Less Survivable Cancers Taskforce: Terms of Reference

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Purpose of document

This document outlines the governance and terms of reference of the Less Survivable Cancers Taskforce (LSCT). It is divided in two sections. Section 1 provides an overview of the work of the Taskforce, its aims, objectives, membership and resourcing. Section 2 sets out the terms of reference for specific subgroups, explaining their purpose, composition and other practicalities.

1. An overview of the Less Survivable Cancers Taskforce

1.1. What is the Less Survivable Cancers Taskforce?

The LSCT campaigns for government and health service action to improve outcomes and care for all people diagnosed with a less survivable cancer across the UK.

The 'less survivable cancers'— lung, liver, brain, oesophagus, pancreas, and stomach — all have a five-year survival rate of under 30%. Often referred to as 'cancers of unmet need', 'low survival cancers', or 'hard to treat' cancers, these six cancers are responsible for half of all deaths from common cancers and account for a quarter of cancer cases. Through more research, better treatment and earlier diagnosis, the LSCT aims to close the deadly cancer gap.

The LSCT was formed by six charities, referred to as the ‘LSCT founding members’, which support patients who have these cancer types. They are joined by ‘LSCT members’ to make up the wider LSCT and together we call for these cancers to be prioritised for positive action across the UK.

The founding members are (along with the cancer type they represent):

- Action Against Heartburn (oesophagus)
- The Brain Tumour Charity (brain)
- Guts UK (stomach)
- Liver Cancer UK (part of the Liver Trust, liver)
- Pancreatic Cancer UK (pancreas, present Chair and Secretariat)
- Roy Castle Lung Cancer Foundation (lung).

The LSCT drives UK-wide action through both the group as a whole as well as at a national level via Subgroups that focusing on Scotland, Wales and England.

1.2. Taskforce aims

The LSCT’s aim is to **secure prioritisation and targeted actions from governments and health services across the UK to improve outcomes and experiences for everyone diagnosed with a less survivable cancer**. To this end, the LSCT will work to secure the following actions:

- The establishment of clear improvement targets to drive progress, including doubling 5-year survivability in the next decade.
- Investment in early detection and faster diagnosis to save lives.
- Optimal pathways for everyone diagnosed with a less survivable cancer.
- A boost in research investment to achieve breakthroughs in diagnostic tests, treatments and symptom management.
- The development of targeted measurements for patient experience and quality of life for people with a less survivable cancer.

1.3. Taskforce objectives

- Raise the profile of less survivable cancers amongst policymakers and politicians and drive increased awareness about the need for action to improve outcomes and experiences for people with a less survivable cancer.
- Use insights from the charities alongside available data and research to develop policy proposals and evidence-based briefings with recommendations on how to improve survival and experiences for people with a less survivable cancer.
- Ensure representatives from the LSCT are on relevant governmental and NHS working groups across the nations, committees and boards to influence policymaking decisions.
- Monitor and respond to the political and policy environment to make the most of opportunities to influence policymaking with the aim of ensuring less survivable cancers are prioritised.

2. Governance, leadership and management of the Taskforce

2.1 Governance and decision making

The LSCT is overseen by its Board. This consists of one seat from each of the six founding members and the Chairs of the nation Subgroups. It is led by the LSCT Chair and supported by the Secretariat.

The Board members also have direction over the Taskforce's annual work programme and will discuss and agree this each year, with regular check ins for direction of travel. Meanwhile, subgroups will discuss the specifics of work in the nation to which they pertain, and decision making about tactics surrounding their own work programmes.

Should a founding member of the LSCT decide to stand down from the Board, another member can apply to take their place. This will be determined by a vote of the remaining Board members.

Decisions are made by the Board through voting and are passed if there is a two-thirds majority in favour; that is, four out of six members. All Board members will have a vote, but only the founding members will vote on topics relating to the structure of the LSCT itself. Votes will be conducted via the poll function on Teams during online meetings.

Where possible, founding members will be given advance notice of upcoming votes at Board meetings to ensure both quoracy and that all founding members are given the opportunity to be involved in decision making.

To be quorate, representatives of all six founding members must be present to vote. If a founding member isn't able to attend, a proxy vote may be used (through another representative attending) or official approval can be sought via email.

2.2 Chair, Vice-Chair and Secretariat

2.2.1 Roles and responsibilities

The **Chair** is held by the CEO or Director of a founding member charity, and this charity will also provide the Secretariat to the LSCT. The Chair of the LSCT is responsible for:

- Chairing Board and all member meetings of the LSCT
- Acting as a LSCT spokesperson at events, panels, and in the media, and signing off quotes
- Acting as the final sign off for any external reports or other significant publications
- Working with the Secretariat to raise funds for the LSCT.

