



**Experience Lab**  
Ritual Respect

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**The Glasgow School of Art**

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**INNOVATION  
SCHOOL  
THE GLASGOW  
SCHOOL OF ART**



**DIGITAL  
HEALTH & CARE  
INSTITUTE**

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**Digital appendix**


- A: Map of current experience of care around miscarriage
  - B: Framework for future care enabling emotional wellbeing
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# Ritual Respect

Ritual Respect employed a participatory design approach to co-design emotional support and care around miscarriage, working with women who have experienced miscarriage, health professionals and practitioners from the third sector.

 Participants: **9**

**Project Output:**  
 - Project film  
 - Report  
 - Presentation to Scottish Early Pregnancy Network (SEPN)  
 x3

## Key Findings:

### 1 Being prepared:

Increasing awareness on early pregnancy loss and training health professionals is key for being prepared and managing expectations.

### 2 Time and space to grieve:

Ensuring early emotional support soon after diagnosis of miscarriage is crucial and sets the tone for rest of the care journey.

### 3 Emotional support:

Provide health professionals the time and tools to create a tailored care plan for the woman, which includes local support and access to information in their own time.

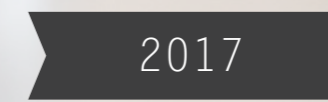
### 4 Remembrance:


Empower women to make personal choices around remembrance and ensure access to physical, digital and symbolic services and platforms.

### 5 Hope for future:


Ensure all women have the freedom to choose support for bereavement, counselling and planning future pregnancies based on personal needs.

**3** Exp. Labs  
 + 3 Pre-Labs




**Lab Team:**   
 »→ Sneha Raman  
 »→ Angela Tulloch

**Locations:**  
 - The Lighthouse, Glasgow  
 - Cafe Coast, Aberdeen  
 - GSA, Forres  
 - GSA, Glasgow  
 - CCA, Glasgow

**Partners:**   
 »→ Prof. Grant Cumming  
 »→ Prof. Susan Klein




**16** Hours Exp. Lab time  
**8** Hours Pre-Lab time

- Tools:**
- Personas
  - Bespoke Charms and Visual story
  - Low fidelity prototypes
  - Experience map

- Methods:**
- Visual story mapping
  - Current state mapping
  - Experience mapping
  - Concept prototyping
  - Visual synthesis

## Key words:

Miscarriage

Emotional support

Co-design

Women's wellbeing





## Executive Summary

Miscarriage is sadly the most common type of complication associated with early pregnancy, with approximately one in four pregnancies ending in miscarriage. For each woman the experience is different, and access to the right information and emotional support at the right time is crucial to enable them to cope with their loss. However, ongoing emotional support provision for women following miscarriage that meets individual needs is notably lacking, which for many can result in enduring

negative effects on their health, relationships, and future pregnancies. This gap in healthcare provision also has wider implications for NHS services, capacity and resources in the long run.

The research project led by The Glasgow School of Art in collaboration with NHS Grampian, and funded by the Digital Health & Care Institute (DHI), aimed to support health professionals, and empower and equip women to improve their emotional wellbeing

following miscarriage from a person-centred perspective. The project employed a participatory design approach, collaborating with: women who have experienced miscarriage, health professionals who are involved in providing care around miscarriage (i.e. consultants, midwives and specialist midwives), and representatives from a perinatal counselling group. A series of engagements including Pre-Lab sessions and three Experience Labs were organised over a period of four months. This report presents the

findings from the project.

Analysis and synthesis of the Lab outcomes (i.e. the conversations, maps, artefacts and concept prototypes) offered rich insights around: women's experiences of miscarriage and scenarios of accessing care; current care pathway capturing key stages and experiences from the perspective of health professionals and women; qualities of preferable care; and concepts for a preferable model of future care by focusing on the emotional care journey.

Ethical approval for the full study involving members of the public was granted by The Glasgow School of Art ethics review committee. The NHS R&D committee granted ethical approval for involving health and care professionals in Scotland.

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### Experience Labs

Experience Labs were developed by The Innovation School at The Glasgow School of Art. They offer a safe and creative environment where researchers, businesses, civic partners and service users can collaborate to find innovative solutions to the health and care challenges facing Scottish society. The Labs are the core element in the Digital Health & Care Institute (DHI); a Scottish Innovation Centre funded by the Scottish Funding Council, in partnership with Scottish Enterprise and Highlands and Islands Enterprise.

In the Experience Labs, researchers use current and emerging design research methods to engage with partners and participants, who are encouraged to share their own experiences. Real-life practice is often replicated to allow new technology, services, processes and behaviour to be trialled rapidly. The resulting concepts become the focus for further research and development, allowing them to achieve their full potential.

### The Digital Health & Care Institute

The Glasgow School of Art is a founding partner in the Digital Health & Care Institute (DHI); a partnership between The University of Strathclyde, NHS 24, Scottish Enterprise and Highlands and Islands Enterprise. The DHI Innovation Centre creates an open community where industry can collaborate effectively with academia, healthcare and social partners on innovation opportunities that promote societal and economic benefits in Scotland. The DHI seeks to co-create sustainable economic growth through new products, services and systems. These solutions are designed to generate high value health and social care solutions for the benefit of the people of Scotland and further afield.

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### Experience Lab Project Team

<b>Sneha Raman</b>	Research Associate, The Glasgow School of Art
<b>Angela Tulloch</b>	Research Associate, The Glasgow School of Art
<b>Hannah Laycock</b>	Film and Photography, Hannah Laycock
<b>Louise Mathers</b>	Film and Photography, No Middle Name

### Project Partner

<b>Prof. Grant Cumming</b>	Consultant Obstetrician and Gynaecologist, NHS Grampian
<b>Prof. Susan Klein</b>	Professor in Trauma Research, Academic Consultant

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### Acknowledgements

We would like to thank all of our participants for giving up their valuable time to take part in the Experience Labs. We would also like to thank Ruth Bender-Atik, National Director of The Miscarriage Association, for her valuable inputs towards reviewing the project plan and recruiting participants. We are grateful for the support of our colleagues at the Glasgow School of Art.

