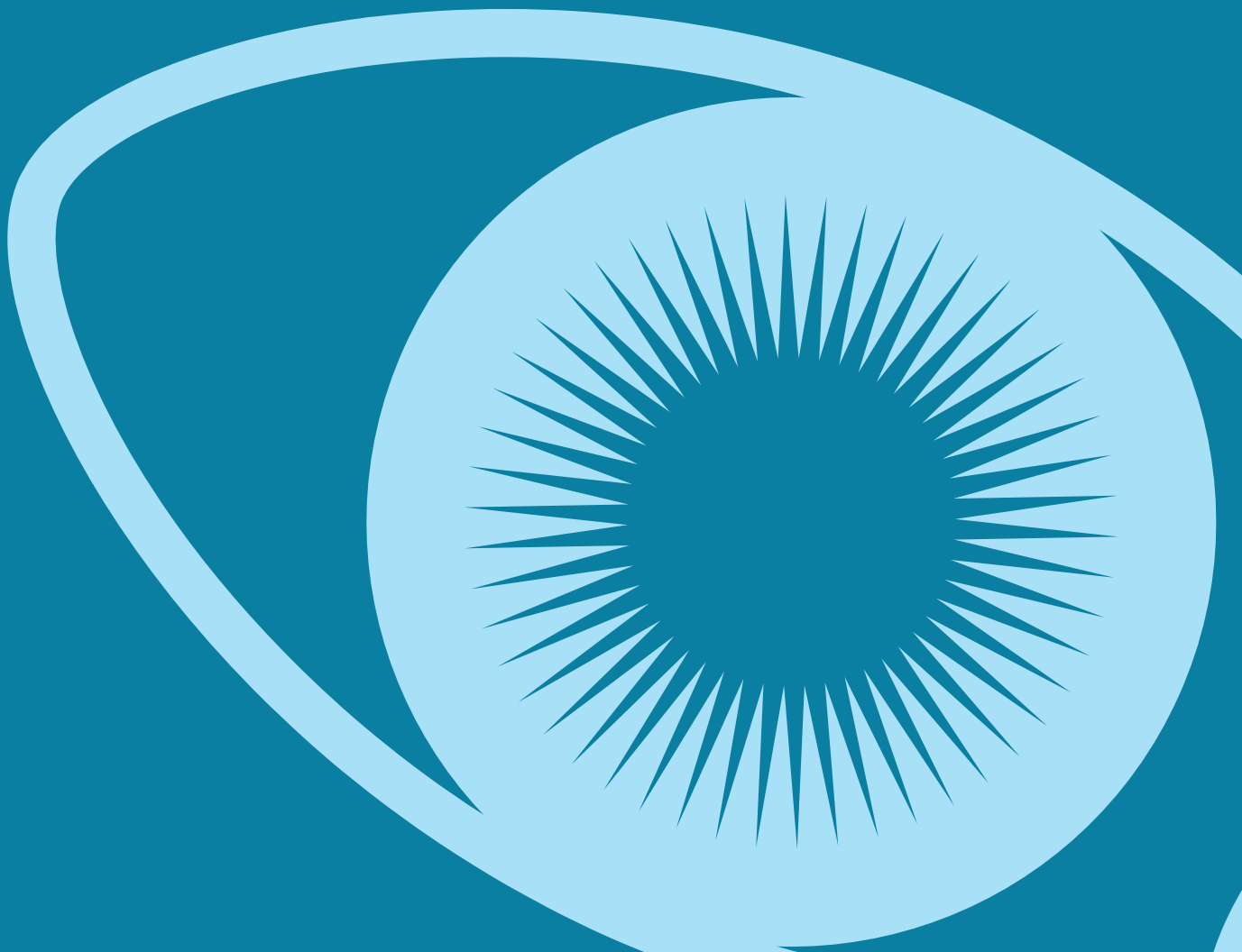
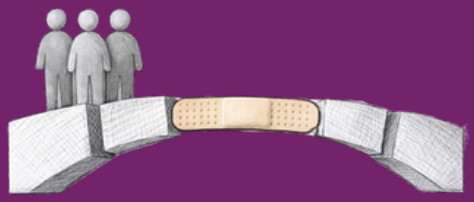
Ocular Melanoma UK
UNITED AGAINST EYE CANCER

Securing Timely Treatment for Ocular Melanoma and Other Rare Cancers



Executive Summary



This report follows directly from the parliamentary reception hosted by Dr Scott Arthur MP and Ocular Melanoma UK, focused on securing timely and fair access to treatment for people with ocular melanoma and other rare cancers. The reception brought together parliamentarians, clinicians, patients, health system representatives, and industry partners to examine barriers to access and to identify practical next steps for policy and system improvement.

