
Scientists' search to uncover genetic secrets of rare and aggressive cancer could drive understanding forward by decades

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The mysteries behind one of the most aggressive but least understood forms of cancer are set to be unravelled thanks to a major new piece of research at UCL (University College London).

A team of 35 scientific experts from across the UK will join forces to investigate approximately 1,000 genetic samples collected from the 100,000 Genomes Project. The samples taken focus on sarcoma, an uncommon cancer of the bone and soft tissue that can affect any part of the body.

Over the next three years, the Sarcoma Genomics England Clinical Interpretation Partnership (GeCIP), aim to find answers to some of the most fundamental questions about the cancer that is diagnosed in 15 people a day in the UK.

Professor Adrienne Flanagan from the UCL Cancer Institute is leading the research project. She says: "What we have now is a major opportunity to get an unprecedented understanding of sarcoma cancer on a molecular level.

"Our lack of knowledge surrounding the different sarcoma subtypes on a genomic basis and the way they develop and evolve, has led to a current treatment vacuum for the disease. The funding from Sarcoma UK is a catalyst that enables us to look at all sarcomas and analyse what happens across all subtypes.

"We're hoping that this research will enable us to better identify patients who are suited to specific targeted therapies, provide personalised medicines and offer clinical trials."

Funded by the national bone and soft tissue cancer charity Sarcoma UK, the research will allow the GeCIP team to examine and catalogue the breadth of variation in genetic mutations in sarcoma for the first time. Like other cancers, sarcoma is caused by changes in the genetic code, similar to spelling errors in the instructions for a person's genetic make-up.

It is hoped that having data from the samples - the largest ever collection of its kind internationally - will make genomic patterns or trends far easier to spot. The data will also give researchers a valuable insight into how sarcoma develops resistance to drugs and treatments. Any new understanding of the disease will be used to drive improvements in personalised treatments and targeted therapies for patients, and ultimately increase the chances of surviving sarcoma in the long term. Currently the five-year survival rate for sarcoma in the UK is 55%.

The resulting comprehensive library of genetic alterations in sarcoma formed by the end of the research will provide a crucial resource for researchers studying sarcoma in the future, as well as a platform for chemists and pharmacologists in their development of new drug strategies.

A combination of factors currently make sarcoma difficult to diagnose, treat and manage. The cancer can occur in any part of the body, both visibly or internally in the body, where it can grow unnoticed. There is a general lack of awareness of the cancer and an overall lack of investment in research. In addition to this, clinical trials into

treatments for sarcoma are seen as a less viable prospect for pharmaceutical companies because of low incidence rates of sarcoma spread even further across the cancer's numerous subtypes.

Richard Davidson, Chief Executive of Sarcoma UK, says: "This is one of the most important pieces of research looking into a cancer that historically has been frequently overlooked. The amount we can learn from this piece of research and the impact it could have on the thousands of people affected by the cancer in the UK and beyond is vast.

"Our understanding of sarcoma lags far behind that of the more common cancers, so this is a genuine opportunity to bring together some of the top minds in sarcoma research to work collaboratively to tackle this neglected cancer."

Notes to editors

For further information, please contact Bevis Man, Communications Director at Sarcoma UK: bevis.man@sarcoma.org.uk or 07931 254 697.

Background to the research project

The full title of the research project is 'GeCIPing Sarcoma: A UK-led initiative to personalise sarcoma treatment.' The UK Government initiated the 100,000 Genomes Project, which involved sequencing 50,000 genomes from patients with cancer. Collection of the approximate 1000 sarcoma samples from this was completed in December 2018.

About Sarcoma UK

Sarcoma UK is a national charity that funds vital research, offers support for anyone affected by sarcoma cancer and campaigns for better treatments. It is the only cancer charity in the UK focusing on all types of sarcoma and is one of the largest funders of sarcoma research in the UK, having invested more than £2million into research to date. sarcoma.org.uk

About UCL (University College London)

UCL was founded in 1826. We were the first English university established after Oxford and Cambridge, the first to open up university education to those previously excluded from it, and the first to provide systematic teaching of law, architecture and medicine. We are among the world's top universities, as reflected by performance in a range of international rankings and tables. UCL currently has over 41,500 students from 150 countries and over 12,500 staff. Our annual income is more than £1 billion.

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About sarcoma

- Sarcoma is cancer of the bone and soft tissue and is more common than previously thought. In 2015 there were 5345 people diagnosed with sarcoma cancer in the UK.
- There are three main types of sarcoma: soft tissue sarcoma, bone sarcoma and gastrointestinal stromal tumours (GIST).
- Sarcoma diagnoses now make up about 1.3% of all cancer diagnoses in the UK.
- The majority of people are diagnosed when their sarcoma is about the size of a large tin of baked beans (10cm).
- Sarcoma survival rates have been very gradually increasing over the last two decades in the UK.
- Almost eight in 10 people (78%) diagnosed with sarcoma in the UK will live up to a year.
- The five-year survival rate for sarcoma is 55%.