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## Project Background

Miscarriage is sadly the most common type of complication associated with early pregnancy, with approximately one in four pregnancies ending in miscarriage. For each woman the experience is different, and access to the right information and emotional support at the right time is crucial to enable them to cope with their loss. However, ongoing emotional support provision for women following miscarriage that meets individual needs is notably lacking, which for many can result in enduring negative effects on their health, relationships, and future pregnancies (Cumming et al., 2007; Rowlands and Lee, 2010; McLean and Flynn, 2013). This gap in healthcare provision also has wider implications for NHS services, capacity and resources in the long run.

'Miscarriage Matters'— a web-based resource offering women extensive information and advice on both the physical and psychological impact of miscarriage was piloted in 2005-2006, by our research partner at NHS Grampian in collaboration with the Aberdeen Centre for Trauma Research, University of Aberdeen (Klein et al., 2012). This was a 14-month online pilot funded by the Chief Scientist Office. The design and content of the website was

informed by a previous study funded by the Chief Scientist Office to identify the emotional burden of miscarriage on women and partners. A further study was undertaken by The Glasgow School of Art in collaboration with the research group to identify the potential users of the website and design considerations. The project was funded by the Institute for Health and Wellbeing Research at the Robert Gordon University.

Additionally, working with the Scottish Early Pregnancy Network (SEPN) and allied health professionals (including psychologists), the research group identified gaps in the current provision of emotional support. This included the: need for an increased focus on raising awareness of miscarriage; acknowledging the loss of an unborn baby, and providing opportunities for women to express their emotions (Roxby, 2014; Bolsover, 2008; Brier, 2008). A key area of interest that emerged from this work was in exploring how digital platforms may be used to connect women in a meaningful way and enhance emotional adjustment following miscarriage. In terms of existing digital resources, established online platforms and smartphone applications offer detailed advice and support for the self-management of

successful pregnancies, but such resources provide limited support for women who do not carry their babies to full term (Ready Steady Baby!, 2013). The strengths and limitations of a range of healthcare services and charitable organisations whose websites currently offer practical information for women who have experienced miscarriage (Miscarriage Association, 2014; Mumsnet, 2014) were also considered. A lack of consistent information and bespoke emotional support combined with varying levels of sensitivity provided by GPs emerged as key issues. The potential for designing an integrated care platform, which engages, encourages expression, and empowers women to externalise their emotional experiences through creative storytelling also emerged (McHattie and Broadley, 2014).



## Aims

Building on previous research, this project explored how a design-led perspective of social, cultural, and technological innovation can support health professionals and empower women to approach emotional wellbeing around miscarriage from a person-centred perspective.

## Objectives

The overall objectives of the research were to:

- Understand women's experiences of bereavement, emotional expression and support following miscarriage.

- Map care and resources made available to women and understand how these are accessed from the perspective of both health professionals and women.
- Co-design ways (including digital) to support health professionals and empower women to approach emotional wellbeing around miscarriage from a person-centred perspective.

## Research Questions

Current pathways and experiences of care following miscarriage in Scotland were captured, and concepts were developed to address the following questions:

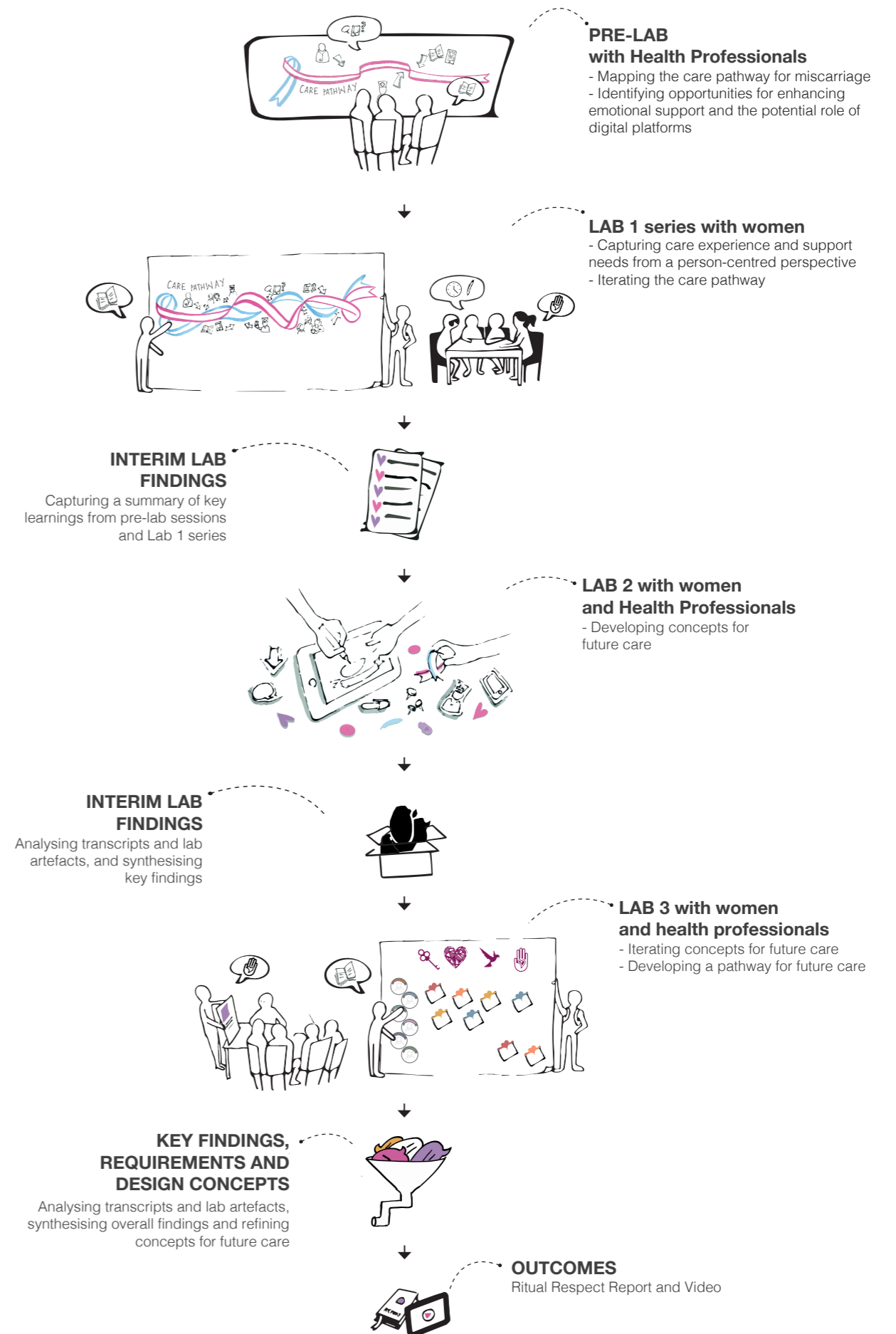
- What information and support is made available, by whom, and when?
- How could care and support be made better?
- Could digital platforms connect women with the right people/ resources in a meaningful way to promote emotional wellbeing following miscarriage?
- How can we co-design support and care around miscarriage in the future, targeting key moments that have a significant impact on women's care journey and emotional wellbeing?

