Our project

Paediatric low-grade gliomas (pLGGs) are the most common childhood brain tumours, yet little is known about how Australian patients and families experience the journey from before diagnosis through to survivorship. To address this gap, we—Sienna Stuart-Williams, Layla Carmeli-Wolski and Thomas Wakeling—created this patient journey map (PJM) as part of our Honours thesis, for our Bachelor of Science Advanced—Global Challenges at Monash University, in collaboration with Ipsen Pharmaceuticals.

While definitions of the 'paediatric' age range vary, this project defined pLGG as any patient diagnosed with a paediatric-type low-grade glioma, recognising that paediatric-type LGGs are biologically and histologically distinct from adult-type LGGs.

The PJM was informed solely by interview data from five pLGG families and three clinicians; it does not represent the experiences of the entire Australian pLGG community. No external references were used, to ensure that the map authentically reflects the lived experiences of participants within an Australian context.

We intend for this resource to be the first of its kind to summarise patient experience in this manner, helping families prepare for the journey ahead and guiding their communities, including treating teams, schools, family, and friends, in how best to support them along the way.

For more information or details on this project, please contact plggmap.monash@gmail.com

October 2025

MUHREC ID: 48409 and 49487

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Paediatric low-grade glioma

PRE-DIAGNOSIS

Uncertainty

Confused

Emotional invalidation

"I think it's something more"

Dismissal from HCP

Moving between HCPs

Expressed first concerns

Referral for MRI

Unexplained symptoms

pLGG suspected

DIAGNOSIS

Relief

Fear

"I was terrified. I didn't know anything about it"

MDT assembled

Hospital management begins

pLGG confirmed

Referral for biopsy

TREATMENT

Anxiety

Frustration

"Watching your child. Slowly get worse. It's the worst torture of your life! Because you've got to sit in this space"

1st line treatment

Monitor progress

2nd line treatment

Monitor progress

3rd line treatment

LIVING WITH PLGG

Resilience

Independence

"In 10 years' time... this is still going to be a thing we're going to be managing and dealing with, like a chronic condition"

Ongoing challenges

Ongoing support

Regular MRI scans

HCP, healthcare professional; MRI, magnetic resonance imaging; pLGG, paediatric low-grade glioma; MDT, multi-disciplinary team

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Patient timelines

No journey is the same...

Diagnosis

Initial Symptom Recognition
Age: 7
→ Nightly vomiting
→ Headaches
→ Dizziness
"[Patient] just kept getting colds"

3 months later
Pilocytic astrocytoma
→ BRAF mutation
→ Cerebellar & brain stem

Surgery
3 days later
→ near total removal of tumour

Watch and wait
Ongoing
→ 6-monthly MRIs

Age: 10

Initial Symptom Recognition
Age: Newborn
→ Collapsed lung

Age: 2
→ Delayed speech development
→ Left side palsy
→ Paralysed palette

Age: 5
→ MRI revealed a non-specific brain lesion

Watch and wait

4 months later
Ganglioglioma suspected
→ Brain stem

Chemotherapy
11 months later
→ Weekly vinblastine for 52 weeks

Biopsy
2 months later
→Tissue sample obtained
→ Ganglioglioma diagnosis confirmed

Chemotherapy
Two weeks later
→ Monthly carboplatin for 11 weeks (incomplete schedule due to anaphylaxis)

Biopsy
3.5 years later
→ Insufficient tissue mass removed for genetic profiling

Targeted therapy
Ongoing
→ Trametinib (MEK inhibitor) via compassionate access

Age: 11

Initial Symptom Recognition
Age: 6
→ Falling
→ Headaches
→ Poor vision
"I was a very keen netballer, but I would fall over all the time"

4 years later
Paediatric-type low grade glioma
→ Cerebellum

Watch and wait
2 days later
→ 6-monthly MRI scans, followed by 3-monthly as the tumour size grew

