# We want to hear your story!

Are you a parent, caregiver, or young person with experience of paediatric low-grade glioma (pLGG) in Australia?

As part of a Monash University Honours research project, in collaboration with Ipsen Pharmaceuticals\*, we're developing a Patient Journey Map (PJM) to capture the real-life experiences of Australian families affected by pLGG—from diagnosis to treatment, follow-up, and beyond.



MUHREC Project ID: 48409

### **Why Your Voice Matters**

There is currently very little Australian research that captures what it's really like to navigate pLGG care. Your insights can help:

- Improve how health services communicate and coordinate care
- Highlight gaps in diagnosis, treatment, and survivorship support
- Empower advocacy with real-world, lived experience evidence
- Support health policy and funding for better access to new therapies

Your contribution will help make this map a powerful tool for health professionals, decision-makers, and advocacy groups to better support future families.

#### **About the interviews**

Plexible (30-90 mins)

Held by phone, Zoom, or in person—whatever suits you

Semi-structured—you guide what you're comfortable sharing

# A thank-you gift voucher provided for your time

#### **Interested or Want to Learn More?**



Scan the QR code to register your interest Or

Email us at: sstu0010@student.monash.edu

## WHO WE'RE LOOKING FOR

You are a parent or caregiver of a child with pLGG

Family members (18+) of pLGC patients

Young adults or adults (18+) who were treated for pLGG during childhood

You feel comfortable sharing your story in an interview

You want to help improve the journey for others navigating pLGG