Discussions highlighted persistent delays and uncertainty within current treatment pathways. Using Chemosat as a clear example, the event demonstrated how existing commissioning, appraisal, and pathway processes can disadvantage patients with rare cancers, and especially those with high unmet treatment needs. This summary sets out the key issues raised and outlines the outcomes and actions emerging from the event.

OMUK, Parliamentarians, clinicians, and patients together calling for timely and fair access to treatment for ocular melanoma and rare cancers.

Access Barriers in Rare Cancers

The parliamentary reception highlighted that people affected by rare cancers, including ocular melanoma, face persistent and systemic barriers to accessing treatment in a timely and equitable way. These barriers were consistently described as arising not from concerns about clinical safety, effectiveness, or the availability of specialist expertise, but from national commissioning and policy processes that have not kept pace with developments in rare cancer treatment.

Participants heard that patients with metastatic ocular melanoma experience a particularly high unmet treatment need, with very limited options once the disease spreads. In this context, delays in access to treatment can have profound consequences, as treatment windows are often narrow and disease progression can be rapid. While treatments with published evidence exist, current access routes frequently prevent patients from receiving them when they are clinically appropriate.

Chemosaturation was used throughout the reception as a clear and practical example of these wider challenges. Clinicians and patients described how commissioning and appraisal processes can result in prolonged uncertainty and situations where potentially life extending treatments are unavailable through the NHS. Although NICE interventional guidance permits local provision under specific arrangements, the absence of mandated funding and the financial pressures faced by individual NHS trusts mean that this route is rarely achievable in practice.

Participants highlighted that current systems often expect levels of evidence that are extremely difficult to generate in rare conditions, particularly for interventional treatments. Repeated and overlapping assessment processes, combined with limited weighting given to expert clinical opinion and established national or international guidance, contribute to further delays without materially improving decision making.

Access Barriers in Rare Cancers

A key concern raised was the lack of clear interim access arrangements while longer term commissioning decisions are under consideration. Without proportionate, time limited solutions, patients may be left without funded options or forced to self fund or crowd fund treatment, creating significant emotional and financial pressure.

The reception underscored the need for greater transparency around decision making timelines, clearer national pathways, and mechanisms that better reflect the realities of rare cancers, so that patients are not disadvantaged while established processes continue.

NHS England's own website states that Individual Funding Requests are there to support the provision of "specialised services to provide treatments for patients with a range of rare and complex conditions". In practice, the requirement to demonstrate exceptionality means that the IFR process is structurally ill suited to rare cancers.

By definition, patients with rare conditions are exceptional because they present with very low numbers, even if they have a similar pattern of disease. Inevitably, this leads to limited research funding, small evidence bases, and few or no alternative treatment options. These features are treated within the IFR framework as reasons for refusal rather than as the very justification for access. As a result, a process intended to enable access for rare conditions is, in effect, failing to do so, creating a disproportionate administrative burden on specialist centres and leaving patients without a reliable or timely route to potentially life extending treatment.

The Chemosat Example

Melphalan Percutaneous Hepatic Perfusion, also known as Chemosaturation, is a liver directed treatment designed to address the pattern of metastatic spread seen in uveal melanoma. The procedure delivers high doses of chemotherapy directly to the liver, using an extracorporeal filtration system to reduce systemic exposure and minimise side effects compared with conventional systemic chemotherapy.

The treatment is delivered at two highly specialised UK centres, University Hospital Southampton and The Christie in Manchester, which have the expertise and multidisciplinary teams required to deliver this complex procedure safely.

