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## Baroness Tessa Jowell kickstarts Universal Cancer Databank project with data donation

Baroness Tessa Jowell DBE, former Labour Secretary of State for Culture, Media and Sport, has become the world's first cancer patient to volunteer her medical data to a new worldwide databank project, which aims to underpin the next generation of cures for rare and intractable cancers.

Signing a pledge at the House of Commons on Thursday, Baroness Jowell tasked the cancer research community and global governments with the responsibility to alleviate suffering and eliminate cancer by using donated patient data to improve drug discovery and quality of care.

"It is my hope that through my cancer journey and sharing of my data, we will be able to develop better treatments for cancer and speed up the discovery of new ones," said Baroness Jowell.

"I'm grateful to the Eliminate Cancer Initiative and all the people who have shown me such support since I learned I had a brain tumour. Together, with hope, we can achieve greater survival for cancer patients across the world."

Baroness Jowell, who is suffering from a rare brain tumour known as glioblastoma, has shown the same courage in battling cancer as she has in a career of political leadership, taking her personal cancer journey and transforming it into a mission to serve others.

Andrew Forrest, the Australian philanthropist leading the Eliminate Cancer Initiative's Universal Cancer Databank project, said philanthropists had responded to Baroness Jowell's challenge to collaborate by developing a 100% philanthropically funded, 100% global and 100% anonymised databank concept to serve cancer patients, incorporating world class data protection protocols.

"My motivation for establishing the Universal Cancer Databank is simple: the bravery, leadership and the challenge set out for us by patients like Tessa Jowell," Mr Forrest said.

"I am an entrepreneur not an oncologist, but I understand that extraordinary challenges require extraordinary measures. In this case that means patients and researchers from around the world sharing clinical and genomic data to break the gridlock on the most deadly cancers."

The long term survival rate for patients with glioblastoma has remained at only around 5% worldwide since the 1970s. While more common cancers have seen dramatic improvements in care in recent decades, rare cancers like glioblastoma are now the cause of the majority of cancer deaths.

The Universal Cancer Databank aims to combat that problem, by offering patients the universal right to donate their data to research.

The UCD has emerged out a series of landmark national Brain Cancer Missions recently launched in the UK, China and Australia, as the governments of those countries recognise that brain cancer sufferers are being left behind, and that new global collaboration is necessary to progress research.

So far those missions have raised GBP110 million towards a global goal of GBP 500 million, including over GBP 7 million from the Minderoo Foundation, to develop new international collaboration around brain cancer, including data sharing and the launch of a major adaptive clinical trial for glioblastoma.



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Discussions on the Brain Cancer Mission and UCD project have included conversations with health department heads from Australia, United Kingdom, China, and the US, as well as peak bodies including The Brain Tumour Charity (UK), Cure Brain Cancer Foundation (Australia), National Brain Tumour Society (US) and the National Foundation for Cancer Research (US).

Leading technology, pharma and research centres such as the Broad Institute of MIT and Harvard, the Dana Farber-Cancer Institute, the Sanger Institute, Cambridge University, Celgene, Ellipses Pharma, 360 Oncology and China's Glioma Genome Atlas have also expressed their commitment to collaborate with ECI on this ground-breaking initiative.

"Cancer patients have demonstrated a clear desire to partner directly with researchers and share their data to help accelerate cures," said Dr. Nikhil Wagle, MD, an associate member at the Broad Institute. "Again and again, these men and women are volunteering their medical data and their stories – and want reassurance that researchers around the world will use this information to make a real difference. We applaud projects like the Universal Cancer Databank, which help ensure this kind of critical information will be widely available to scientists in the search for treatments and cures."

"ECI's visionary approach will help us more rapidly pave the way for novel therapies and shape the future of cancer care," said Paul Richardson, MD, Clinical Program Leader and Director of Clinical Research, Jerome Lipper Multiple Myeloma Center, Dana-Farber Cancer Institute.

"It is vital that the community comes together to learn from the past and provide all scientists and clinicians with access to high quality data in order to defeat cancer," said Professor Richard J. Gilbertson, Director, CRUK Cambridge Centre at Cambridge University.

"We commend ECI on driving toward better patient outcomes and expedited drug discovery," said Mark J. Alles, CEO of Celgene Corporation.

The UCD project aims to connect a range of existing and developing database projects into a unified databank, including the UK's landmark BRIAN database, led by Britain's major brain tumour charity.

"We know that data is key to unlocking a cure for brain tumours. We also know that most people affected by the disease are ready and willing to share information about their diagnosis and experience," said Sarah Lindsell, chief executive of The Brain Tumour Charity.

"Many have already done so through The Brain Tumour Charity's web-app, BRIAN (the Brain Tumour Information and Analysis Network). We welcome the ECI's commitment to developing a Universal Cancer Databank and we are delighted that it will operate in collaboration with BRIAN to maximise the benefits of data-sharing for those around the world who are diagnosed with a brain tumour."

The UCD will gather medical information on patients, and then combine that with individual patient genome sequencing and profiling. The UCD will be a global repository of patient data that is modular, open source, community-driven and provides standardized data for interoperability. The UCD is slated to first serve as the technology behind the landmark GBM AGILE adaptive brain cancer trial, due to launch later this year, and will then serve as a platform to accelerate collaboration and research across all cancers. ENDS.

*Make your pledge or find out more at: <https://ucd.eliminatecancer.org/>*

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