first 100 days of JIA

Re-designing the first 100 days of JIA with families

SOLUTION MAP

stage | family journey | key insights | key problem areas | proposed solutions

GP/ED

Family journey: First symptoms | Present to GP/ED | Tests + ultrasound | GP writes referral | Referral sent

Key insights

- *First families are experiencing what signs to look for in their child*
- *Parents often feel dismissed by their GP, leading to delays in presentation to specialist*
- *Inaccurate or incomplete referrals are common, increasing wait times for families*

Key problem areas

- Lack of public awareness about JIA
- Lack of GP education + awareness
- Lack of referral advice and support for GPs

Proposed solutions

- *outside the scope of this project*
- *outside the scope of this project*
- **Updated criteria** — *Update triage criteria to include more detailed and accurate guidance*
- **Website** — *Provide virtual information and support for GPs*

referral

Family journey: Receive triage letter | Wait for appointment booking | Receive appt. letter | Call from admin confirming appt. | Automated reminder texts

Key insights

- *In some cases the category a child is triaged to does not reflect the child's needs, often due to incomplete or inaccurate referrals*
- *Many families are left waiting beyond the recommended wait period without clear communication*
- *The child's condition may deteriorate before the first appointment, leading to initial triage inaccurate and requiring interim treatment*
- *Families receive very little communication and information to set expectations for the first appointment - most have no idea what Rheumatologists mean*

Key problem areas

- Inaccurate triage
- Wait times exceeding triage window
- Deterioration after triage
- Lack of communication and unclear expectations

Proposed solutions

- **Rapid review clinic** — *Establish a weekly multidisciplinary meeting dedicated to urgent appointments, minimizing unnecessary waitlist management*
- **Re-triage pathway** — *Create a clear pathway for re-triage a patient if required*
- **Interim care advice** — *Support GPs with interim treatment advice to prevent further deterioration in the appointment*
- **Pre-appointment communication** — *Provide families with information prior to the appointment, so they know what to expect*

first appointment

Family journey: Check in at 2E | Clinic Nurse records height and weight | Wait for appointment | Rheumatologist consult | Nurse consult

Key insights

- *Families are overwhelmed by the long wait times in clinic*
- *Parents use the current education folder as a primary source of information and advice, but the quality of information they receive is inconsistent and lacking in many key areas*
- *Families whose first language is not English have access to less information, and interpretation must take home information has not been translated into other languages*
- *Despite regularly diagnosing children with JIA, rheumatologists had no idea how other clinicians could provide the most helpful support in the first appointment, and wanted to know how they could better support families*
- *There is currently no space for nurses to work out of the 2E clinic area during clinic, meaning that they need to walk back and forth from the clinic to see individual patients, disrupting their admin work and affecting the level of support they can provide*

Key problem areas

- Unexpected wait times
- Difficulty understanding and retaining information
- Fragmented team

Proposed solutions

- **Pre-appointment survey** — *Families are given a questionnaire to share their concerns and preferences, saving time in their appointment*
- **Hygienist** — *Appoint a dietitian to support families with patients and the rheumatology multidisciplinary team from being pulled away during clinics*
- **Visual aids** — *Design or find images and videos that can be shown during clinic to help families understand what is being discussed and sending them home with families*
- **Post-appointment summary** — *Provide families with a short summary document after attending the diagnosis, their medication plan and what will happen next*
- **JIA passport** — *Design a "passport" for families to keep a record of the contents of all the appointments they attend*
- **Supportive letter** — *Re-design the appointment letter to be more inviting, making the language more accessible, engaging and digestible*
- **Transliteration services** — *Create translated versions of the current culturally inappropriate but CALD families*
- **Clinician cheat sheet** — *Create a one-pager for clinicians to share with families, easy, accessible "tips" on how to support families and can be immediately implemented the first 100 days for families*
- **Question cards** — *Create cards with common questions families want to ask about the diagnosis and treatment, making it easier to select or generate questions during the appointment*
- **HOT clinic area** — *Create space for the rheumatology team to attend to JIA during clinic so they can easily see families and speak to families without disrupting their admin work*

follow up

Family journey: MTX education with nurse | Receive diagnosis letter | Visit GP | Tell the child's school | Tell friends and family | Apply for financial support | Manage lifestyle changes | Infectious Disease Clinic (immunisations) appointment | Connect with other families | Follow-up phone call with nurse | Regular blood tests | Ophthalmology appointment | Review appointment | Day-to-day support