## Methodology

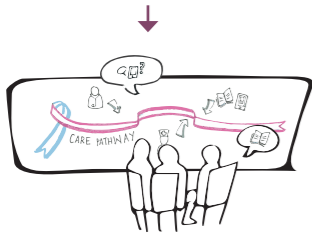
A participatory design approach was used to engage with women who have experienced miscarriage and health professionals who are involved in providing care around miscarriage (i.e, consultants, midwives and specialist midwives) and representatives from a perinatal counselling group. A series of engagements

including Pre-Lab sessions and three Experience Labs were organised over a four-month period. Considering the sensitive nature of the project, the Labs focussed on creating a safe space and flexible plan responsive to the participants' emotions. An academic consultant specialising in trauma research took part in

the sessions involving women to help mitigate any potential discomfort experienced through recounting personal experiences.



# Pre-Lab 1



## What we did

The Pre-Lab sessions were a series of one-to-one sessions of 2-hours duration with health professionals held in Forres and Glasgow. In these sessions, researchers worked with three health professionals – two consultants and a specialist midwife, to visually map the care pathway following miscarriage from different health professionals’ perspectives and understand how care is currently delivered. The aim was to create a base map for further exploring care pathways and experiences from the perspective of women and other health professionals in the subsequent Labs.

## Methods

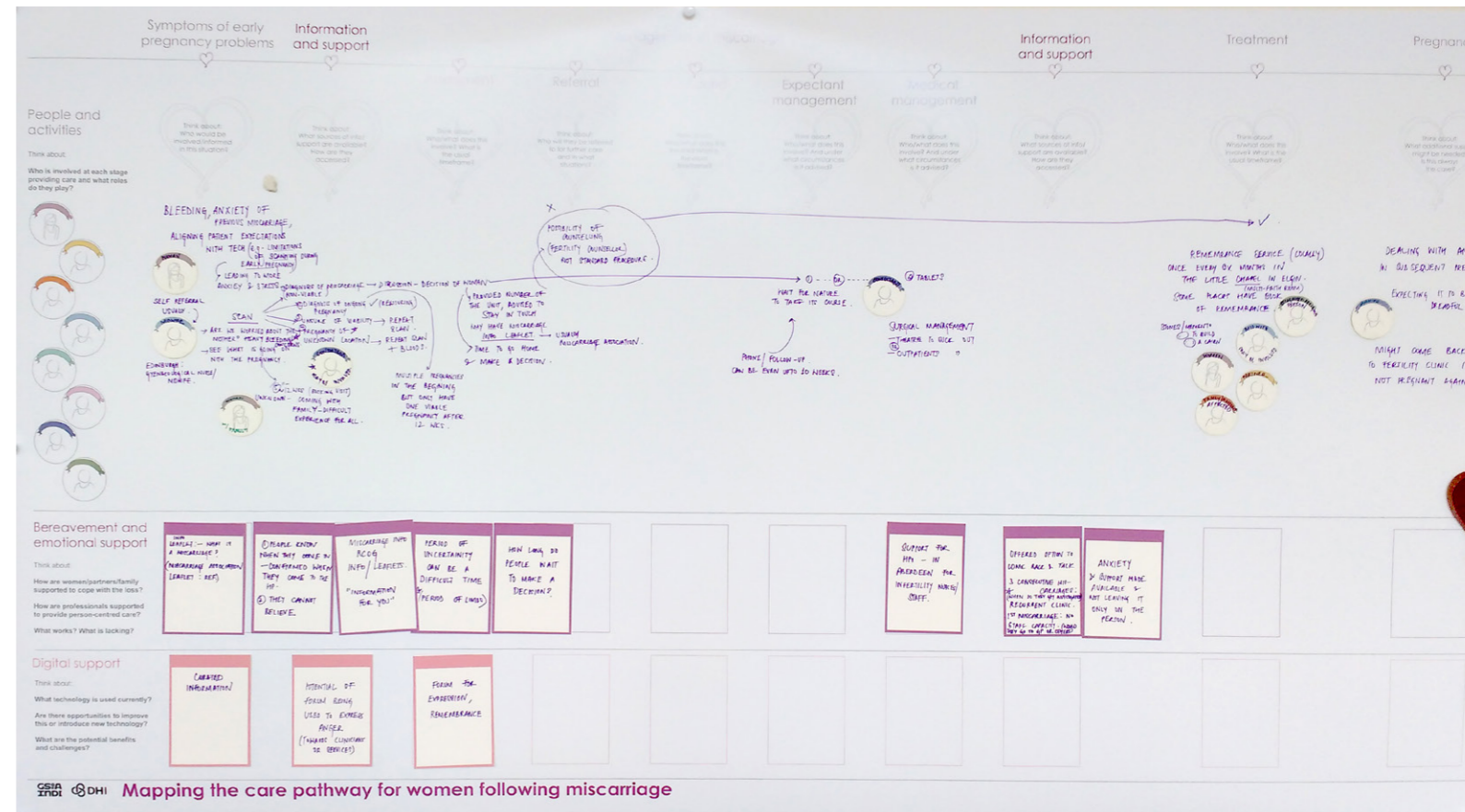
Researchers created a base map dividing the key stages of the care pathways based on the NICE Guidelines (2016), along with prompts for each stage of the care pathway to capture an understanding of: who is involved; what information/resources are available; access to emotional/ bereavement support, and criteria for referral/ follow-up etc.