Surgery
3 years later
→ Insufficient tissue mass removed

Surgery
4 days later
→ More tumour mass removed

Surgery
5 years later
→ More tumour mass removed
→ Genetic profiling confirmed pLGG

Watch and wait
Ongoing
→ Regular 6-monthly MRI scans

Age: 19

Initial Symptom Recognition
Age: 5 months
→ Slower development
→ Delayed crawling and communication

8 months later
Pilocytic astrocytoma
→ Cerebellum

Surgery
2 months later
→ Tumour mass removed

Chemotherapy
1 week later
→ Monthly carboplatin for 18 months

Surgery
6 years later
→ Tumour mass removed

Watch and wait
Ongoing
→ Regular MRI scans (originally 6-monthly, now yearly)

Age: 21

Initial Symptom Recognition
Age: 19
→ Double vision
"I thought I just needed glasses"

3 weeks later
Pilocytic astrocytoma
→ Brain stem

Biopsy
5 days later
→ Tumour deemed inoperable
→ Tissue sample obtained

Radiation therapy*
4 months later
→ Treated for 3 months

Watch and wait
Ongoing
→ Regular MRI scans (originally 3-monthly, now 2-yearly)
"my tumour hasn't grown in 13, 14 years"

Age: 32

*This patient was treated several years ago. Currently, radiation therapy is strongly discouraged in pLGG as its significant and lasting morbidities (inc. fertility concerns and the risk of secondary malignancy) outweigh its potential benefits.

Pre-diagnosis

What's going on??

PATIENT EXPERIENCE

- Early symptoms were often **confusing** and **minimised**
- **Unexplained**, worrying **changes** included dropping objects, double vision, stumbling or sudden, frightening events such as falls, collapsing and seizures
- Symptoms often **disrupted daily life**

"I thought I just needed glasses...[cancer] didn't cross my mind"

"I would probably be picked up at least once a month [from school]"

CAREGIVER EXPERIENCE

- Persistent **worry**, **exhausted** nights in ED, juggling other children and work, and deep frustration when concerns were dismissed.
- Feeling **dismissed** or told it was likely something else
- Parents were hand-balled between several specialists

*"I felt ghastly because I was going, **I think it's something more**"*

"You're just being... a helicopter parent"

CLINICAL PATHWAY

- Most diagnoses hinged on **MRIs**, but routes to MRI were highly variable
- Where non-GP HCPs (e.g. optometrist, ENT or ophthalmologist) insisted on imaging, diagnosis was often reached faster
- Frequent **attribution to other causes**

*"I think we were in a place of very **blissful ignorance**, because whilst we had concerns, and whilst we knew something was wrong. They had presented a very plausible explanation for us"*

SIGNS AND SYMPTOMS

- Persistent headaches
- Unexplained nightly vomiting
- Visual disturbances
- Frequent falls, unsteady gait
- Developmental delay or regression
- Palate paralysis / speech / swallowing challenges

UNMET NEEDS

- HCPs unable to attribute symptoms to a potential brain tumour
- Earlier referrals to MRIs could have saved critical time

"If ED had more understanding of what signs to look out for in potential brain tumour kids, that would have been helpful... by the time they diagnosed him it was considered life-threatening"

"There was, like, this really extended period of time where we felt like doctors and people dismissed us. They told us there was nothing wrong with our child. And I know it's not an uncommon story"

ED , emergency department; HCP , healthcare professionals; MRI, magnetic resonance imaging

Diagnosis

Finally some answers...

