

DEVELOPMENT OF SMS4DADS NICU MESSAGE SET

Below is some background information about the development of text messages for dads who have a baby in the Neonatal Intensive Care Unit.

INFORMATION GATHERING

Message development began in early 2022.

Data was collected from parents with lived experience of having a baby in the NICU through social media and email requests between February and April 2022. The platforms for the requests were the Miracle Babies (MB) and Life's Little Treasures Foundations, (LLTF) two Australian charities supporting families with infants in NICU. Parents were asked to complete a survey with questions derived organically in a 'what was missing from your experience' approach.

TABLE 1. SURVEY ITEMS

ITEMS FOR MOTHERS	ITEMS FOR FATHERS
Many dads feel uninformed and therefore powerless when their babies are in NICU.	Many dads feel uninformed and therefore powerless when their babies are in NICU.
What do you wish your partner had known when your baby was in NICU?	What do you wish you had known when your baby was in NICU?
It is common for dads to feel left out in NICU. What helped or would have helped your partner feel more involved while your baby was in NICU?	It is common for dads to feel left out in NICU. What helped or would have helped you feel more involved while your baby was in NICU?
Dads often have a roller coaster of emotions while their baby is in NICU. What helped or would have helped your partner to cope with the situation?	Dads often have a roller coaster of emotions while their baby is in NICU. What helped or would have helped you to cope with the situation?

153 comments were received.

MB: 70 from mums (N=23); 21 from dads (N=8)

LLTF: 41 from mums (N=13); 21 from dads (N=7)

Total: 111 from mums (N=36) and 42 from dads (N=15).

[Two people (CM and RL) created twelve themes from the 153 free-text responses that guided us in mapping the new messages. An example of a theme was difficulty in adjusting and coping with the unplanned, unexpected situation of being in the NICU.]

Three project staff were allocated a set of comments and tasked with identifying a possible message topic from each comment in early July.

Next, CM and RL studied each comment and corresponding topic and decided whether a message could be created in response to the comment and what the aim of the message was.

Following this we applied the SMS4dads message matrix that stipulates characteristics of the message such as maximum 160 characters, tone, suitable web-link, and which pillar from self-care, infant bonding, or relationship with partner the message fits in. As previously stated, this part took around 14 weeks to complete and produced 57 draft messages.

The next step was to invite the two foundations (Miracle Babies and Life's Little Treasures) that had co-designed the survey with us to comment on the new messages. We also invited a dad who has a podcast called 'dadsofthenicu' to comment as we had established a consultative and mutually beneficial relationship with him. In response to their feedback, we modified the wording of some of the messages.

By the end of October one of the researchers had created 14 surveys in REDCap, 7 for dads and 7 for clinicians. Each survey contained around 8 messages and asked the participants to judge whether each message was easy to understand, important, and aligned with clinical practice (for clinicians).

The two foundations then invited their communities by social media posts and emails to sign up to complete a survey via a web-form on the SMS4dads website.

When dads completed the web-form, which included an information statement, we sent them an allocated REDCap survey link by text message using ClickSend.

The clinician network was already established from previous involvement in SMS4dads work and a conference for neonatal nurses in September 2022 in which we garnered interest. Clinicians received an email with their allocated survey link and reminders after one week if non-responsive. This part took approximately 4 weeks to complete, and we received an average of 4.9 responses per survey.

Survey number	Number of clinicians	Number of parents
1	4	6
2	4	5
3	4	5

4	5	5
5	4	5
6	4	4
7	9	4
Total	34	34

Over two three-hour sessions in late November/early December the two researchers studied the REDCap responses and modified any message that had a low quantitative score or a suitable recommendation to adjust the wording.

Two messages were discarded as they were triggering or unhelpful.

The broader SMS4dads team were sent the final 55 messages to appraise mid December. Following this step, the messages were collated in a final REDCap survey. The link was sent to all previous participants (dads and clinicians) to assess acceptability.

8/2/23

The final survey was completed by 11 clinicians and 13 parents. Summary table here.

18 messages were acceptable to all respondents.

