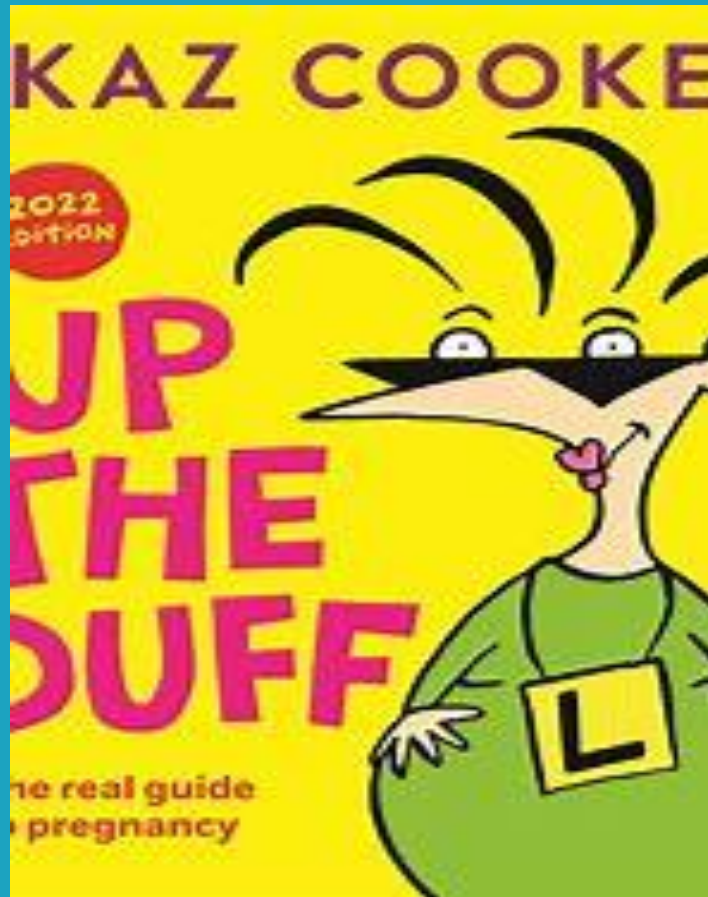


**Fiona d'Young  
MS Nurse Auckland  
Hospital  
MSNA Podium  
20<sup>th</sup> October 2023**

**MS & PREGNANCY: EXPERIENCES  
AND EXPECTATIONS OF NZ WOMEN  
WITH MS**

# The 2 big pregnancy E's





04/06/2012 23:24



# Inciting Incident

- Kiri (32) on Tysabri, stopped for pregnancy
- 18 week miscarriage Feb 2018
- No liaison between private Obs Med and DHB neuro 3/12 window
- DNA'd neuro appointments
- Kiri and family have limited English
- What if?



# So, we wondered.....

How might we best support women with MS through the stages of pregnancy, from the planning phase to the early stages of motherhood

# MS PREGNANCY PROJECT



## BACKGROUND

Lack of local knowledge

Negative personal stories from women with MS

No repository of information for women with MS or LMC's



## PARTNERS

Collaboration with MS Society Auckland

Input from DHB performance improvement team

Liaise with DHB ethics board



## PLAN

Interview women post partum to learn from their experience

Workshop 'pregnancy planning' women with MS to learn expectations

## 2018-2023

- **Dobson et al 2019** UK consensus on pregnancy in multiple sclerosis Association of *British Neurologists Pract Neurol* 2019;19:106-14
- **Farakoudi A, Rumbold A, Grzeskowiak 2023** Family planning and MS: a qualitative study of patient experiences to understand information needs and promote informed decision making.  
*Patient educ & counselling* 110(2023) 107673



# OUR APPROACH

We used a person-centred design process, to develop solutions to this opportunity by involving the human perspective in all steps of the process. By understanding what matters most to people we are more likely to design solutions that work for the end user.