## Key Findings

The insights from each of the engagements with health professionals were layered on top of each other, and helped to create a holistic picture of care provided at different stages: early symptoms; assessment; referral; ultrasound; management of miscarriage; and treatment and future pregnancy.

The discussions highlighted key points where information and support is currently made available to women, and variations and gaps in the process/resources across different health boards and hospitals in Scotland. For example:



- Information leaflets are usually provided to women following the management of miscarriage.
- There is no standardised information, and health professionals often signpost women to third sector organisations such as the 'Miscarriage Association' or 'Stillbirth and Neonatal Death charity (SANDS)'.
- Remembrance services also vary across the hospitals.
- Counselling services are generally made available to women following three

or more consecutive miscarriages, leaving other women with no formal follow-up or support to help them cope.

The insights were used to create a base map for the care pathway to support further discussion and iteration in the subsequent Labs.



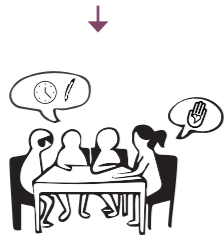


A  
Space that  
will never be  
filled  
♡

“...the wee empty bottle, a space that will never be filled. Just because you have another baby or whatever doesn't mean to say that space has been filled ...”

- Specialist Midwife

## Exp. Lab 1



### What we did

Experience Lab 1 was a series of two half-day workshops held in Glasgow and Aberdeen respectively, and involved 2 women who have experienced miscarriage. The aim of this series of Labs was to understand the care experience and support needs around miscarriage from a person-centred perspective and to capture the key aspects of preferable future care. Building on the findings from the Pre-Labs, the care pathway was further reviewed and iterated from the women's perspective.

### Method

Participants were asked to consider their individual experiences of care following miscarriage, including: the various aspects of their care needs (i.e., physical, emotional, social; how they felt about the care received in response to these needs), and personal ways of coping with the loss. Participants were asked to visualise this using craft materials and charms with a view to support them to express their emotions and feelings. They were given the option to work together or individually. Participants chose to work together as it allowed them to



share and build on each other's experiences.

The care pathway generated from the Pre-Lab session was then reviewed by the participants, further adding key insights based on their personal journey – who was involved, what information and support was available, how and when did they access different services, what were the positive aspects of the care received, and what could have been different at various stages of their care journey. Participants also discussed their aspirations around the qualities of care in the future and used the craft materials provided to build a representation of future care. They chose the form of a dreamcatcher – traditionally thought to be a symbol of protection and more widely associated with hope and healing, as seen in the image to the right.



### Key Findings

The activities with women in Lab 1 uncovered rich stories based on their personal experiences of care following miscarriage, and highlighted emerging areas of focus for future care. These are presented below, along with a list of preferable qualities of future care around miscarriage.

#### Early support, personalisation and continuity of care

Participants highlighted the importance of bereavement support in early stages in order to reduce anxiety later on.

- More compassion and support should be provided in the early stages to women (and all those affected) with a focus on normalising (rather than medicalising) bereavement.
- Participants also emphasised that each woman responds differently to miscarriage, and their care needs are

often shaped by all aspects of their life and not based on a single event. It is therefore important that there is sufficient time provided to understand the individual circumstances and care needs in the early stages.

- It is important to put together a tailored care plan that ensures continuity of care and offers a range of options for access to information and support that are appropriate to the various stages, including support in person and through digital platforms.

#### Improving awareness

Participants discussed the importance of supporting all women to be prepared in the event of a miscarriage.