Key insights

- *Many families are receiving their diagnosis letters late or not at all, causing them to miss their school support and funding, as well as communicate with their GP*
- *School support is one of the most important factors as the child's condition affects their JIA, however many schools are not aware of their responsibilities to make for JIA*
- *Many families struggle to explain JIA to friends and family, and are met with questions and judgement, causing stress to their overwhelm*
- *Siblings of children with JIA struggle to understand why their family dynamic after diagnosis*
- *There are several avenues for financial support, however many families are not aware of these or struggle through complex application processes*
- *Many parents express the desire for more holistic lifestyle support, helping them understand what they can support their child through JIA, exercise and environmental factors*
- *In the first appointment families are told that they will receive a call from the Infectious Disease Clinic*
- *Those who connected with other families early on felt more supported, however many families struggle to find other families, due to a lack of awareness of existing organisations or general awareness*
- *In the first appointment families are told that they will receive a call from the Infectious Disease Clinic*
- *The Rheumatology admin and nurses are overwhelmed by time chasing pathology results*
- *On top of treatment and procedures, families need to attend regular blood tests, which can be challenging for children*
- *Unless a child's condition is particularly severe and they require a GA, families are told to miss most appointments and instead continue attending the bedside rounds to travel to the hospital sometimes multiple times per week.*
- *Families are told in the first appointment that they will see the Ophthalmologist every three months, however the actual wait time is often a different story*
- *Families are told in the first appointment that they will see the Rheumatologist every three months, however the actual wait time is often a different story*
- *Families felt very supported during appointments and follow-ups with the nurses, however they struggled the most with the day-to-day management of JIA away and they needed to manage JIA day-to-day, unsure where to go with questions and concerns*
- *Despite requiring giving informal feedback to the Admin Officer and Nurses via phone or email, unless a complaint or compliment is formally logged, no feedback is collected. The PREMS survey (most due?) this information isn't regularly captured to understand and improve their experience*

Key problem areas

- Late diagnosis letters
- Difficulty navigating school support
- Burden to educate
- Struggling siblings
- Difficulty accessing financial support
- Lack of holistic lifestyle support and support
- Inconsistent communication
- Lack of connection
- Lack of pathology results
- Difficulty managing appointments and testing
- Unscheduled appointments
- Expectations VS reality
- Lack of communication
- Large admin load
- Lack of continued connection with families

Proposed solutions

- **Post-appointment summary** — *Provide families with a short summary document after attending the diagnosis, their treatment plan and what will happen next*
- **Mark Kneebone as Rheumatology specialist** — *There are several steps that the team can take to speed up the arrival of the appointment letter, including contacting Mark Kneebone and making sure families are CC'd.*
- **Guide JIA to school** — *Create a guide to JIA in schools. Begin to build awareness of JIA in schools by advocating for the condition to be included in school forms - currently if a parent is completing a form for their child, there is no space to let them know under existing medical conditions.*
- **Juvenile Idiopathic Arthritis Foundation**
- **Education folder** — *Create a comprehensive education folder, given to families at the first appointment, that includes information on JIA, a glossary of medical terms, resources for friends/family/teachers, information for schools, information on the NDIS, information on Medicare, information on Centrelink, information on Medicare lifestyle management advice, a glossary of JIA terms and a guide to navigating the hospital medical system*
- **Group education sessions** — *Create opportunities for families to come together in a group setting, ideally in the first 100 days, both in-person and virtually*
- **Pre-appointment survey** — *Ask the pathology provider to provide a pre-appointment survey, allowing the nurse to be ready to answer the results*
- **JIA passport** — *Include treatment and medication plan, appointment, individualised "tips" and "tricks" for managing JIA, and a "wish list" (and their current) keep track*
- **Telehealth + Local providers** — *Continue to build workforce/connections to local providers (Podiatrists, Physiotherapists, etc.) and speak model supplemented care, including telehealth, to the broad burden on families*
- **Lived experience support worker** — *Create a role for someone who has lived experience of JIA to provide a counselling/peer support experience to connect with families throughout their journey, providing support with day-to-day and self realistic expectations*
- **Dedicated Rheumatology Admin** — *Carve out additional time for nurses and admin officers to chase up pathology results, ideally a dedicated Rheumatology admin officer.*
- **Consumer feedback tools** — *Develop engaging evaluation tools for families to complete after each appointment, to inform continuous improvement and monitor ongoing concerns, complaints and feedback in the department's DMS*

treatment

Family journey: Pick up cyclosporin box from Clinical Consumables | Joint injections | Steroid infusions | At-home mtx treatment

Key insights

- *Clinical consumables are an example of a hospital service that families are given information about, but not offered to non-paid*
- *Families are need to travel to QCH for treatment - particularly those in regional areas - are disgusted from their communities for weekly or fortnightly infusions*
- *It's not uncommon for children with JIA to develop needle phobias, and many families are not offered distraction techniques, offers, and families are left to develop their own strategies*
- *Many families struggle the most when they first themselves or their child has to inject themselves, a form as yet, side effects or challenging injections, unsure what to do or where to turn*

Key problem areas

- Difficulty navigating the medical system
- Displacement from community
- Lack of procedural anxiety prevention
- Difficulty accessing other/non-paid support

Proposed solutions

- **Education folder** — *Within the education folder, include information on medical terms, common side effects, and a glossary of terms*
- **Dedicated accommodation for regional families** — *Provide hotel/accommodation for regional families to stay with other members of their community, creating a support that feels more like home*
- **Peer Support Program** — *Develop strategies for families to connect with other families, Occupational Therapy support from the outset*
- **CALM Care** — *Connect with CALM care and provide them with post-strategies and resources for families*
- **Treatment tips and tricks from other families** — *Document the insights that families have gathered from their experiences with treatment at home treatments, filtering the best and tricks for other families*
- **Distraction techniques and support with CALM care** — *Connect with CALM care and provide them with post-strategies and resources for families*