PATIENT EXPERIENCE

- Children demonstrated an awareness of their circumstances, reflecting a maturity as they engaged actively by asking questions. They appreciated **honest explanations** from parents and HCPs
- Adolescents described **terror** on hearing the word "tumour," while some younger children initially accepted the news without much need for detail

CAREGIVER EXPERIENCE

- Diagnosis was marked by **acute shock**, and **fear of what's to come**, paired with the relief of **finally knowing what was wrong**
- Several parents described an intense 24-hour period after hearing a "*lesion*" existed in their child's brain. For some, treatment was immediate, but others described an extended waiting period with **limited answers** *("we will see you in three months").* This prolonged anxiety and fear of the unknown
- **Support services,** such as advocacy groups and therapy, were available not just for the patient, but also **for families,** acknowledging that family members were also affected by the news of diagnosis

Parental Advocacy

The responsibility of advocacy fell heavily on parents, with one parent reflecting that **persistence** with ED staff "saved" their child. Parents repeatedly described being the coordinators of their child's care at this stage, chasing results, insisting on further tests, and not accepting dismissals. Their persistence often determined whether diagnosis and treatment happened promptly

CLINICAL PATHWAY

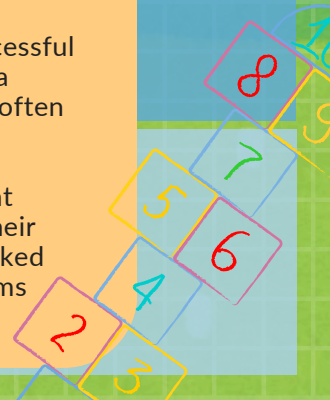
- **MRI was the pivotal diagnostic tool**, signalling seriousness and often triggering urgent escalation. For some, MRI and surgical consultation happened within days and for others, interpretation delays stretched into weeks or months
- While MRI revealed abnormalities, it did not always provide a conclusive pLGG diagnosis (i.e. which specific subtype of pLGG), which required **biopsy** for histology and grading. Biopsies clarified these details but were not always possible due to tumour location or insufficient tissue mass. **Genetic testing**, when feasible, provided important insights

SYMPTOMS

- The immediate triggers for MRI and further workup were **neurological or functional red flags.** These symptoms represented a **tipping point** where other explanations were no longer accepted

UNMET NEEDS

- Insensitive explanation of the diagnosis to parents
- Those unable to have a successful biopsy did not always have a conclusive pLGG diagnosis, often leading to more uncertainty
- Diagnostic delays meant that patients suffered through their symptoms for longer and risked tumour growth and symptoms worsening



HCP, healthcare professional; MRI, magnetic resonance imaging; ED, emergency department

Treatment

It's a balancing act...

PATIENT EXPERIENCE

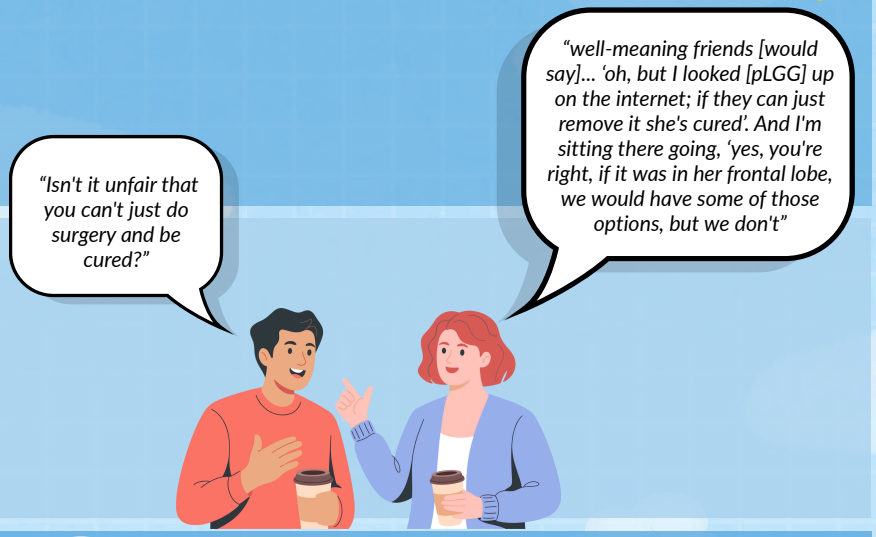
- Across modalities, patients experienced **fear**, **frustration**, and **loss of normal childhood/adolescence**. Many felt "*different*" from peers as they missed school, sport and grieved missed social milestones
- Treatments often meant dependence on parents, aides, or medical staff. Older adolescents highlighted frustration at being overprotected, while **younger children more readily adapted**

