefs, communications plans)		N/A	N/A