The **Vice Chair** is appointed by founding member approval and can come from any founding member charity as long as it is different to that of the current Chair. The Vice-Chair of the LSCT is responsible for:

- Acting as a LSCT spokesperson at events, panels, and in the media, and signing off quotes
- Deputising for the Chair, in line with the responsibilities listed above.

The **Secretariat** is provided by the same charity which provides the Chair for the LSCT. Its responsibilities include:

- Managing and holding contracts with funders of the LSCT
- Managing the LSCT budget and finances
- Working with the Chair to raise funds for the LSCT
- Working with a consultancy to provide the administration for the LSCT, as well as policy, public affairs, and media capability
- Providing regular updates to the Board on the LSCT's financial position
- Proactively review LSCT materials to ensure these remain up to date.

2.2.2 Reviewing role postholders

The LSCT Chair, Vice-Chair and Secretariat postholders will be reviewed every 3 years by the Board. At the end of each 3-year term, any charity that is a **founding member** of the LSCT can apply to provide the Chair (and therefore also the Secretariat) or Vice-Chair roles, subject to a majority vote at a Board meeting.

A register will be kept on when roles were appointed and when they will be next considered for review.

Applications for Chair should cover:

- How the founding member proposes to resource the work of chairing and providing secretariat to the LSCT
- A clear proposal of how they would coordinate the logistics of the LSCT to provide these functions
- How the founding member would work to raise funds for the LSCT.

Applications for the Vice-Chair should cover:

- How the founding member proposes to resource the work of Vice-Chair of the LSCT
- How they would work closely with the Chair and Secretariat to provide leadership to the LSCT.

2.3 Consultancy support

The LSCT uses external consultancy to support the administration of the LSCT and deliver policy, public affairs and media work. This relationship is led by the Secretariat.

The contract for consultancy support will be considered for re-tendering every three years by the Board in line with best practice and to ensure value for money. This will be staggered timing-wise with the reconsideration of the Chair, Vice-Chair and Secretariat postholders so there is not too much change within the Board at any given time, and a level of consistency is maintained.

The incumbent consultancy is welcome to reapply for the consultancy support contract should the Board decide to retender this.

2.4 Membership

The LSCT is made up of founding members and members. Its approach to membership will be reviewed every three years to ensure it is sustainable and representative.

Any cancer charity that works on the less survivable cancers, either on an individual basis (e.g. work specifically on pancreatic cancer) or as part of their workstream (e.g. have a focus on the less survivable cancers within their work programme), can apply to join the Taskforce as a member.

Voting membership of the Board, however, remains open only to the six original members of the Taskforce. Subgroup chairs will still attend but will not vote on governance decisions. If at any point one of the founding members decides to step down from the Board, that vacancy can be filled by another member applying for Board membership, and this being approved by a Board vote.

2.4.1 All member meetings

All member meetings will be held at regular intervals throughout the year. They will be an opportunity for the whole LSCT membership to come together and hear relevant updates from the LSCT Chair and the Subgroup Chairs, and to discuss key issues together.

At one extraordinary all member meeting per year, supporting charities (see 2.5.4) will also be invited to attend to hear updates and be part of discussions.

2.4.2 Responsibilities of founding members

Founding charities are responsible for:

- Making time for a senior representative to attend Board meetings to input to the direction and activities of the LSCT, and vote on key decisions. The representative at the meeting should have the authority to make decisions at meetings.
- Supporting the LSCT on an ad-hoc basis as required, for example, by coordinating with case studies for media stories, by inputting evidence and insights to policy work, and by taking part in events and acting as a spokesperson.
- Setting and overseeing the development and delivery of the LSCT's annual workplan, including consultation with the wider membership.

2.4.3 Responsibilities of all members

All members of the LSCT, founding or otherwise, are expected to:

- Make time for all member meetings, and any Subgroup meetings they are part of.
- Take forward agreed actions within the timeframe agreed as a group. If unable to do so, members will communicate this in a timely way.
- Keep each other updated about relevant meetings we attend, including sharing outcomes, intelligence and actions arising that relate to the taskforce.
- Where possible and appropriate, feed into the development of LSCT outputs, such as reports, going out in the LSCT's name. The timeframe for contributions will be determined by the urgency of the request.
- Contribute to the development of the LSCT's annual plan, with aims and objectives, and align member organisation activity to this too, where mutually beneficial.

2.4.4 Supporting charities (non-members)

Where a charity supports the aims of the LSCT whilst not specifically focusing its work on the less survivable cancers, they have the option to become LSCT **supporting charities**. These may include, for example, generalist cancer charities.