## UNDERSTAND



Understand the current experience of women with MS who have been, plan to be or are currently pregnant

## IDENTIFY



Identify the things that mattered to them during their pregnancy journey.

## LEARN

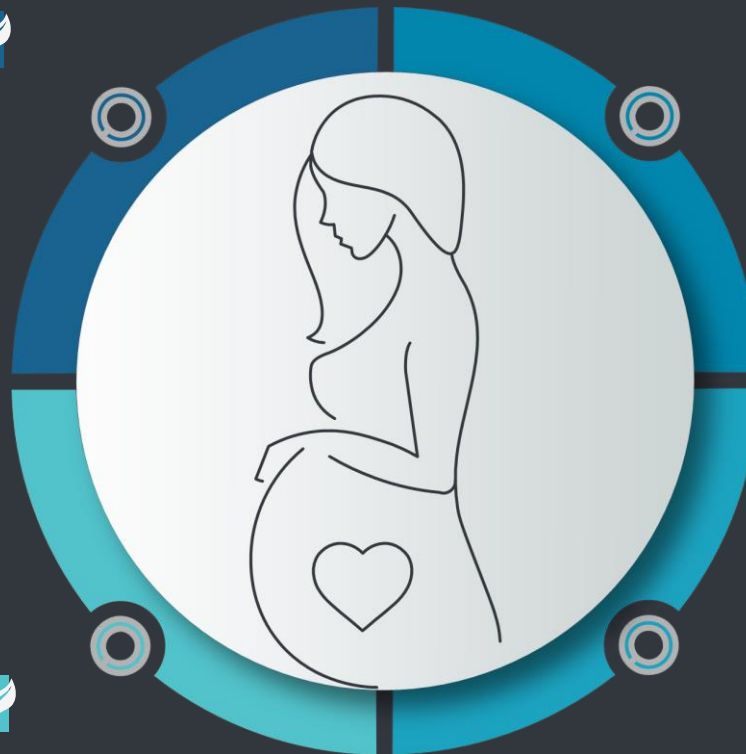


Learn from the prototypes and develop the solution/s.

## DEVELOP AND PROTOTYPE



Develop and prototype ideas to support women with MS on their future pregnancy journeys.