"Mum! I decided to name the thing in my brainstem... I'm going to call it Rainbow"

CAREGIVER EXPERIENCE

- **Disruption** to daily routine, siblings missed out on attention, parents missed work, and **routines were reshaped around hospital visits** and the child's energy levels
- Families reported at least one caregiver needing to **alter their regular work schedule** in order to look after the patient
- Parents carried **anxiety** about survival, long-term side effects, and the future
- Parents are offered **choices** by the hospital team when appropriate: "*The choice between vinblastine and carboplatin... depends on the family's preference*"

"We know that if we've ever got any concerns, his team at [the hospital] are there down the line anytime, so we can call them if we've got any concerns"



CLINICAL PATHWAY

- There are no Australia-wide pLGG treatment guidelines, since **available treatments are constantly evolving**. **Treatment can and does vary across different hospitals**
- Determining treatment is a balancing act, **weighing up the burden** of symptoms, the side effects of treatment, and the risks of tumour growth if untreated
- Operable tumours were treated with **surgery** when risks were considered acceptable and the tumour location dictated the extent of resection
- Inoperable or incompletely resected tumours required alternate approaches such as **chemotherapy**, **targeted therapy** or **watch-and-wait**
- Surgical care was managed by **neurosurgeons**, with ongoing treatment transferred to a **neuro-oncological team** if resection was incomplete
- **Targeted therapy** is an **emerging option,** but **access is limited** when genetic testing cannot be performed due to unsuccessful or absent biopsy
- Treatment involved complex multi-disciplinary care from various medical fields

COST

Treatment often meant spending a lot of time in the hospital. Although formal support services were available and the cost of primary care was covered while in hospital, the significant associated costs of treatment were often overlooked (e.g. parking, missing work, organising meals, and complementary medicines etc.)

"*It just progressively adds up*"

UNMET NEEDS

- Regional hospitals often lacked experience with pLGG, leaving parents to educate staff themselves
- Medication access gaps forced families to bring in their own supplies to regional hospitals
- Parking, travel, and out-of-pocket costs for medications and supplies were heavy
- Some families felt overlooked due to "low-grade" diagnosis: *"If she had [a more common childhood cancer] ... there would have been a team of social workers. But it's like, oh, it's just low-grade glioma ... That's been really impactful"*

DIPG, diffuse intrinsic pontine glioma (high-grade glioma)