These supporting charities will be able to support LSCT activities (e.g. events, report launches and campaigns) and will be kept up to date with these but will not be members and therefore will not be entitled to have a seat at Board, Subgroup or regular all member meetings. They will be invited to one extraordinary all member meeting each year, however, to receive updates and be part of discussions. No fees are payable to be a supporting charity.

Organisations can apply to become a supporting charity by contacting the LSCT Secretariat and stating the reasons they wish to join; a decision on this will then be taken at the following Board meeting.

2.5 Membership application process

2.5.1 Criteria for joining the LSCT

Any cancer charity that works on the less survivable cancers, either as the exclusive focus of its work (e.g. the charity works solely on pancreatic cancer) or as a workstream within its wider work, can apply to join the LSCT.

2.5.2 Admission process

Charities looking to join the LSCT must submit an expression of interest to the Secretariat. This will be considered and voted on by the Board at the next planned Board meeting following the application.

When they submit their expression of interest, the organisation must outline its suitability for the taskforce, as well as confirm its willingness to contribute financially. Meanwhile, the Board will take into consideration the following when discussing expressions of interest:

- The ability of the organisation to contribute to the LSCT (financially and resource wise) – i.e. can they contribute to at least one of the subgroups and attend Board meetings
- The number of organisations with a focus on the specific cause that are already members - ie ensuring balance. Does this organisation have a specific area of expertise/ interest that will add value (e.g. a focus on early diagnosis of a certain cancer site)
- Whether the organisation works across the UK. If not, does their expertise in one nation add significant value to the organisations who are already members?

2.6 Funding

2.6.1 Pharmaceutical industry funding

The LSCT receives most of its funding from the pharmaceutical industry. Pharmaceutical funders are kept up to date with the work of the LSCT, but do not have any control over the direction and activities of the LSCT to ensure independence.

The LSCT will always aim to have two or more pharmaceutical funders, as this reduces the reputational risk of being linked to one company.

2.6.2 Membership fees

The LSCT receives funding for its core work from its membership and aims for 10% of its annual income to be raised from membership fees, but this figure is purely for guidance. Should income from the pharmaceutical industry rise above £100,000, the Board will review this 10% figure as membership fees are not expected to increase proportionately exponentially.

The rate that members pay varies depending on whether or not they are a founding member and a therefore voting Board member and there is also a sliding scale linked to the annual turnover of each charity.

To keep the LSCT resourced but ensure costs remain affordable, we propose raising member contributions by 2% every year in line with expected inflation, subject to annual approval by the Board at the end of each financial year.

Founding members are expected to pay higher memberships fees that other members, and fees for the financial year 2025/6 are as follows:

Founding member charity contributions (FY 2026/27)				
Charity's annual turnover	Over £5 million	Between £1 - £5 million	£500,000 - £1,000,000	Less than £500,000
Expected contribution	£3,120	£2,160	£1,560	£480

Other members are expected to pay the following fees for the financial year 2025/6 (33% less than founding members):

Non-founding member charity contributions (FY 2026/27)				
Charity's annual turnover	Over £5 million	Between £1 - £5 million	£500,000 - £1,000,000	Less than £500,000
Expected contribution	£2,110	£1,447	£1,045	£322

2.6.3 Non-contributions and leniency

There may be exceptional circumstances in which a member charity may not be able to pay the full amount of their membership. If this happens, the member will be expected to raise this with the Chair and Vice-Chair at the earliest opportunity so that they can work together with the member to find a reasonable way forward that ensures the charity can remain a part of the LSCT. This may include (but not be limited to), a reduction in the amount owed.

The Chair and Vice-Chair will work with members on a case-by-case basis, and year by year. If a member requests financial assistant over two consecutive years, this will trigger a discussion about the feasibility of the member's continued membership.

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3. Subgroup operations

3.1 Role and operations of Subgroups

As health is a devolved policy area, the LSCT has developed Subgroups to drive progress in England, Scotland and Wales. The Subgroups action the agreed LSCT annual plan and respond to opportunities and challenges within each nation. They also feedback intelligence to the Board which helps shape plans.

While there is currently no Northern Ireland subgroup, OGCancerNI, a Northern Ireland oesophageal and upper-GI cancer charity, provides the LSCT with expertise and support when needed, alongside Pancreatic Cancer UK.

Subgroups are open to all members. A Subgroup Chair is elected by members of the subgroup by a two-thirds majority vote (one vote per organisation) and serves a three year term. The Subgroups are required to operate in line with the Aims and Objectives of the LSCT, and the parameters of the agreed annual plans. Any activity outside of this requires approval from the Chair and the Board.

