

## **1. Nurture Information Hub – Nurture ‘E’ The Triple E Impact**

## **2. Lead Organization(s) and Country/Region**

Miracle Babies Foundation – Australia

Miracle Babies is a woman-led organisation, with all females currently employed, including our CEO. Our Board is 62% female. Miracle Babies’ was founded in 2005 by a team of 8 mothers with a lived NICU experience. We are now Australia’s leading organisation helping to improve, support and enhance all lives impacted by a premature or sick birth. Our award-winning programs are globally recognised.

## **3. Problem Statement (100–150 words) – What health or service gap does this address?**

Each year 48,000 babies are born sick or premature and will need specialised care. For families, the experience of having a baby come into the world not as expected or planned is life changing. Without support, this overwhelming and traumatic experience can have lifelong effects on the emotional wellbeing of these miracle families. Babies born premature, small for their gestational age or babies that have had complications that lead to their NICU/SCN stay run a higher risk of challenges, including disability, developmental and social challenges. These challenges can be present from birth into adulthood. Once a premature baby leaves the NICU, parents are often at a loss as follow on clinics cease, private allied health has long waiting lists and are often expensive and are not always available locally.

The *Nurture* Information Hub is a central resource written in parent language, that empowers families with long-term support and evidence-based education of their child’s risk factors, health impacts and needs throughout all life stages.

## **4. Innovation or Practice Description (200–300 words) – What was done, by whom, and how? Geographical scope.**

*Nurture* InformationHub was developed by Miracle Babies in consultation with a Parent Advisory Team (7 members), Parent Contribution Team (12 members) and Clinical Advisory Team (29 health care professionals and organisations – now 50). Miracle Babies consulted participants on their lived experience and parenting of children through development years who were born premature or sick. The Hub also has 7 collaborating organisations including the Cerebral Palsy Alliance and Epilepsy Foundation Australia.

A website design was developed and a Topics List devised that would provide easy-to-read information for families, useful links on where to get more help and simple navigation of topic lists for each life stage. There are now 137 information topics over 7 life stages. In 2024 the Hub was made even more accessible through the implementation of *Recite Me*, which makes the Hub available in over 100 different languages and contains features such as audio support, visual support, covert to text format and more.

Stage 1:

(Initial focus) Primary School Years, High School Years and Adulthood

Stage 2:

(Current topics) Pregnancy, In Hospital, Post Pregnancy Care, The Early Years, Research

Stage 3:

(Currently in development) congenital and rare conditions

Evidence:

Accessible information on current and relevant evidence-based research so families can be kept updated and informed on treatments and outcomes.

Where possible, the hub also includes information on any current trials and studies available for participation to further help improve outcomes.

Education:

Information and education that is language friendly for parents and carers to help them be the best advocate for their child as they navigate the years ahead.

Empowerment:

Empowering families with the right knowledge and a direction on how to find out more if families have any concerns for their child. Miracle Babies is here to assist families in being able to confidently advocate within their family and in their community for the family and child.

The Nurture Information Hub is available on the Miracle Babies Foundation website ([www.miraclebabies.org.au](http://www.miraclebabies.org.au)) and can be accessed globally.

## **5. Results and Evidence of Impact (150–250 words) – Include quantitative or qualitative data, outcomes, or evaluation results**

Since *Nurture* Information Hub launch in September 2021 until September 2024, website page views have more than doubled. There are now between 40,000 – 60,000 views per month.

Between 2023 and 2024 there was a 24% growth in unique visitors, Latest stats show we now reach more than 550,000 annual page views, from approximately 200,000 unique visitors annually.

In 2023 at the [EFCNI](#) Parent Organisation Summit in Germany, Miracle Babies Foundation was awarded an international EFCNI Award for the *Nurture* Information Hub and was invited to present at the FAOPS in Tokyo.