9 to all except for 1 parent who did not like the use of the 'baby voice'.

12 messages were unacceptable to 1 respondent.

2 messages to 1 respondent and the parent who did not like the baby voice

6 messages were unacceptable to 2 respondents.

That gave a total of 47 messages that were considered acceptable (2 or less respondents found unacceptable) for the final message set in terms of general consensus from respondents and total overall score from the short surveys. 2 further messages were considered of value due to their high previous scores and so were accepted with modifications derived from comments in the final survey.

18 of the messages were modified in response to comments made by survey responders.

The wording of 6 messages was modified when RL and CM applied a strengths-based approach to the set and identified negative language in these messages. This action followed from reading a document from Frameworks Institute.

THEMES AND MESSAGES

Themes – sourced from this mapping exercise

- Adjusting/coping/settling in to NICU
- Understanding dads' authority/rights/responsibility with decision making

- Self-care especially when leaving family behind at hospital
- Being aware of a plan and goals for going home
- Filling knowledge gaps about the setting and operations
- Developing a bond with baby
- Nurturing the relationship with mum

THEME | Adjusting/coping/settling in to NICU

Co-design survey comment	Draft Message	Clinician/Parent Comment	Final message
I was so scared that I would hurt her, I just wish staff had've helped guide me a bit more.	4DadinNICU: Hey Dad. The nurses can show you how to hold, change, bath and feed me. Ask them for tips so we can hang out together. M51	<p>You feel so helpless and like you will do it wrong or break them. The nurses are amazing but it can feel like you can't participate Some reassurance would be perfect. (p)</p> <p>Why would a baby send a text. This message should explicitly encourage dads to be more hands on (p)</p>	4DadNICU: The nurses can show you how to hold, change, bathe and feed me Dad. Ask them for tips so we can hang out together.

THEME | Understanding dads' authority/rights/responsibility with decision making

Co-design survey comment	Draft Message	Clinician/Parent Comment	Final message
<p>Fathers are the ones who are consulted first. Fathers are often the ones making the first decisions eg. Injections, blood transfusions, heal prick testing, research.</p>	<p>4DadinNICU: When decisions are being made about me, I want you to be involved dad. Two parents are wiser than one. M2</p> <p>4DadinNICU: You are now my legal guardian dad. It is a shared responsibility. Ask for information so that you can be involved in decisions. M11</p>	<p>I'm not sure about the phrase two parents are wiser than one- 2 brains are better than one. (cl)</p> <p>It has a very negative feel towards the father. maybe wording around 'all decisions for me are a family decision' (p)</p> <p>Often dads are the first ones to make decisions. Especially when there is an emergency and questions get fired at you all at once. But once things settle down then yes two are better than one. (p)</p> <p>"Legal guardian" sounds wrong. Just "dad" (p)</p> <p>I would think about adding something like: 'a shared and equal responsibility' some dads may not know they have an equal right in their children's decisions. (p)</p>	<p>Merged with below re-draft.</p> <p>4DadNICU: I trust you to make decisions about me Dad. I know you care about me. 69/92</p>

		<p>This is important but it's more about family Integrated care- lose the jargon. (p)</p> <p>Seems strange that it's from the point of view of the baby? (p)</p> <p>Both parents share the responsibility and legal guardianship for children. At times, if dads aren't in hospital as much as mums, so this can be difficult. You can ask questions and for information so that you are involved in decisions. (cl)</p>	
--	--	--	--

THEME | Self-care especially when leaving family behind at hospital

Co-design survey comment	Draft Message	Clinician/Parent Comment	Final message
I found it difficult to go home and leave my wife and baby in hospital. Someone telling me it's ok to go home and rest actually meant a lot as I didn't feel like I was letting people down by not being there	4DadinNICU: Leaving family at hospital is difficult for new dads. It might not seem right when life outside carries on. Keep in touch by text and talk. M10	You could add- it's ok not to be ok, that's why reaching out and talking is so important (p) Maybe specify to keep in touch with friends/family when dad is in a 'nicu bubble' and loses track of the outside world? (p) Leaving family at hospital can be difficult for new dads. It might not seem right when life outside carries on. Keep in touch by text and talk. (cl)	4DadNICU: Dads often have to leave their family and travel home in a world that carries on as usual. Keep in touch with your family by text and talk.