The Subgroups Chairs each have a seat on Board so that they and the wider LSCT are aligned and informed in terms of insight, plans and activity. Other Subgroup members will be entitled to attend all member meetings.

The operations and outcomes of Subgroups will be regularly reviewed.

3.2 Scotland subgroup

3.2.1 Purpose

The purpose of the Scotland Subgroup is to keep less survivable cancers a high priority for the Scottish Government through a stronger united voice:

- To ensure that making progress in improving outcomes and experiences for people with a less survivable cancer in Scotland is a key priority for the Scottish Government.
- For members and supporters of the Less Survivable Cancers Taskforce to work together to make the most of the opportunities presented by the Scottish Government's Cancer Strategy to improve experiences and outcomes for people in Scotland living with one of the less survivable cancers.

3.2.2 Scope

The scope of the Scotland Subgroup is to provide a forum, through regular meetings and emails, for the charity representatives to:

- Ensure making progress to improve outcomes and experiences, including palliative care, for people with a less survivable cancer is a priority for the Scottish Government;
- Monitor and influence the implementation of the Recovery and Redesign Action Plan to ensure progress is being made to improve outcomes and experiences for people with a less survivable cancer;
- Share updates with and gather insight from other members to ensure a cohesive approach from a LSC perspective through the LSCT representative sitting on each workstream or directly to the Scottish Government's Cancer Policy Team;
- Gather additional insights and feedback from the working group's advisors on particular topics to inform the workstreams / Cancer Policy Team / Scottish Government.
- Laise and share updates with the Scottish Cancer Coalition and other relevant networks as relevant.

3.2.3 Meetings

The Subgroup will meet online monthly to share updates and insights to inform all the Scottish Government working groups. Additional ad hoc meetings may be agreed, and some monthly meetings may be deleted if there are no agenda items.

3.3 Wales Subgroup

3.3.1 Purpose

The purpose of the Wales Subgroup is to make less survivable cancers a high priority issue for the Welsh Government through a stronger united voice:

- Ensure that making progress in improving outcomes and experiences for people diagnosed with a less survivable cancer in Wales is a key priority for the Welsh Government and senior NHS leaders
- For members and the wider support network to collaborate on opportunities that arise through the development of the new Cancer Services Action Plan
- To strengthen the voice of people with a less survivable cancer, and the charities representing them, in policy development and with the Welsh Government and MSs.

3.3.2 Scope

The scope of the Wales Subgroup is to provide a forum, through regular meetings and emails, for the charity patient organisation representatives to:

- Drive a programme of work with MSs, the Welsh Government and policy makers that raises awareness of the need for targeted action to improve outcomes and experiences for people with a less survivable cancer in Wales.
- Strengthen the voice of people with a less survivable cancer, and the charities representing them, in policy development and with the Welsh Government and MSs.
- Convince the Welsh Government to prioritise action to improve outcomes and experiences for people with a less survivable cancer in Wales.
- Monitor and influence the implementation of the upcoming Cancer Plan to ensure progress is being made to improve outcomes and experiences for people with a less survivable cancer.
- Gather additional insights and feedback from the working group's expert advisors and patient advocates on particular topics to inform policy development.
- Liaise and share updates with the Wales Cancer Network and other relevant networks as relevant.

3.3.3 Meetings

The Subgroup will meet quarterly to share updates and insights and to drive forward joint work. Additional ad hoc meetings may be agreed.

Additional expert advisers may be invited to join the Subgroup as required.

3.4 England subgroup

3.4.1 Purpose

The purpose of the England Subgroup is to implement the decisions of the Board with Westminster, the Department of Health and Social Care and other relevant bodies.

- Ensure that making progress in improving outcomes and experiences for people diagnosed with a less survivable cancer in England is a key priority for Westminster and senior NHS leaders
- For members and the wider support network to collaborate on opportunities that arise through the implementation of the new National Cancer Plan
- To strengthen the voice of people with a less survivable cancer, and the charities representing them, in policy development and with the Welsh Government and MSs.

3.4.2 Scope

The scope of the England Subgroup is to provide a forum, through regular meetings and emails, for members to:

- Ensure making progress to improve outcomes and experiences, including palliative care, for people with a less survivable cancer is a priority for the UK Government;
- Monitor and influence the implementation of the National Cancer Plan to ensure progress is being made to improve outcomes and experiences for people with a less survivable cancer;
- Laise and share updates with Cancer 52, One Cancer Voice and other relevant networks as relevant.

3.4.3 Meetings

The England Subgroup will meet online monthly to share updates and insights on England-level work. Additional ad hoc meetings may be agreed.

Additional advisors may be invited to join the working group as required. The operations and outcomes of the group will be reviewed annually to ensure maximum impact.

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