



## Oracle Cancer Trust Research Strategy

Oracle Cancer Trust (Oracle) was founded in 2000 to address the medical research and delivery gaps facing Head & Neck cancer patients in the UK. Since then, Oracle has been a leading UK funder of early-stage medical research in Head & Neck Cancer. The charity has supported over 50 research programmes and provided over £7million in funding towards better outcomes and more advanced treatment approaches in this area of cancer. Our successes include improved delivery of radiotherapy, reducing the legacy of lifelong side-effects and pioneering advances in immunotherapy.

Over the course of Q4 2021 and Q1 2022 Oracle conducted a market listening exercise to gather input into where the greatest areas of need are in Head and Neck Cancer, to understand where other organisations are operating and to identify where the gaps are. This included a patient and caregiver survey (156 participants) and a healthcare practitioner (46 participants) survey. Through this exercise we realised that there is still much to do. Head and Neck Cancers are under recognised, underfunded and have significant unmet diagnosis and treatment advance possibilities. Yet the numbers of patients are growing within the UK and global populations.

Today Head and Neck Cancers are the 4th most common cancer in men in the UK and the 6th most common cancer for all population groups in the world. There were an estimated 12,400 cases of Head and Neck Cancer diagnosed each year in the UK according to the latest CRUK data from 2018<sup>1</sup>. Although still a relatively rare area of disease the awareness of Head and Neck cancers is significantly below where it should be in comparison to other cancers and healthcare conditions. There is very little understanding of Head and Neck cancer symptoms, most at risk population groups and best treatment approaches not only amongst the general public but also amongst primary care practitioners (PCPs), dentists and other medical care professionals. In the UK, many Head and Neck Cancer Multi-Disciplinary Teams within the NHS are frustrated by a lack of funding and awareness to help unblock areas of inefficiency and help ensure that patients are diagnosed as early as possible, have quick access to the best treatment approaches and have high quality of life outcomes.

This lack of understanding of Head and Neck Cancers is confounded by unique complexity amongst Head and Neck Cancers. Tumours can present in 14 different physical sites of the Head and Neck and can comprise of 30 different cancer types/tumour strains. Diagnosis can require biopsies or other imaging scans and treatment can include surgery, robotic assisted surgery, chemotherapy, immunotherapy, radiotherapy etc with many patients experiencing debilitating speech, eating and respiratory problems as well as psychological effects of loss of function and change in body image.

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<sup>1</sup> CRUK

The deficit in funding and therefore research into new treatment approaches is amplified by the lack of data, analysis and learnings from existing diagnoses and treatment outcomes in the UK because there is no national Head and Neck Cancer Audit within the NHS.

The good news is that an estimated 88% of head and neck cancers are preventable in the UK. Positive outcomes are correlated to early diagnosis and quick access to treatment. However the lack of awareness, socio-economic barriers and deprivation are all contributing to delayed diagnosis. In England cases in females are 64% higher in the most deprived quintile, and in males are 101% higher in the most deprived quintile (2013-2017). COVID-19 has widened these gaps even further and the NHS is struggling to respond, leaving many communities behind.

Whilst the situation around Head and Neck Cancer is worrying, Oracle believes that there are many areas where positive impact can be realised and many individuals, partners and communities who have projects waiting for funding. In specific the charity has decided to focus on three key areas;

- Increasing awareness of Head & Neck cancers in the wider community
- Supporting service delivery innovation within NHS Head & Neck cancer centres
- Promoting discovery of better treatments through research grants.

### **Research Strategy**

Oracle's research strategy is aligned with our charity's vision and strategy and aims to clearly set out the areas of research, service delivery and project scope that Oracle will support and fund. This will also shape our fundraising strategy and impact monitoring. Perhaps most importantly, the research strategy and decision-making aims to incorporate the input of the wider UK Head and Neck Cancer community and in particular Head and Neck Cancer patients, survivors and carers. Our stakeholders and the community are the heart of everything we do.

In the course of development of this Research Strategy we gathered input of 156 patients and carers, 46 Healthcare Practitioners, 13 other key Head and Neck Cancer charities via the UK Head and Neck Cancer Coalition and via discussions with various industry partners.

This document lays out Oracle's Research Strategy for the five years between 2022 - 2027. At the time of writing (June 2022), Oracle is funding ten pioneering head and neck cancer research projects on a range of exciting topics. The aim is to continue to grow and invest in key impact projects but with a broader scope and range to reflect the pronged purpose and strategy of the charity as outlined above.

With the aim of addressing the key areas of need identified, Oracle Cancer Trust would like to focus its research and funding in areas that address and improve the Inequalities in Head and Neck Cancers. Areas that we see falling under this area could include:

- **Better data and more awareness highlighting the inequalities in Head and Neck Cancers:** Head and neck (H&N) cancers, particularly non-HPV related cancers, have a social gradient in both incidence and mortality, with the most disadvantaged groups having higher incidence and mortality rates. In particular populations that are characterised by lower socioeconomic status, high tobacco/betel leaf usage, poor oral hygiene and certain ethnic minorities seem to have higher prevalence of these tumours. Although initial research has been undertaken to understand socio economic and ethnic risk factors in Head and Neck cancer, there is a

significant and noticeable gap in data to guide where and how this can be addressed. Diagnostic, treatment and post-treatment resources are also very variable by postcode across the UK with some centres offering the best, most comprehensive and fastest services available and other hospitals delivering outdated, slow and very poor services altogether. Data driven and evidence based approaches to reduce this inequality needs to take place but first we need the data to be collected and analysed. This will help provide input into policymaking, treatment and pathway reviews and patient support programmes.