THEME | Being aware of a plan and goals for going home

Survey comment	Draft Message	Clinician/Parent Comment	Final message
Knowing what progress indicators to look for and understanding little steps forward were actually a big deal.	4DadinNICU: If you ask the team they should be able to tell you what goals I need to kick before I can go home. Keep asking as these often change. M15	Good message just seems weird to have it from the babies point of view (p) If you ask the team they should be able to tell you what goals I need to kick before I can go home.	4DadNICU: If you ask the team they should be able to tell you what goals I need to kick before I can go home Dad. Keep asking as

		Sometimes the goal posts change though, as my health changes. Keep asking as these often change. (cl)	the goal posts can change.
--	--	---	----------------------------

THEME | Filling knowledge gaps about the setting and operations

Survey comment	Draft Message	Clinician/Parent Comment	Final message
Listen and Ask questions on the rounds. The doctors will explain everything very well but ask clarifying questions.	4DadinNICU: Staff will usually do their best to pass on the right amount of info. If you need more info, ask. If you are getting too much, let them know. M13	Also if they don't understand something, always ask again until you do (p) Staff will usually do their best to pass on the right amount of info. Everyone's need for the amount of information is different. If you need more info, ask. If you are getting too much, let them know. (cl)	4DadNICU: Staff will usually do their best to pass on the right amount of info. Let them know when you need more, less, or clearer information.

THEME | Developing a bond with baby

Survey comment	Draft Message	Clinician/Parent Comment	Final message
How to be more involved in my baby's care. Tips on how to bond with her in the unique circumstances would also have been	4DadinNICU: I am using all my senses to bond with you dad. I smell you, hear you and thrive on your touch. See more info here [*StaticLink*] M33	I had to read it a few times before I understood the message. Words okay but I think if I got that out of the blue it would confuse me a	4DadNICU: I am using my senses to bond with you Dad. I smell you, hear you and thrive on

helpful. At times I felt very helpless.

little bit. Maybe some warning or acknowledgment of the sms intent. This may have already been considered. Great knowledge to know though, I never got informed of this just that kangaroo cuddles are great. Maybe at the end add recommendations to how these can be actioned to their child like suggesting kangaroo cuddles bare chested, I use to sing or hum to my daughter so she could hear my voice and feel through my chest. Smell is a good one. We got told not to wear cologne so maybe suggest using a soap that she can recognise as her carer, not sure on this one. (p)

if you can afford the characters i would say, "thrive on your gentle touch". (cl)

Difficult to judge clinical practice relevance without knowing what the external link will be. I think it would be good to have really specific info on the sorts of

your gentle touch. See more info here [[*StaticLink*](#)]

		<p>physical touch that is helpful/safe for preterm infants. (cl)</p> <p>* all *of my senses-- very broad and vague- sight/ taste - is not used... . maybe consider replacing * thrive* with *know/love* (cl)</p>	
--	--	--	--

THEME | Nurturing the relationship with mum

Survey comment	Draft Message	Clinician/Parent Comment	Final message
I wish I had known how to better support my wife.	4DadinNICU: Mum will cope better if she gets regular breaks from the NICU. You need a plan to make this happen. I know you can do it dad. M32	<p>Thanks for helping mum be strong instead of I know you can do it. Less pressure on the dad. (p)</p> <p>just going to the grocery store was a good little break and a feeling of normalcy (p)</p> <p>I am worried that it will put pressure on dads if they have to make this happen. I think the principle behind it is true, but maybe the wording is very strong. Could it be expressed more as a question, for</p>	4DadNICU: Mum will cope better if she gets regular breaks from the NICU. Even a quick trip to the shops can help. You can help her plan these trips Dad.

example: Can you help her to achieve this? (cl)

I would change the tone of the last sentence. To my untrained ears, that sentence sounds more appropriate to a child. I wonder if it might sound condescending. (cl)