- This should be done through sensitively educating women (and the public) and raising general awareness around miscarriage, using curated

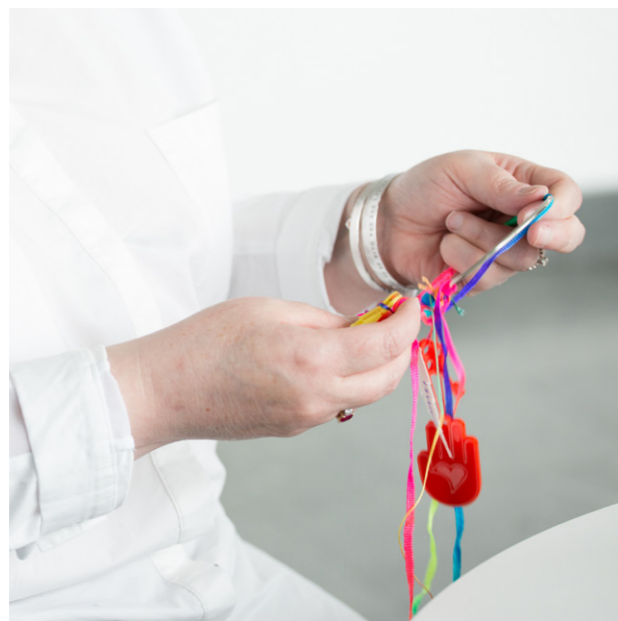
and reliable educational tools/content.

- Participants also noted that information should be made available at different points in the care journey as women may not have taken onboard all information provided following a diagnosis of miscarriage due to experiencing initial shock.
- Also, as women may have questions later on, it is important that they are signposted to the right people/resources for further information and ongoing support.

#### Training health professionals

It emerged that there is a need to focus on improving communication skills of health professionals, as how they deliver bad news has a huge impact on women.

- Participants noted that



all health professionals working in early pregnancy loss should be trained to communicate with women following miscarriage in a sensitive and respectful manner, and have the necessary 'counselling skills' to offer appropriate support. 'Counselling skills' in this context do not mean that all health professionals are trained to be counsellors; it means enhancing soft skills and etiquette associated with counselling such as listening and empathy, and developing an understanding and sensitivity towards how people receive information when they are in distress.

→ It was also noted that health professionals need to be provided training and support to ensure their own wellbeing when dealing with sensitive issues.

→ Participants proposed that there is an opportunity to create guidelines towards providing emotional care and use digital tools to facilitate training for health professionals.

#### 'Permission to grieve'

'Acknowledgement' and 'remembrance of loss' both represented a key focus of discussion within the Lab. One of the participants noted that women are often in a 'state of shock' and they need to be given 'permission to grieve.'

→ It is important to acknowledge the loss following the event and support bereavement, and empower women to make personal choices around remembrance, especially during sensitive periods such as due dates, anniversaries and holidays.



#### Qualities of future care

When discussing the preferable qualities of future care, participants highlighted the following as key: time; choice; trust; being prepared; being in control; frank communication; credibility and accuracy of information; acknowledgement; empathy; permission to grieve; and hope for the future.

# Personal experiences

The visuals presented here detail two participant's personal experiences of pregnancy loss, exploring their circles of care throughout their individual journeys and highlighting the fundamental insights. Pseudonyms have been used to protect the women's identity.

## Maureen

Maureen experienced one miscarriage before she had her daughter her 'rainbow baby'. Her experience is represented over time as Before, During, After and Long Term.

### Before

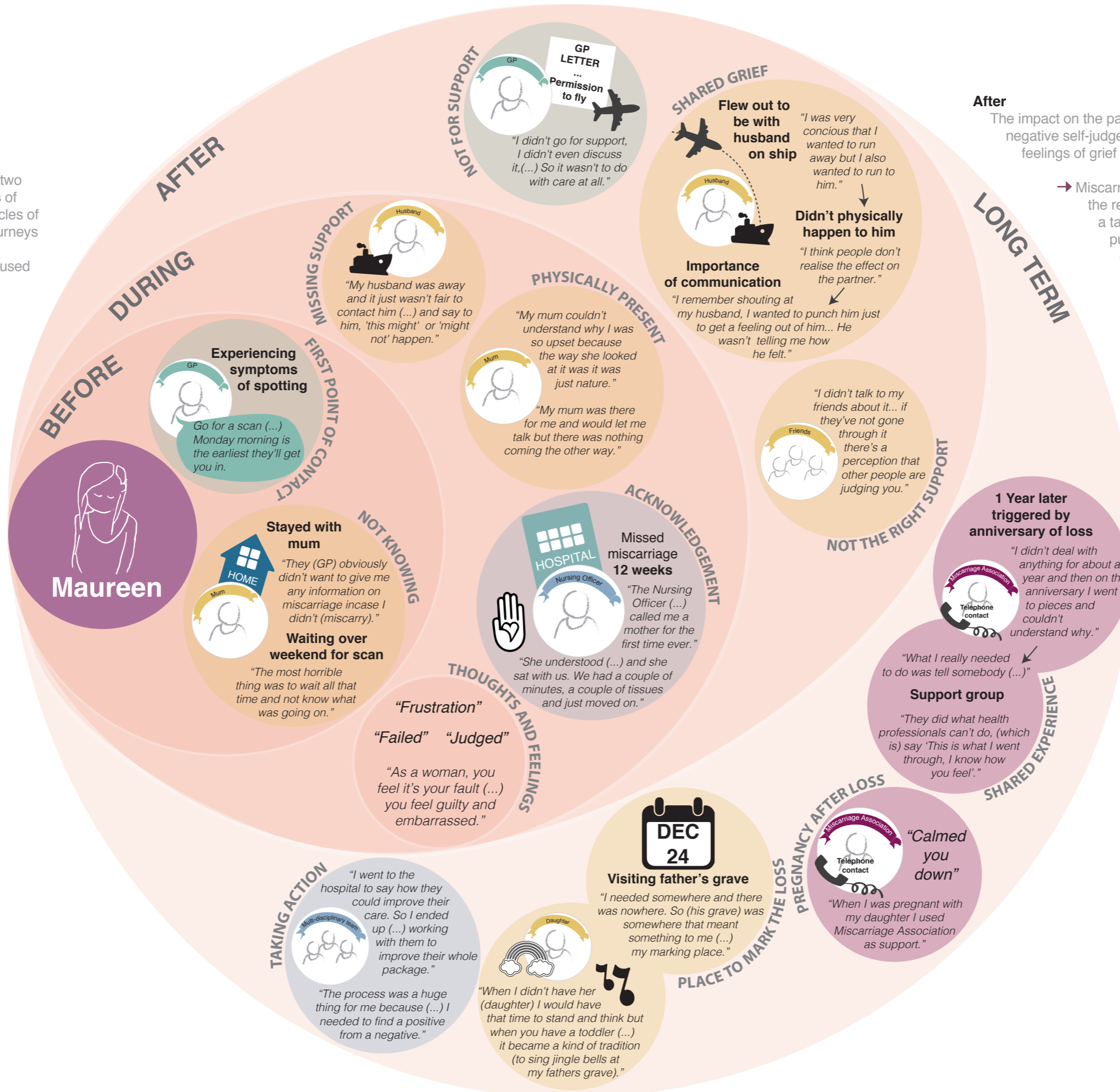
A lack of information was provided by the GP when Maureen presented with symptoms of spotting, leading to anxiety.