Reported outcomes from a Parent Advisory focus group included:

- Improved ability to advocate for themselves and parents on behalf of their child (75% of parents said they feel more confident)
- 83% of parents said this is a resource they would share with their child when they are of an age they can advocate for themselves
- More informed health choices leading to better health outcomes
- Improve parental mental health
- Improved support from an organisation who understands their experience
- Kept updated and informed on research treatments and outcomes

**6. Scalability & Sustainability (100–150 words) – Is it adaptable for other contexts? What resources or policies support it?**

As a digital health solution, the Nurture Information Hub is very adaptable in other contexts. Miracle Babies strongly encourages sharing of education and support tools. The *Nurture* Information Hub aligns with the World Health Organization statement that Digital health ‘can help make health systems more efficient and sustainable, enabling them to deliver good quality, affordable and equitable care’. WHO’s Strategy for Digital Health #4: “Advocate people-centred health systems that are enabled by digital health. This strategic objective advances digital health literacy, gender equality and women’s empowerment and inclusive approaches to adoption and management of digital health technologies. The strategic objective places people at the centre of digital health through the adoption and use of digital health technologies in scaling up and strengthening health service delivery.” The *Nurture* Information Hub is a sustainable solution to filling the gap in healthcare when it comes to long-term information and support for families of premature and sick babies.

**7. Lessons Learned or Key Insights**

After launching the Nurture Information Hub, Miracle Babies’ has learnt there is an overwhelming demand for long-term education and support in the community for families of premature and sick babies.

“Social and emotional development and sensory issues that are becoming more prevalent. Learning difficulties. I am so concerned about her physical development as well.”

“My baby has a health condition (that impacts his eating). I am worried about how this will impact him in the long term.”

When asked ‘How important do you believe it is to be educated on longer term health risks of a baby born premature or sick?’ A recent focus group answered 83% responded that it was of ‘Highest Importance’.

Our content strategy is to continue to work with parental advisory groups and consumer advocates on developing the most relevant and needed topics among families of premature and sick babies.

We continue to monitor user engagement to ensure accessibility and user-friendly design. Our 2024 implementation of Recite Me is an example of the importance of inclusivity to Miracle Babies, and reaching as many families as possible.

Improvements for future include proactive feedback mechanisms to gather even greater user-generated insight into the impact the Nurture Information Hub is having on families.

## 1. Partner Quotes or Community Voice (optional but encouraged)

*“This is a very valuable resource for parents of a preterm baby to help them understand the challenges which may be faced in childhood and adolescence, and how best to advocate for their child in a variety of settings.” - Professor Lex Doyle*

*“I hope that thousands of parents worldwide will discover, share and use the Evidence Education and Empowerment program to help their children achieve their fullest potential.” - Prof. William Tarnow-Mordi*

*“I will be recommending it to people that I know.” – Ash, mum to Charlie born at 23 weeks*

*“Information was hard to find and everything was conflicting when we had our babies. I was completely unaware of how much detail and information there was there (on the Information Hub) and I personally I feel better educated knowing what I know now.” – Luke, Dad to two premature babies*

### **Cited:**

- World Health Organization, *Global Strategy on Digital Health 2020 – 2025*, Published 18 August 2021
- Miracle Babies Foundation Parent Advisory Group meeting, First Quarter 2025
- Google Analytics; Website Graph 2025

### **Nurture Information Hub contributors:**

#### **PARENT ADVISORY TEAM**

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#### **COLLABORATING ORGANISATIONS**

- Australian Dyslexic Association
- Cerebral Palsy Alliance
- ADHD Australia
- Epilepsy Foundation Australia
- Down Syndrome Australia
- NEC Society
- The Global Gastroschisis Foundation
- Kidney Health Australia
- Heart Kids Limited
- Autism Awareness Australia
- Centre of Perinatal Excellence (COPE)
- Developmental Coordination Disorder Australia Inc
- Stroke Foundation
- Continence Health Australia
- Birth Trauma Australia
- Immune Deficiencies Foundation Australia
- Diabetes Australia

- Down syndrome Australia

### **PREVIOUS CONTRIBUTORS**

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