We met with



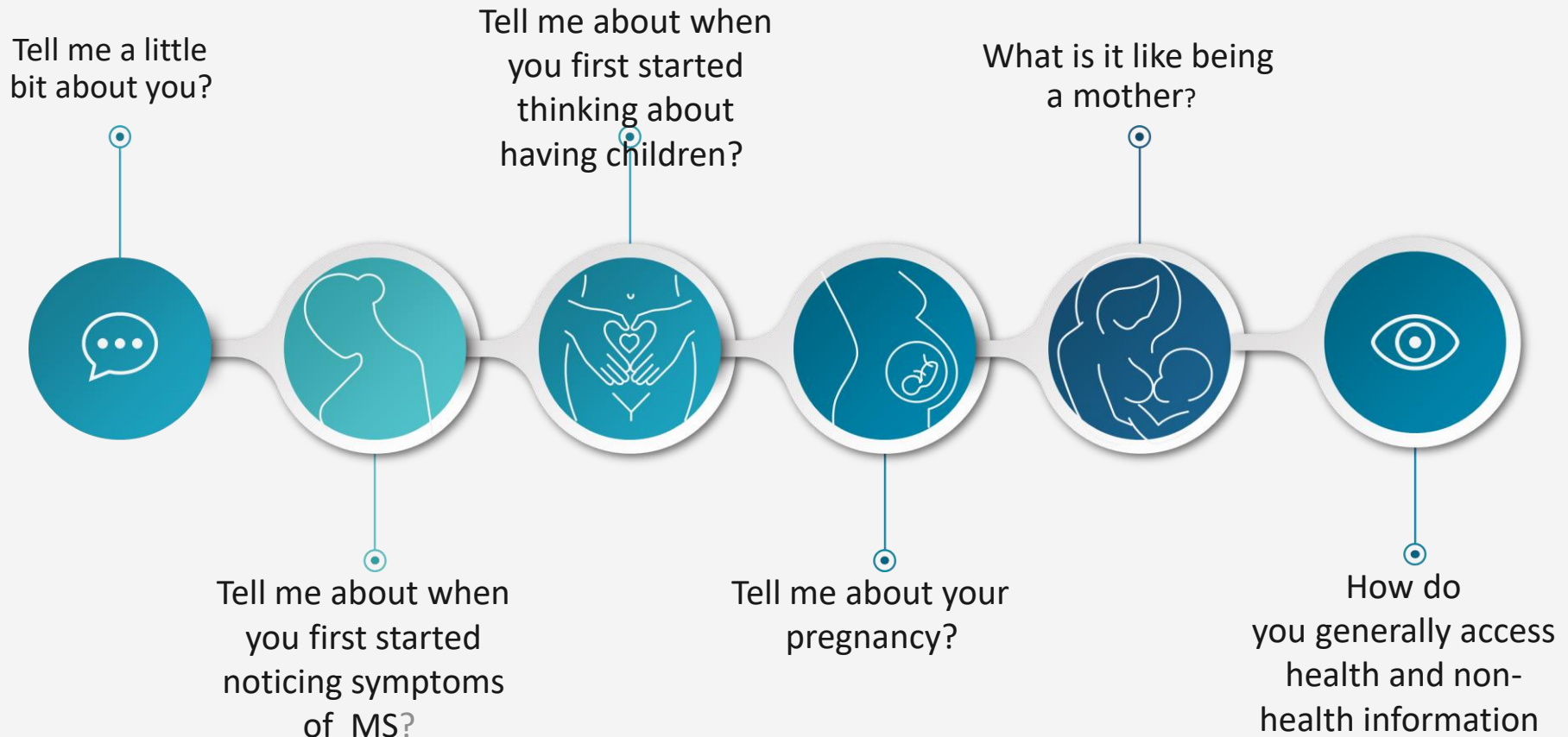
women

from across Auckland who  
have MS and who have  
been or are pregnant

Following a semi-structured  
interview framework, they  
shared their experience of MS, and  
their pregnancy journey,  
including motherhood.

The interviews were recorded and we  
used a deductive coding process to  
identify themes and insights from  
the qualitative data.

# Understanding the experience of women with MS





# THE INSIGHTS

Insights are pieces of knowledge that have been extracted from the combined experiences of the people we interviewed

# THE INSIGHTS

## When planning my pregnancy

I want to understand how MS might impact my child and how my health will be impacted by pregnancy, and what supports are available and how to access them.



## When pregnant

I want to be fully informed on how to manage my health post birth & what to expect as a mother with MS.

I want to feel empowered to make decisions and be involved when services communicate about me.



## When a mother

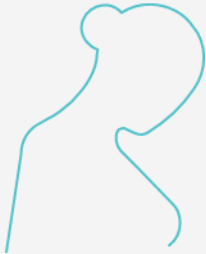
I want to know how to maintain my own wellbeing, be the best mother I can be and connect with others who understand what it's like.



## As a woman with MS

I want the system to be proactive and reach out so I can be reassured that they are keeping an eye on me because I may not know what to look out for.





## AS A WOMAN WITH MS

I want services to be proactive in reaching out and empathetic and I want others to understand my reality

### INSIGHTS FROM THE INTERVIEWS



As a young woman with a recent MS diagnosis, I feel like people didn't believe me when I reported symptoms, because young women should be healthy, but there were missed opportunities for early diagnosis and treatment



"I didn't tell my good friends until I'd had it for 5 years and looking back that was really stupid and made for a horrible time"



# WHEN PLANNING MY PREGNANCY

I want to understand how MS might impact my child and how my health will be impacted by pregnancy, what supports are available and how to access them.

