

## Executive Overview

Encephalitis is a thief. In the same way that we have watched other neurological conditions rob people of their lives and loved ones, encephalitis has quietly been at work for hundreds - if not thousands - of years. It robs families of those they love, and even where life is spared, it often steals the very essence of a person: their memories, personality, and the abilities many of us take for granted - concentration, judgement, inhibition, and independence. For many, the consequences extend further, including epilepsy and profound, life-limiting fatigue that can make a return to work or education impossible. And for too many, survival is not the outcome.

Globally in 2021, encephalitis was the fourth leading cause of neurological health loss in children aged under 5 years and the 13th overall across all age groups. For decades, encephalitis has been overlooked - frequently mischaracterised as rare and relegated to the margins of neurological and global health priorities. Yet evidence, including that presented in this report and reinforced by the [World Health Organization's technical brief on encephalitis](#), demonstrates that encephalitis is neither rare nor insignificant. In many countries, its incidence exceeds that of motor neuron disease/ALS, bacterial meningitis, and multiple sclerosis. The WHO further highlights encephalitis as a public health concern, and a complex and growing global health challenge, shaped by emerging and re-emerging infections, climate change, population movement, and persistent inequities in health systems, particularly in low- and middle-income countries.

Crucially, the WHO technical brief underscores long-standing and systemic gaps that this report also identifies: inconsistent surveillance, under-recognition and misdiagnosis, limited access to timely diagnostics (including cerebrospinal fluid testing), and inequitable access to treatment and rehabilitation. It also draws attention to the substantial, yet often hidden, long-term burden on individuals, families, and societies - burdens that extend far beyond the acute phase of illness and are insufficiently captured in current data systems.

At the same time, there is cause for optimism. Scientific advances, improved understanding of infectious and autoimmune causes, and the availability of effective vaccines for several encephalitis-causing pathogens mean that prevention, earlier diagnosis, and better outcomes are within reach. The WHO calls for a coordinated, multi-sectoral response – one that integrates surveillance, diagnostics, clinical care, vaccination, and long-term support - echoing the priorities and recommendations set out in this report.

Encephalitis International is over 30 years old and has developed unparalleled expertise in the condition and its lifelong impact on patients, families, and those bereaved. Strengthened governance, infrastructure, and a dedicated global approach have enabled us to annually update this comprehensive global baseline situational analysis. This report represents a collaborative effort involving our Chief Executive and leadership team, Global Scientific Advisory Panel, and Board of Trustees, alongside other global partners and stakeholders.

This report not only defines the scale and scope of the problem - from epidemiology and economic burden to prevention, diagnosis, treatment, and survivorship - but also sets out practical, evidence-informed solutions. Importantly, it aligns with and operationalises the priorities articulated by the WHO technical brief, positioning encephalitis firmly within the global health agenda.

Encephalitis International is uniquely placed to convene and lead a global, collaborative response. Building on the momentum generated by both this report and the WHO's calls to action, we will bring together international health organisations, governments, clinicians, researchers, and patient communities to drive meaningful change. This will include strengthening surveillance systems, improving access to diagnostics and vaccines, advancing research, and ensuring that the voices and needs of those affected are central to all efforts.

Now is the moment to act. The convergence of new global evidence, growing recognition, and clear strategic direction presents a rare opportunity to transform outcomes for people affected by encephalitis worldwide. This report is not just an analysis - it is a catalyst. It marks the beginning of a coordinated global commitment to reduce the incidence of encephalitis, minimise its devastating impacts, and build a future where fewer lives are lost, fewer futures are diminished, and more people are able to survive - and truly live - beyond encephalitis.