Isolation

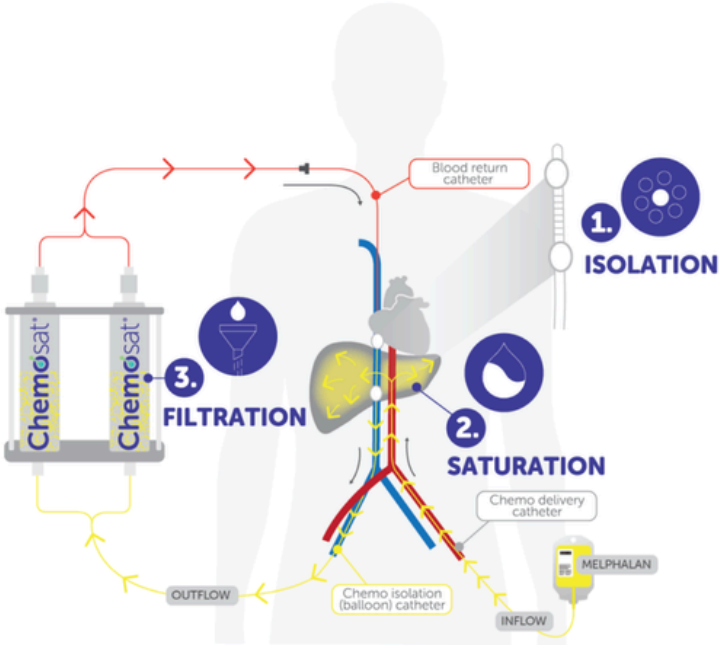
Isolating the liver blood supply allows for the benefits of high-dose melphalan while reducing systemic toxicity[3,4]

Saturation

A 30-minute infusion of high-dose melphalan saturates the liver, effectively delivering treatment to the entire organ[1,3]

Filtration

A 30-minute washout period limits systemic drug exposure (mean [SD] filter efficiency of 82.7% [14.4%] for the total filtration period)[1]



The Southampton team has delivered Chemosaturation since 2012 but has never secured routine NHS funding. While early treatment was supported through compassionate provision and trial participation, increasing financial constraints mean that Chemosaturation is now only available to privately funded patients or those funded by overseas health systems. UK patients face costs of around £40,000 per cycle, and patients may need up to 6 cycles.

The Chemosat Example

Clinical evidence includes published outcomes from Southampton in 2022, reporting a clinical benefit rate of 84.1 percent across 81 patients. The international FOCUS trial further demonstrated meaningful tumour response and an average survival of 20.5 months, leading to FDA approval and routine availability in the United States and several European countries.

Despite this, Chemosaturation is not routinely commissioned in England. This is currently on NHS England's workplan for review; however, this is a lengthy process, and the outcome will not benefit patients living with current metastatic disease, as there is no alternative treatment currently available.

Although NICE interventional procedures guidance supports its use under special arrangements, there is no associated funding, and current commissioning routes remain slow and uncertain. As a result, around 60 percent of patients with metastatic uveal melanoma have no approved treatments specific to their disease and rely on therapies developed for cutaneous melanoma, which offer limited or uncertain benefit.

The reception highlighted the urgent need for proportionate, time limited solutions to ensure patients are not left without access to potentially beneficial treatment while national processes continue.

The Patient Experience

Patient contributions were a central and defining part of the parliamentary reception. Individuals living with ocular melanoma spoke about the reality of navigating a rare cancer pathway where uncertainty, delay, and inconsistency are common features of care. Their accounts provided clear evidence of the human impact of systemic barriers to timely treatment access.

Patients described the emotional and psychological strain of waiting for decisions while their disease progresses, often with limited or no alternative treatment options available. The absence of clear timelines and the reliance on complex funding processes were highlighted as sources of ongoing anxiety, compounding the physical effects of the illness itself. Several speakers noted that uncertainty around access to treatment can be as distressing as the diagnosis.

One patient described being forced to self fund Chemosaturation at a cost of around £40,000 per cycle in order to access treatment. Having never previously asked for financial support, they spoke about the distress of exhausting personal savings, cashing in pensions in their early fifties, and using family inheritance to fund care. When these resources were depleted, they turned to public fundraising.

They described the emotional toll of losing privacy, appearing on radio and television, and having their personal story widely shared in order to survive. Despite this, the patient emphasised that the treatment itself was well tolerated and had a significant positive impact, describing minimal side effects and a rapid recovery. For them, the experience highlighted the contrast between the effectiveness of treatment and the personal cost required to access it.