## INSIGHTS FROM THE INTERVIEWS

When planning pregnancy I want to have support from my neuro team when I need it, so I can do everything right for me and my baby.

I want to know if I will pass MS on to my child (during pregnancy or through breastfeeding), so I can emotionally prepare better and consider my options.



“I didn’t know if I ever wanted a family because I didn’t know if I’d be able to hold the baby safely, and carry him”



‘I don’t think information is readily available”



## WHEN PREGNANT

I want to be fully informed about pregnancy, how to manage my health post birth and what to expect as a mother with MS. I want to feel empowered to make decisions and be involved when services communicate about me.

### INSIGHTS FROM THE INTERVIEWS

As an expectant mother, I google information on MS and pregnancy, because I want to be fully informed to manage my health and my baby's health, but I am not confident on what information is accurate.

As a person with mild MS, I have lots of questions about my baby's health, but I don't feel able to access specialist advice as others are worse off than me and there are limited resources.



“After the first initial bad experience [at high risk pregnancy clinic] it stopped me asking questions. I kind of stopped asking anyone any questions”



“You do wonder, am I going to pass it (MS) on?”





## WHEN A MOTHER

I want to know how to maintain my own wellbeing, be the best mother I can be, and connect with others who understand what it's like.

### INSIGHTS FROM THE INTERVIEWS

As a mother with MS, I need support with my wellbeing because parenting is hard and MS makes me tired, but I'm too tired to get help and where would I go for this help?

Becoming a mother, I want to be perfect because society/my culture expects it of me, but my MS makes me tired and I am weak and I can't be the perfect mum.

”

“I wanted to be a Stepford Wife, and I always wanted to be the Mum with the best cupcakes”

”

“Be mindful that every patient is different with different coping strategies”

# We held a workshop

7

couples from across Auckland who have MS and who are planning a pregnancy attended

A semi-structured co-design workshop, helped us better understand what women and whanau would want to know about pregnancy and parenthood and how they would prefer to access this information

We asked attendees to help design potential solutions for prototyping



# IDEA GENERATION

We ran ideation sessions with women who have MS and are planning for pregnancy. The session included partners and focussed on the following “How might we’ opportunities:

1. **Provide** information on how MS impacts your child and you when pregnant ?
2. **Empower** you to own your birth plan and feel confident to make your own choices?
3. **Communicate** better with you during pregnancy?
4. **Support** you to have a plan in case of relapse post pregnancy?
5. **Support** you to achieve your parenting goals?

# THE IDEAS

MSinfo TOOL KIT

MY HEALTH PLAN

WEBINAR SERIES

EDUCATE LMC's

# MSinfo Tool Kit

- Practical comprehensive & validated information about MS & Pregnancy
- A resource hub to help people navigate the system such as a list of MS midwives
- Educational videos from both the health and personal experience perspectives



## Educate Clinicians

Build core relationships with 3x obstetric medical departments across Auckland



Introduce MS team to each named LMC to track pregnancies



Website link for LMC's to access MS maternity specific academic papers and guidelines





# Journal Publication



# WEBINARS/PEER SUPPORT

Webinars could be delivered by people with lived experience and/or specialist nurses, neurologists, etc.

Pregnancy peer support groups facilitated by MS Akld with successful groups still in contact a parents





# My Health Plan

A personalised plan held by the woman that focuses on her health and wellness during pregnancy and post birth to mitigate against the risk of relapse post birth.

This could be attached to existing booklets such as the Plunket book and/or downloadable through the tool kit.





# PROGRESS

- **Collaboration with MSNZ for addition to national website**
- **Video's filmed for women planning pregnancy**
- **Video's filmed for obstetric and midwifery reference**
- **Liaison with midwifery council to create awareness of the work**
- **Forge close links with local obstetric medicine teams so key timeframes eg DMT re-start dates are clear**
- **Case by case interaction with named LMC as pregnancy progresses**



08/08/2012 22:54

# What's around the corner?