Treatment	Patient experience	Side effects	Family/Caregiver experience
SURGERY If a patient's tumour is located in a **safely operable region**, and if the deficits caused by the tumour are significant, then surgery is often pursued. **Complete resection** (i.e. removing the tumour completely) is the ideal outcome, however, **partial resection** can also provide patients with symptom relief by minimising the tumour's size. Surgery is sometimes encouraged solely for the sake of a **biopsy** for genetic testing	• Surgery felt **frightening** at first, but patients were often **reassured** by clear explanations • Recovery was variable, **some bounced back** quickly, while others had **lasting deficits** (e.g. nerve damage, chronic fatigue, headaches, etc.): *"Learning how to walk again, and pretty much function as a human was quite hard"* • Length of **post-surgery hospital stays** varied between a few days to several weeks	• Side effects from surgery varied, described as both **short and long-lasting,** including physical and cognitive fatigue, loss of fine motor skills, migraines, imbalance, nerve damage and chronic pain • Surgery caused relief of some tumour-induced symptoms in some	• Depending on tumour location parents **didn't feel they had a choice** but rather *"it was, it's surgery or die" and "time wasn't on our side"* • Surgical consent process was described as **traumatising** • Families frequently described the **fear** of not knowing if they would see their loved one again, and the effect on siblings seeing them in the hospital: *"the stress of knowing that his brother was going into the hospital and may not be coming out … it was a lot"*
CHEMOTHERAPY If resection is incomplete or not safe, then chemotherapy is the **typical next step**. Patients described treatment with two different chemotherapies: carboplatin and vinblastine. **Carboplatin** is administered **once every 4 weeks** (beneficial for patients who wish to reduce travel burden), typically for 12 months. **Vinblastine** is administered **weekly**, and schedule lengths vary from 52-72 weeks. Other chemotherapies are considered if all other treatment options have been exhausted	• Chemotherapy was described as **exhausting** and **physically harsh** • Due to significant side effects, some patients required more appointments, therefore missing a lot of school • Visible physical changes negatively impacted children's **body image** • Patients mentioned **increased anxiety**, social isolation and loss of independence • Treatment is **lengthy**, and it is unclear whether the standard duration of therapy is necessary	• Common symptoms include: vomiting, nausea, allergies, fatigue • Patients can develop an **intolerance** to **carboplatin,** which can worsen with each dose and occasionally develop into full anaphylaxis • Patients experience **fewer fluctuations** in their health while on **vinblastine**	• Families described an **emotionally draining time** due to the visible suffering of their child • Recounted long hours in hospitals, impacts on schooling, siblings and **disrupted** family routine • There was shared **uncertainty** among parents about balancing the risk and benefit of chemotherapy when the side effects were severe • Monthly carboplatin over weekly vinblastine is often appreciated by families to **reduce the travel burden** • **'Hospital at home'** care is offered when appropriate to ease the travel burden
TARGETED THERAPY Targeted therapy is still relatively new. Access is limited to clinical trials, the PBS, or compassionate access programs, all of which have strict eligibility criteria. Patients without clear or conclusive genetic testing results often face difficulties in qualifying	• Patient experienced **improved quality of life** due to a **reduction in symptoms** and tumour size • **Fear** of a rebound effect (i.e. tumour regrowth at a faster rate) once treatment ceases • **Side effects** have been found to be intolerable for some	• Side effects included rashes, paronychia, fatigue, skin conditions, infection	• **Financial anxiety,** as many of these treatments aren't yet covered by the PBS, therefore families rely on compassionate access schemes from pharmaceutical companies (which can be withdrawn at any moment) • Fear **of relapse** once/if treatment ceases, since research is still relatively novel
WATCH & WAIT 'Watch and wait' refers to the process of closely monitoring the tumour through regular check-ups, rather than pursuing active treatment (as above). It was followed when the risks of treatment are considered greater than the risks of leaving the tumour untreated	• Patients accepted surveillance as part of their journey, though **the uncertainty created anxiety** • **Symptoms sometimes worsen** during watch and wait, leading to heightened stress • If symptoms worsen and the tumour grows, there is a **reconsideration of the treatment approach**	• Symptoms are consistent with those experienced during the pre-diagnosis stage	• Families described observation as **emotionally exhausting**, especially when symptoms worsened, but intervention was delayed • Parents often felt powerless while watching their child decline: "*Watching your child. Slowly get worse. It's the worst torture of your life! Because you've got to sit in this space*"

MTOP, medical treatment overseas program; PBS, pharmaceutical benefits scheme

Living with pLGG

A cycle of peaks and troughs...

pLGG is a chronic condition. It's a lifelong journey marked by periods of intense treatment mixed with stretches of relative normalcy

PATIENT EXPERIENCE

- **Ongoing anxiety** around regular scans
- Long-term social and 'life-progression' challenges (e.g. inability to work while studying, concerns about fertility, etc.)
- **Younger children adapted more easily**, while teens/young adults carried heavier psychosocial burdens
- Once patients turn 18, treatment is transferred to an adult hospital: *"a lot of these kids we've known since they were little, and so, to trust a new clinician and a new team is such a foreign thing"*
- *Many drew resilience from their experience and developed a motivation to 'seize the day'*

