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Description automatically generated**APPG on Less Survivable Cancers**

**Spotlight session on unlocking innovation: promoting a more research-friendly environment**

**Monday 12th May, 16.00-17.30, Portcullis House**

**Full list of attendees**

**Members**

* Paulette Hamilton, APPG Chair
* Charlie Maynard, APPG Co-Chair
* Lord Moylan, APPG Officer
* Allison Gardner, APPG Officer
* Lord Aberdare, APPG Member

**Speakers**

* Professor Eithne Costello - Professor of Molecular Oncology, Molecular and Clinical Cancer Medicine at the Institute of Systems, Molecular and Integrative Biology, Faculty of Health and Life Sciences, University of Liverpool
* Professor Peter Sasieni - Professor of Cancer Epidemiology, Centre Co-Lead for the Centre for Cancer Screening, Prevention and Early Diagnosis, Queen Mary University of London
* Nicola Nuttall - Trustee, Our Brain Bank

**Other**

* Josh Fenton-Glynn MP
* Gillian Rosenberg - NHS England
* Caitlin Eckley – Department of Health and Social Care
* Abigail Bateman - Pancreatic Cancer UK
* Helen Ross - Principle Consulting
* Valentina Garcia - Principle Consulting

# **Introduction to Session - Paulette Hamilton MP, APPG Chair**

# As Chair of the APPG on Less Survivable Cancers, Paulette Hamilton MP welcomed attendees to the spotlight session on unlocking innovation: promoting a more research friendly environment for the less survivable cancers. The less survivable cancers are pancreatic, lung, liver, stomach, oesophageal and brain cancer.

# Paulette Hamilton is the MP for Birmingham Erdington. Alongside her role on this APPG, she also sits on the Health and Social Care Committee and will shortly become its interim Chair.

# She gave a special welcome to the expert panelists in the room, and also the external observers who joined the session virtually. Paulette noted that the session was being recorded for note taking purposes.

# Paulette mentioned the recent conclusion of the mini-inquiry into earlier detection and faster diagnosis. The report will be published in early June. During the last session, researchers highlighted some of the challenges they face on a regular basis, including regulatory delays, the need for greater collaboration between the research and medical communities, and barriers in integrating new innovations into the NHS. The session was an opportunity to build on previous discussions with a focus on clinical trials and data.

# **Summary of Discussion**

# The roundtable, chaired by Paulette Hamilton MP, focused on the systemic challenges facing research into less survivable cancers particularly in early detection, clinical trials, data usage, and regulatory processes.

# The conversation opened with remarks that highlighted research on diabetes as a potential early indicator for pancreatic cancer, and the difficulty of engaging overstretched GPs in research. The need to simplify and incentivise participation in primary care settings was also emphasised.

# There was a call for large-scale early detection trials which require major structural reform and significant NHS infrastructure. A comparison was made between the streamlined systems and private investment in the US and the bureaucratic delays in the UK, citing issues like slow trial approvals and complex contracting.

# Concerns were raised about data access, privacy, and the implications of NHS structural changes. While the benefit of a centralised health system was recognised, questions were raised about whether planned reforms (e.g. the NHS England’s abolition) would improve or hinder research coordination.

# Technology readiness and resource disparities were also discussed, with the observation that well-resourced multinationals dominate UK trials while independent researchers struggle to gain access. The potential economic advantage of NHS-backed trials was emphasised, but long approval delays were noted to discourage innovation.

# The discussion focused at one point on glioblastoma, expressing concern about the opacity and inefficiency of funding decisions and calling for greater transparency and leadership. There was an emphasis on the need to preserve tumour samples post-surgery and leverage AI and genomic tools to advance treatment, pointing out significant regional disparities in research capacity.

# The conversation returned to data infrastructure and ethics, with accounts of years-long delays in obtaining cancer registry data and problems with overly complex consent frameworks. Attendees mentioned that early signs of pancreatic cancer are often missed because system-level signals are not integrated, and data is not routinely shared with researchers.