→ There is a need for upfront, clear information of the eventualities so that women are more prepared in the case of a miscarriage.

### During

During diagnosis a contrast in types of support were highlighted.

→ Sometimes family members do not know how to respond to the loss or support the person. There is a need to create more awareness and support people following loss, as well as ensure that health professionals are trained to respond appropriately.



### After

The impact on the partner in these situations and negative self-judgement make communicating feelings of grief difficult with the people closest.

→ Miscarriage can be a natural part of the reproductive cycle yet is seen as a taboo. There is a need to create public awareness to begin to break down barriers.

### Long Term

Grief can remain dormant for a long time but is often triggered by certain events.

→ It is important to have coping mechanisms and a source of comfort and reassurance, a place to mark or positive action.

## Linda

Linda experienced 10 pregnancy losses including 9 miscarriages and 1 ectopic pregnancy. She does not have any children. The experiences represented here are the ones that stood out in Linda's memory: the First, Worst and Most recent.

### First

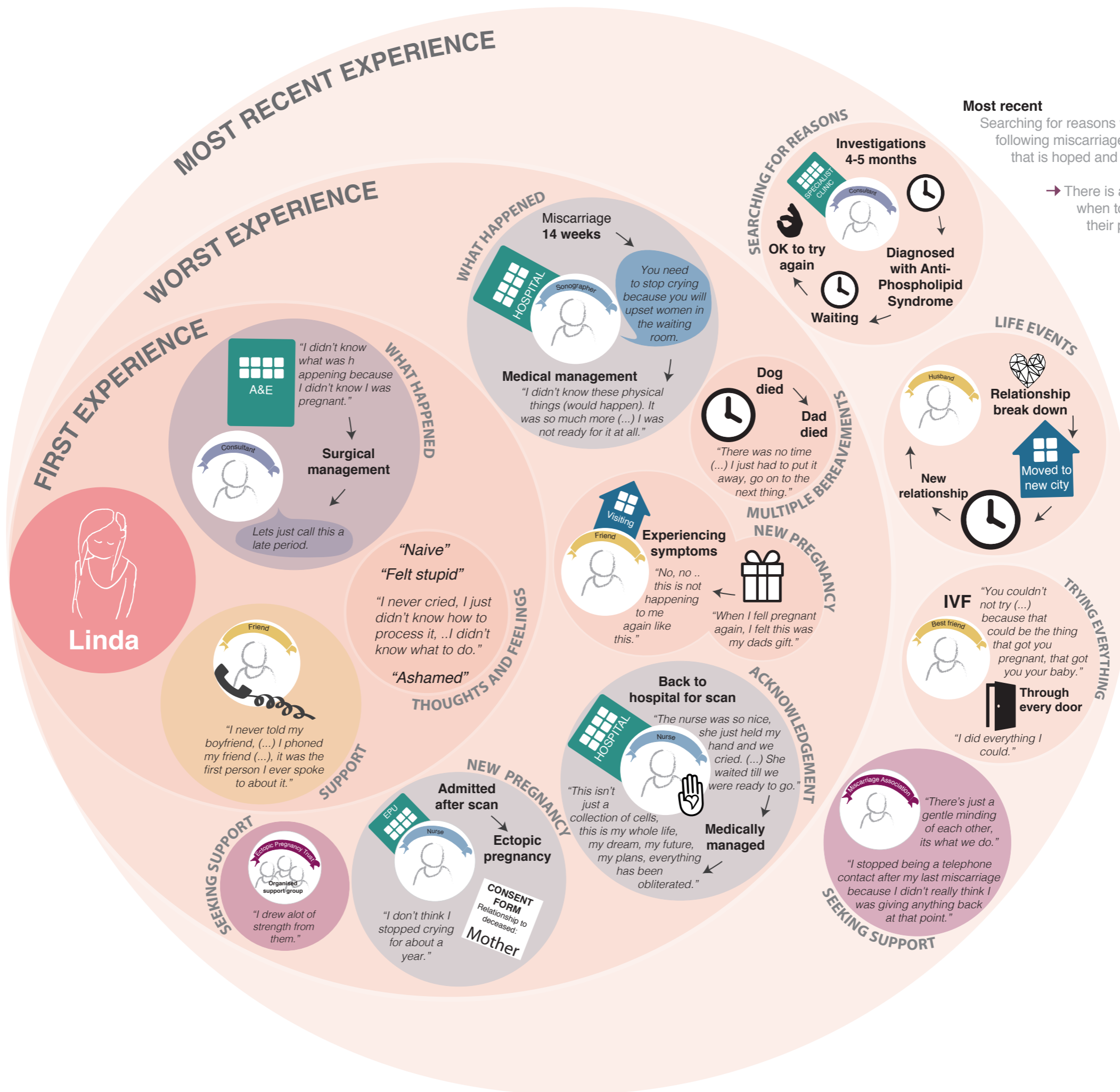
A breadth of negative emotions were expressed around this experience, impacting on the ability to process the grief.