The Patient Experience

Another patient spoke about living with permanent medical conditions as a result of standard treatment options, describing a significant and ongoing impact on daily functioning. Although they may appear outwardly well, they explained that most days are physically and emotionally challenging, with lasting effects on their quality of life.

They reflected on the difficulty of living with the only routinely available treatment option, describing it as hard to tolerate and limiting. At one point, they were suitable for Chemosaturation, but were unable to raise sufficient funds through crowdfunding. Despite strong support from friends and family, the financial target remained out of reach. As soon as funding becomes available, this treatment could still be an option for this patient. They remain aware that there is a risk that their disease may progress past the point of suitability before access to this treatment becomes available.

The patient described the distress of having to share deeply personal details publicly in an attempt to fund treatment, only to fall short. Their experience underscored the inequity faced by patients who are aware that an alternative treatment exists, but are unable to access it due to cost rather than clinical suitability.

The financial and emotional burden placed on patients and families was a recurring theme. Some described the pressure to consider self funding or crowd funding treatment when NHS routes were unavailable, creating additional stress at a time of significant vulnerability.

Our third patient speaker spoke about being diagnosed with ocular melanoma following a sudden change in vision, describing how what initially appeared to be a routine eye problem rapidly escalated to a cancer diagnosis. They reflected on the shock of being told they had cancer with little time to process what this meant, and on the immediate need to make significant treatment decisions.

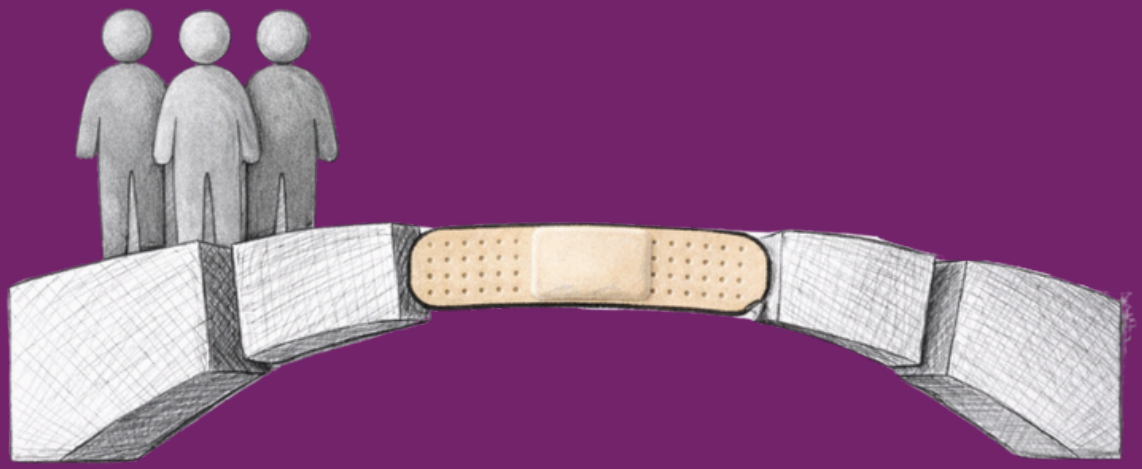
The Patient Experience

They described undergoing removal of the affected eye as the only viable treatment option due to the size of the tumour, followed by a period of close monitoring. Although there was initially no evidence of spread, the cancer later progressed to the liver and lungs, leading to multiple lines of treatment. They spoke about the physical toll of treatment and prolonged hospitalisation, alongside the emotional impact of repeated scans showing further progression.

They emphasised the importance of timely access to effective treatments, noting that eligibility for some options depends on narrow clinical windows that can close as the disease advances. They reflected on the distress of losing access to potential treatments once progression had occurred, and on the need for funding and decision making processes that move quickly enough to give patients a meaningful chance.

Overall, patient voices reinforced the need for pathways that are responsive to the realities of rare cancers. Their experiences underscored the importance of timely decision making, transparency, and proportionate access arrangements, so that people affected by ocular melanoma are supported with dignity, clarity, and fairness throughout their care.