# The group also explored the use of mobile diagnostic units, building on success in Liverpool, and discussed the benefits of repurposing COVID-era infrastructure for national genomic and proteomic research programmes.

# **Key Challenges Identified**

**Overburdened primary care**: GPs lack time and incentives to engage in research.

**Structural barriers**: Bureaucratic delays in trial approvals; lack of research integration into NHS systems.

**Data access**: Fragmented, delayed, or overly restricted access to patient and registry data.

**Regulatory bottlenecks**: Complex and under-resourced approval processes.

**Inequities in access**: Disparities in clinical trial engagement, geographical gaps in sample collection.

**Lack of long-term oversight**: No consistent leadership or accountability for implementing change.

**Transparency and funding allocation**: Absence of clear oversight for where research funding goes.

**Consent complexity**: Ethical hurdles limit sample collection and long-term data use.

**Delayed adoption of innovations**: New technologies like AI-based detection and mobile units face slow uptake.

**Poor integration of genomics/proteomics into routine care**: Limited infrastructure for post-surgery sample freezing and tissue tracking.

**Proposed Solutions & Key Contributions**

* **Incentivise GP involvement**Simplify processes and compensate primary care teams for participating in early detection research.
* **Create NHS-based research clinics**Develop NHS-funded clinics with diagnostic capabilities (e.g. endoscopy, scanning) dedicated to research.
* **Improve trial infrastructure and funding**Reduce contracting complexity and use NHS scale to attract more trials.
* **Strengthen Data Integration and Timeliness**Speed up access to cancer registry data, simplify consent processes, and promote secure but efficient data linking.
* **Leverage Proteomics and Genomics**Go beyond genomics to proteomic analysis for early detection; integrate these into primary care datasets.
* **Implement Mobile Diagnostic Units**Expand mobile screening services (e.g. lung and pancreatic cancer) with appropriate equipment (e.g. freezers for tissue preservation).
* **Empower Patients and Improve Consent Frameworks**Make post-mortem donation and trial participation easier through streamlined consent and better patient communication.
* **Increase Transparency in Research Funding**Assign a named person to oversee and explain research funding decisions.
* **Build Research into Clinical Roles**The Royal College of Physicians should embed research time into NHS job plans.
* **Adopt AI and ‘Right to Try’ Principles**Be more open to new or non-standard treatments; prioritise patient access in terminal cases.
* **Establish Long-Term Accountability**Appoint a dedicated leader for a 5-year term to track implementation of cancer research reforms.

**Further Questions Arising from the Discussion**

**What has been the follow-up to the O'Shaughnessy Review?**Whether the Department of Health and Social Care (DHSC) or NHS is actively tracking and implementing the review’s recommendations.

**Is the current cancer registry fit for purpose?**Participants questioned whether it adequately captures essential data, such as radiotherapy, chemotherapy, and direct access metrics.

**Who holds responsibility for improving cancer data systems post-transition to the National Disease Registration Service (NDRS)?**There was uncertainty over leadership and accountability for registry reform.

**How can equity in screening, sample collection, and research participation be ensured across regions and income levels?**There is a need to address geographical and socioeconomic disparities.

**Can pandemic-era infrastructure (e.g. mobile testing units, central labs) be repurposed to support early detection research?**The possibility to reuse resources to accelerate progress in genomics and proteomics.

**How can consent frameworks be streamlined to balance ethical safeguards with research access?**The current inefficiencies require clearer, standardised processes.

**What regulatory reforms are needed to reduce bottlenecks in trial approval and data access?**

Concerns were raised about under-resourcing at the Health Research Authority (HRA) and the need to revisit its role and remit.

**What would a properly funded and coordinated national early detection strategy look like in practice?**A recurring question, reflecting consensus on the need for a more proactive, joined-up approach.