→ The way a woman is communicated with immediately after diagnosis of miscarriage can have a lasting impact on how grief is managed and future pregnancy experiences.

### Worst

This is not one singular experience but the build up of multiple bereavements and associated meaning which contributed to the significance of this experience. There were also incidents where a lack of information and communication contributed to anxiety for both her and her partner.

→ Other life events can cause stress, trauma and anxiety, a person-centered approach to supporting women around miscarriage is needed to build a holistic understanding of care.

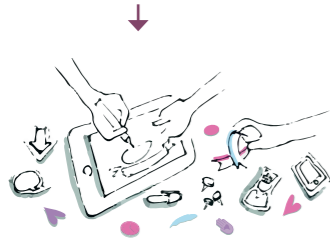


### Most recent

Searching for reasons why is a common reaction following miscarriage as having a child can be all that is hoped and dreamt of for the future.

→ There is a need for support in deciding when to stop trying and reimagining their personal future plans.

## Exp. Lab 2



### What we did

Experience Lab 2 was a half day session held in Glasgow, and brought together women who have experienced miscarriage and health professionals. Participants were introduced to the key qualities of care and artefacts emerging from Lab 1. They were then asked to capture their expectations and motivations around improving care by creating an artefact to share with each other and add this on to a pop-up wooden tree.

Two design briefs created by the researchers were introduced to participants to facilitate discussion and the co-design activities. The aim was to draw on key insights and themes from the Pre-Lab sessions and Lab 1 to generate ideas around future care. One brief focussed on early intervention and support, and the second brief focussed on training and awareness around miscarriage.

### Methods

The current care pathway used in Lab 1 to capture emerging insights around women's experiences, key moments where emotional support could be enhanced and ideas for

improving care was organised thematically. These insights were then presented on the wall for reference and further iteration throughout Lab 2. For the warm-up activity, participants were provided with laser-cut shapes, charms and craft materials to make an artefact. Each participant described their artefact to the group and added it to a pop-up tree. The tree also exhibited artefacts created by women in Lab 1, such as those representing their personal experiences of loss and the dreamcatcher.

For the next activity, participants were divided into two small groups each consisting of women with experience of miscarriage, health professionals and representatives from a perinatal counselling group. Participants were provided a poster with a summary of the key insights from the Pre-Lab sessions and Lab 1 to inform the discussion in the groups, and a selection of artefacts such as bespoke charms and craft materials to develop and prototype concepts in response to the briefs provided to co-design future care.

Participants were invited to create a preferable care pack for women in response to the first brief, considering their needs in the early stages of loss, including appropriate sources of information, etiquette such as interaction between health professionals and women, care values and emotional support. Participants in the second group were invited to develop communication tools for creating awareness and a training kit to enable health professionals to deliver future care with greater sensitivity.



### Key Findings

Participants reflected on their personal expectations and motivations for improving care, which led to the emergence of key insights such as: acknowledging that miscarriage leaves 'a space that will never be filled', and making a difference to the parents loss by giving hope, compassion and making sure that people get the support they need.

The concepts emerging for future care focused on:

- ways in which to improve access to support for women right from the start, and
- developing skills and training for health professionals.

There were some overlaps in the recommendations for future care. Following further synthesis and analysis, the two concepts for future care are presented below.

## Concept 1

### Care during early stages of loss

All participants strongly agreed that there is a gap in current care in the early stages of loss, due to an absence of clear guidelines or pathways for information and emotional support for women. Participants in this group explored the idea of a care pack focussing on the early stages of loss for women, capturing the following key characteristics and benefits:

### Validation of the loss

Participants agreed that it is important for health professionals to validate and acknowledge the loss and provide time, space and 'permission to grieve' in the very early stages when bad news has been received, as the

woman is often in shock and disbelief and does not know what to do.

- Participants proposed a bereavement toolkit introduced upon validation of the loss to prepare women and families to go through different stages of grief. The toolkit would provide continued reassurance, build hope for the future, and support remembrance of loss.

### Standardised information

Participants agreed that there is a need for developing a Scotland-wide standard information pack that is given to all women who experience miscarriage. Regarding the current information leaflets, it was also pointed out that they are often 'photocopies of photocopies of photocopies ...' and subliminally reflect poor

quality of care.

- Participants highlighted that it is important to ensure that all resources that are made available are of good quality.
- A standardised information pack should provide details such as where to get appropriate information on miscarriage by referring to reliable information sources, and offer tailored support for the individual such as including local contact and support groups in their area.
- Participants discussed that clear communication and access to the right resources would empower women to make informed choices around their care and be more in control, which can have a positive impact on how they cope with the loss.



### Mobile/ digital app

A mobile/digital app was proposed by participants, which could be introduced to women soon after diagnosis to ensure that they get the right information at the right time from that point onwards.

- Participants noted that the app needs to be simple and clear, and include topics covering both physical and emotional concerns. It was suggested to include videos on frequently raised concerns.
- Participants felt that if health professionals working in the Early Pregnancy Unit that the woman has been to are involved in making and uploading the videos locally, it could help in reinforcing continuity of care.

### Local contact

Participants also suggested including a card with the contact detail for a local support person (e.g. 'Miscarriage Association' telephone contact or local volunteer), adding that even though the person might never need to use it, having the card could offer a sense of security that if they need to speak to someone they have the choice.