An Interim Solution



The image illustrates a gap between patients and treatment created by timing and process, not by a lack of evidence or expertise.

The bridge itself does not need to be rebuilt. Long-term commissioning decisions should continue as planned.

What is needed now is a simple, interim way across. A proportionate, time limited solution would allow patients with urgent need to access treatment while national processes are ongoing, ensuring they are not left without options while decisions are made.

Requested Considerations

The parliamentary reception called for clarity and action to ensure that patients with metastatic uveal melanoma, and those with other rare cancers in comparable circumstances, are not left without access to potentially beneficial treatment while long term commissioning decisions remain under review. In this context, the reception called for the following considerations.

- What immediate interim access pathway will be made available for patients currently living with metastatic uveal melanoma and other rare cancers in comparable circumstances, whose lives are at risk.

- Whether the Department will introduce a short-term measure, such as removing the exceptionality requirement from Individual Funding Requests for Chemosaturation, and comparable interventions for people whose lives are at risk, so that eligible patients can access treatment without delay, where their clinician feels it is the most appropriate treatment.

- Whether a medium-term solution could be implemented through the CPAG process for current patients with metastatic rare cancers whose lives are at risk, while longer-term commissioning decisions are ongoing.

- When NHS England expects to publish the draft commissioning policy for Chemosaturation, and whether there will be a clear and transparent timeline for decision making, implementation, and funding that reflects the urgent needs of patients currently living with metastatic disease.

Progress since our reception.

Since the Parliamentary Reception, Ocular Melanoma UK has moved quickly to maintain momentum and translate discussion into action. Given the pace of developments, this summary report has been produced at speed to ensure Parliament and stakeholders have a clear and timely account of progress.

- Ocular melanoma and the use of Chemosat were raised in the House of Lords by Baroness Finlay of Llandaff during the Rare Cancer Bill debate, directly reflecting the issues discussed at the reception and reinforcing the urgency of interim access solutions for patients with rare cancers.

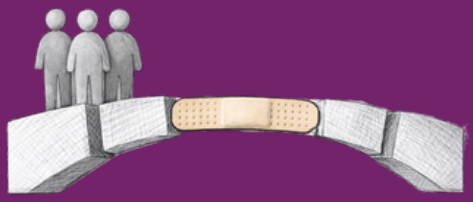
- OMUK has engaged in discussions relating to implementation, with a particular focus on how commitments made during the reception can translate into practical access routes for patients while national commissioning decisions remain unresolved.

- All Members of Parliament who attended the reception have received a copy of the joint parliamentary letter calling for time limited interim access arrangements. We have received a positive response to this correspondence, with parliamentarians expressing support for the issues raised and an interest in further engagement.

- Parliamentary Questions have also been tabled to the Government, raising the concerns discussed at the reception and seeking clarity on access, commissioning timelines, and interim funding arrangements for rare cancer treatments.

- In parallel, a press release has been drafted and is now being shared with the media, with the aim of increasing public awareness and reinforcing parliamentary scrutiny of the current access gap facing patients with ocular melanoma.

Next Steps



The parliamentary reception highlighted the urgent need for interim solutions to ensure that patients with rare cancers are not left without access to potentially life extending treatment while long term commissioning decisions remain unresolved.

We invite parliamentarians to support this work by adding their name to our joint parliamentary letter to the Department of Health and Social Care, NHS England, and NICE. The letter calls for immediate, time limited interim access arrangements for patients whose lives are at risk, alongside clear and transparent commissioning timelines.

Patients with ocular melanoma and other rare cancers are also encouraged to raise this issue with ministers or NHS England through parliamentary questions or correspondence, and to share relevant constituency casework where appropriate to illustrate the real world impact of delayed access.

Alongside parliamentary support, Ocular Melanoma UK will progress a focused programme of action to strengthen the case for change. This includes raising public awareness through targeted media engagement, documenting where existing access routes have failed, seeking clarity directly from NHS England leadership, and gathering evidence on the number of patients who have been unable to access treatment or who have been forced to self fund or crowdfund care. We will also explore whether interim or central funding mechanisms, and clearer consideration of affordability and system impact, could support access while national processes continue.

Engagement with NICE leadership and relevant research bodies will form part of this work, with an emphasis on transparency, accountability, and alignment between guidance and access in practice.