- **Understanding and Treatment Advances for Rare and Hard to Treat Head and Neck Cancers:** HPV positive Head and Neck Cancers have received positive attention and funding in recent years. This has been hugely positive and will over the medium term significantly reduce the occurrence of this subset of Head and Neck Cancers. These cancers also often have a positive prognosis, generally responding favourably to radiation and anticancer drugs. Unfortunately the more complex and lesser well known HPV negative Head and Neck Cancers are more associated with unfavourable prognosis and in many cases are still being treated with standard care approaches, including highly invasive surgery, chemotherapy and radiation. Although significant advances have been made in recent years, including the use of immunotherapy and robotic assisted surgery, there is still a significant gap of knowledge and research into how best to treat the more rare cancers such as ACC, paranasal sinus cancer, nasal cavity cancer etc. The quality of life for these patients is inadequate leaving patients with debilitating speech, eating, swallowing and/or respiratory problems as well as psychological effects of loss of function and change in body image. Many of these outcomes are life changing and can be permanent.
- **High risk community awareness campaigns:** Awareness campaigns are KEY to early detection for all cancers including Head and Neck Cancers. Oracle is working with a coalition of other Head and Neck Cancer charities to push the Government to create greater national awareness campaigns similar to those that have been run for other cancers such as Breast Cancer. If taken forward these have the potential to raise awareness not only amongst the general public but amongst GPs and Dentists. Even if the coalition is successful this will take time to put in place and will be rolled out at a national level. Local and targeted campaigns need to be run in parallel if the most at risk groups are to be reached. Change requires repeated messages and ongoing efforts; it does not result from a single message. Community focused awareness campaigns need to ensure a focus on inclusivity so that traditionally hard to reach groups are not left further behind. This should include consideration of location, format, content, language and mechanism of delivery. There should be engagement with Ambassadors in hard to reach groups in areas of high Head and Neck Cancer prevalence to understand concerns, issues, barriers and opportunities for greater engagement.
- **Research that leads to EXISTING treatment approaches resulting in better outcomes and quality of life for patients:** There is significant opportunity to improve existing treatment approaches by focusing on quality of life vs survivorship in outcomes. There have been significant advances in recent years driven by research that has introduced immunotherapy and increased use of robotic assisted surgery for Head and Neck Cancers but these are not yet available to all patients in all centres. There is much more that can be done to reduce toxicity and have more targeted delivery of radiation treatments and there are opportunities to take more personalised and less invasive approaches to surgery. Promoting and supporting new innovations that achieve these objectives is a key focus of Oracle's research.

- **Research that leads to NEW kinder treatments and better quality of life outcomes:** In addition to improving existing treatment approaches there is opportunity to research and innovate around new cancer drugs and other novel therapies. Access to these treatments needs to be across all population groups and patients regardless of their postcode.

### Quality assurance

Oracle Cancer Trust are members of the Association of Medical Research Charities (AMRC) which is our badge of quality. Membership means that we meet high standards of research governance and as a funder we punch above our weight. Much of our work has been carried out in collaboration with some of the UK's leading scientific research institutions including the Institute of Cancer Research, Bart's/Queen Mary's University, Newcastle University, The Royal Marsden Hospital, and Brunel University.

In addition, we strive to meet the highest standards as a responsible research funder. For us this means:

- 1) We focus on areas where there is a clear lack of existing funding; we do not replicate or duplicate funding in areas where significant funding already exists.
- 2) We invest only in projects that we believe will be run with high levels of governance, transparency and research best practice. As part of this we conduct due diligence on the research centres we work.
- 3) We fully assess all research proposals, taking a balanced approach to our assessments with appropriate levels of expertise and review.
- 4) Our projects all support Oracle's strategy and objectives and therefore support and promote the charity purpose and mission.
- 5) We support and fund a range of innovative projects with balanced diversity of types, geography and focus.
- 6) We fund projects that can demonstrate high potential to progress or positively impact clinical treatment for patient within the NHS and/or will provide a public health benefit.
- 7) We actively engage and communicate with our researchers, donors, patients and the wider Head and Neck Cancer community to ensure that our processes and decision making reflects the inputs of our community.
- 8) We collect data and report on our impact, ensuring that we track whether and how our research is making a difference. This helps inform future research strategy and provides concrete benefits to share with the public and key stakeholders.
- 9) We are transparent and rigorous in our approach to dealing with conflicts of interest. We ensure that our scientific advisory panels and experts remain objective in helping us select, monitor and review research programmes.
- 10) Ensure that everything we report on provides information both to medical professionals and the wider Head and Neck Cancer community so that the full stakeholder community can see where, how and what the value of Oracle's funded work is.
- 11) We aim to fund projects that demonstrate a value for money both in terms of feasibility and realism in terms of downstream implementation and being appropriately resourced and costed to deliver on the research objective. We ask researchers to provide us with metrics that allow us to review and monitor to this end.