"An illness isn't gonna stop me... it might have its own challenges, but it's not going to stop me from living"

CAREGIVER EXPERIENCE

- Parents balanced hope with fear, often **finding strength in their child's survival and positive disposition**
- Siblings and family dynamics were often disrupted or altered, although parents described strong resilience and unity and a strong ability to adapt
- It can take a while for anxiety to reduce and for a feeling of normalcy to return
- **Ongoing anxiety** around regular scans

"We don't know what the future looks like...we try and put a positive turn onto all of what is"

CLINICAL PATHWAY

- Survivorship always involves **ongoing surveillance** of the tumour in the form of **regular MRIs** after treatment, tapering from 3-monthly to annual scans if stable. Sometimes clinicians have to look at more than just imaging to assess disease progression (e.g. side effects)
- Ongoing allied health services are often required, including occupational therapy, physiotherapy, psychology, and fertility specialists
- Finding the right **therapist/supportive care** was often challenging, but transformational when successful
- During the **'off' periods**, when patients are not receiving active treatment, hospital support is limited. However, the introduction of a 'survivorship' clinical nurse consultant role in some hospitals has been transformative for patients

UNMET NEEDS

- Survivors and families highlighted a lack of understanding and empathy from schools
- Families often had to educate schools and advocate heavily for support and accommodations.
- pLGG is often socially invisible, leading to isolation from peers and a lack of understanding in the community

"End of treatment's a big one, because they've seen [the medical team] every week or every month, and [then] they just go into this abyss...Not having [the team] at their beck and call is really, really hard"

"I think there's a difference between surviving and living ... surviving you're just waking up each day, but living you're actually making meaning"

TUMOUR/TREATMENT DEFICITS

- Fatigue
- Speech and hearing deficits
- Functional deficits

SUPPORTIVE CARE

- Therapy had a transformative impact on both patients and other family members. Music therapy was highlighted as especially powerful for patients.
- Advocacy group events fostered community and purpose
- Support from the NDIS and schools, in the form of aides, therapy and allied health, was valued

"The [hospital school was] involved in helping with the transition back to school in the community. Without them it would have been much harder"

MRI, magnetic resonance imaging; MDT, multidisciplinary team; HCP, healthcare professionals

How to meet needs

FAMILIES

HEALTHCARE SYSTEM

PRE-DIAGNOSIS

- **Trust your instincts,** you know your child best.
- Don't be afraid to advocate and ask for more tests if symptoms persist.
- Keep notes of symptoms and changes. This helps your care team.
- Seek advice or second opinions early if you feel dismissed.
- **Connect** with other families for reassurance and advocacy tips.
- Use community and advocacy group resources to learn red flags and referral options.

- Recognise and escalate neurological red flags early.
- Provide clear next steps when symptoms remain unexplained.
- **Avoid minimising parental concerns** by listening actively and validating them.

DIAGNOSIS

- Ask your clinical team to explain results in plain language.
- Encourage **open, age-appropriate conversations** with your child.
- **Reach out** for psychosocial, emotional, and financial support. It's available and there to support you.
- Use advocacy networks to find practical guides and peer connections.

Remember: your persistence matters! Your voice helps shape your child's care.

"It took a bit of adjustment for [the school and community] to figure it out, but they're really good about it now"

- Deliver results with **empathy**, clarity, and time for questions.
- Immediately **connect families** to psychosocial and financial support.
- Provide written or digital summaries that families can refer back to.
- Communicate diagnostic updates back to GPs to improve brain tumour symptom recognition awareness.

TREATMENT

- Stay involved: you are an essential part of the care team.
- Ask about treatment options, side effects, and available supports.
- Reach out to advocacy groups and charities for travel and cost assistance.
- Look after **your wellbeing.** Caring for yourself helps your child.
- Keep school, friends, and siblings connected through updates and inclusion.
- Share your experience with advocacy groups to help other families.