We would welcome ongoing engagement as this work progresses and would be happy to provide further briefings, case studies, or discussions on request.

Images from our reception

Ocular Melanoma UK
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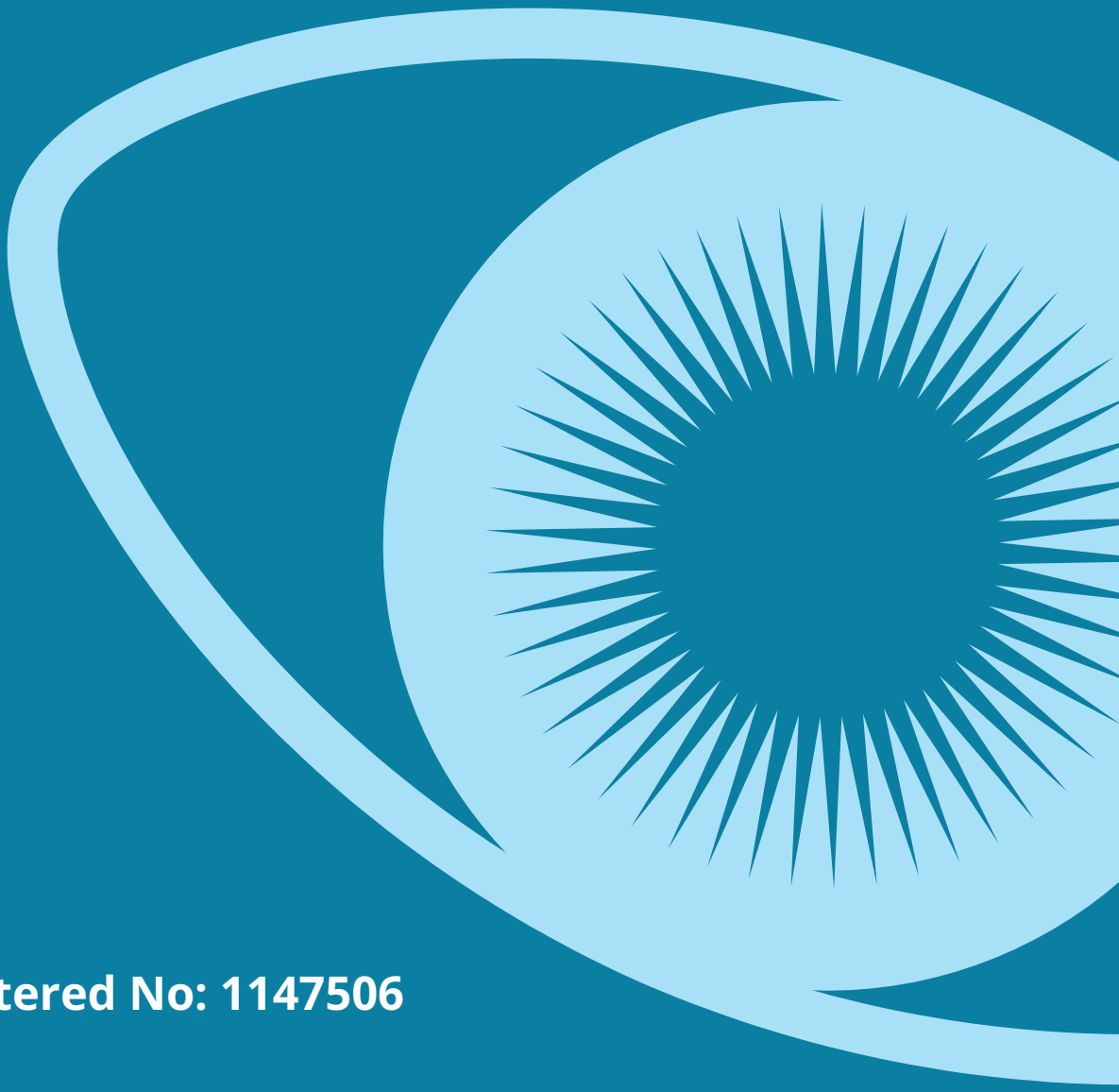
We support action to end delays in ocular melanoma and rare cancer treatment.



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