"I found a good therapist there that really turned things around for me"

- Provide **clear explanations** of treatment goals and side effects.
- Coordinate between tertiary and regional centres to avoid gaps in care.
- **Normalise psychosocial support** as part of routine treatment.
- Advocate for equitable access to therapies and medications.
- Check in regularly about caregiver wellbeing and practical challenges.

LIVING WITH PLGG

- Continue and value the regular follow-ups to encourage stability and confidence.
- **Encourage your child's independence** while recognising ongoing challenges.
- Don't hesitate to **ask for school or workplace accommodations.**
- Seek peer or mentorship programs for long-term support.
- **Celebrate milestones**: focus on living fully, not just surviving.
- When it becomes age appropriate, educate your child on their diagnosis and pathway.
- Keep advocating: your lived experience helps drive system change.

- Provide structured survivorship and **transition-to-adult-care plans.**
- Offer ongoing allied health and psychological support.
- Ensure **clear collaboration** between paediatric and adult services.
- Support education and workplace reintegration.
- Recognise pLGG as a **chronic, lifelong condition requiring ongoing care and monitoring.**

GP, general practitioner; ED, emergency department; MRI, magnetic resonance imaging; MDT, multi-disciplinary team

Support services

Redkite – For families facing childhood cancer	Support call line where you can talk to them about anything and everything. They have all sorts of practical help, information and support to help you plan for the long term and stay on top of things when new challenges pop up. Additionally, they can work with you to help relieve some of the financial pressure.
Camp Quality	Camp Quality offers a range of services for families with kids aged 0-15, including FREE camps, getaways, fun days, and special experiences designed to help you relax, recharge, and rediscover laughter. Resources to help children understand cancer in a child friendly way. Additionally, they provide counselling and peer support services.
RCD Foundation	Supporting families by organising and funding emotionally invaluable rehabilitation therapies. These include the Music Matters program, providing blocks of 10 private, in-home music therapy sessions for children and young adults under 25 across Australia.
Children's Cancer Foundation	Provides a wide range of practical supports and resources such as counselling services to assist families in navigating their unique challenges. The CCF has partnered with My Room Children's Cancer Charity to fund a new national program that will provide fertility preservation services.
canteen	Canteen provides a wide range of free support services to help them overcome the specific challenges they're dealing with. They also provide services for parents dealing with cancer in their family.
peace of mind	Provides vital support for brain tumour patients and families through advocacy, navigation, financial aid, counselling, and community connection.
my room – Children's Cancer Charity	Providing funding for household bills, funerals, and other immediate needs, as well as providing uplifting experiences to brighten spirits along the way.
Ronald McDonald House Charities Australia	Through our accommodation and support services, we strive to keep families together when life gets turned upside down due to a child's illness. Provides a home away from home for families with children in hospital and education support for school-aged children who medically cannot go to school.
Challenge – supporting kids with cancer	Challenge aims to manage the impact of a cancer diagnosis by addressing the emotional, social, and practical needs of your family. Whether it is help at home or a weekend away, we tailor our services to meet the requirements of each individual within the family unit.
Brain Tumour Alliance Australia – 1800 857 221	BTAA seeks to provide peer support to people living with a brain tumour. They extend this to their carers, families and friends. BTAA provides information resources for newly diagnosed patients and can assist with referrals to the most appropriate support services in their area.

Acknowledgements

We would like to sincerely thank all those who contributed to the development of this Patient Journey Map. To the interviewees who so generously and courageously shared their experiences, your willingness to be vulnerable has provided invaluable insight into the realities of living with paediatric low-grade glioma.

We also acknowledge the clinicians and professionals who took the time to review this map and offer thoughtful feedback to ensure its accuracy and relevance. Our gratitude extends to our industry partner, Ipsen, and to our Monash University supervisors for their ongoing guidance and support throughout this project.

Finally, we thank the patient advocacy groups who connected us with families and helped us to better understand the community's needs. This would have been impossible without each of you.

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