### Support groups and forums

Similarly, participants felt that women should be introduced to verified online forums and support groups (e.g. 'Miscarriage Association' Facebook group) from the early stages soon after diagnosis. Currently the 'Miscarriage Association' leaflets are provided after the miscarriage, or in some cases there are no leaflets and women have to search for information.

### Follow-up care

Participants noted that as soon as a woman is diagnosed with miscarriage it should be standard practice for health professionals to offer a date in the calendar for someone in the care team to follow-up via email or phone and check how they are coping following the loss.

### Plan for the future

Participants highlighted that only by validating the loss and enabling women to cope with the bereavement first can they be supported to move forward and nurture hope for the future. One of the participants who had experienced recurrent miscarriages noted that women should be provided information and support to plan for the future in a realistic and honest way.

## Concept 2

### Support and training for health professionals

A need for greater sensitivity in communication and a lack of specialised training available for health professionals focussing on bereavement following miscarriage were highlighted as key issues. The group explored scenarios and tools focussing on communication and training for health professionals, capturing the following key characteristics and benefits:

### Signposting new information and services

Participants acknowledged that it is challenging for health professionals to remember and keep up-to-date with all information and services. However, health professionals play a key role in ensuring that women receive appropriate and timely information.

- A tool for signposting health professionals to updated information and services that can be tailored to the woman's needs, along with verifying the reliability and quality of information and support available was thought to be useful.

### Emotional wellbeing of Health Professionals

Participants noted that continuously dealing with grief can lead to compassion fatigue for health professionals.

- It was suggested that peer support and access to other formal and informal support networks for health

professionals need to be put in place to ensure emotional wellbeing of health professionals, in order to enable them to offer appropriate emotional support to women.

### Communication and 'counselling skills'

Participants highlighted that training health professionals to respond appropriately to grief could help to prevent mental morbidity in women. Recognising that miscarriage could mean different things to different women but they have all suffered a loss, and acknowledging the loss clearly was considered as a key aspect of good communication. Key expectations of women around

communication by health professionals include:

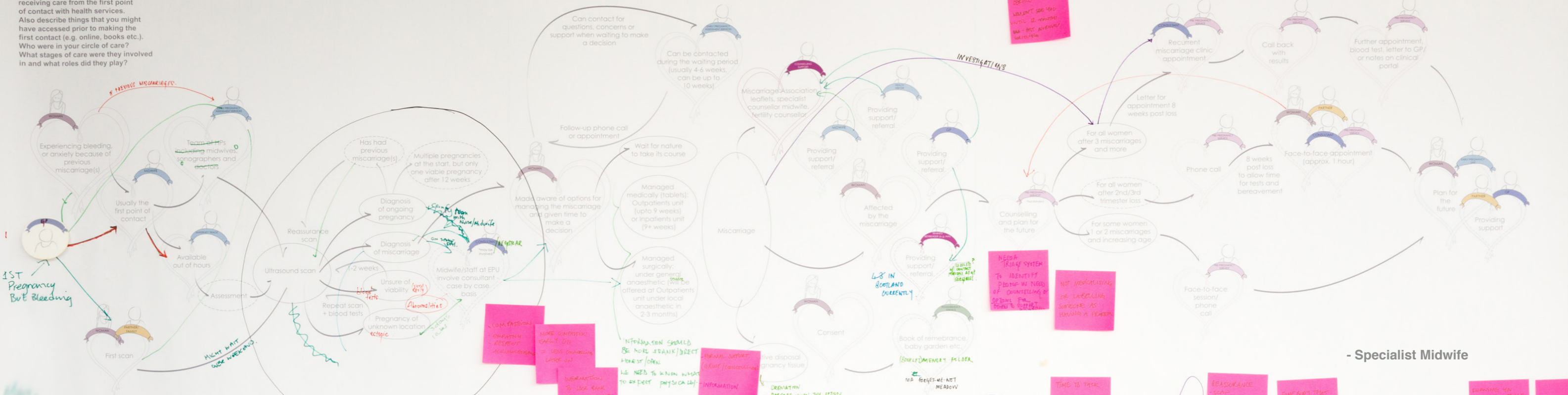
- basic 'counselling skills' when delivering bad news;
- use of clear and simple language;
- honesty, and a balance between compassion and professionalism.





# Care experience

Tell us about your experience of receiving care from the first point of contact with health services. Also describe things that you might have accessed prior to making the first contact (e.g. online, books etc.). Who were in your circle of care? What stages of care were they involved in and what roles did they play?



### Bereavement and emotional support

What support did you need/seek at each stage? How did you know when to find info/support? How did the person/resource make you feel supported?

What role does digital technology play in your lives already? What is it doing well at? What is it struggling with? What is in new ways using it? What would make it more helpful and accessible?

### Bereavement Support in Early Stages

**ACKNOWLEDGING THE GRIEF EARLY ON**  
- NORMALISING NOT MENTALISING

**ANXIETY & SUPPORT MADE AVAILABLE & NOT LEAVING IT ONLY ON THE PERSON.**

**DIAGNOSED WITH MISCARRIAGE**  
(EARLY PREGNANCY AN ONWARDS TIME FOR THE EXPECTANT WOMAN)

**PERIOD OF UNCERTAINTY CAN BE A DIFFICULT TIME**  
(PERIODS OF LIMBO)

**DEDICATED SERVICES FOR EARLY PREGNANCY UNIT (SEPARATE FROM MATERNITY)**

**SEPARATE AREAS IN HOSPITALS**

**HAVE A DIFFERENT WAY FOR WOMEN TO GO OUT AFTER SCAN IF THEY NEED TO.**

### PERSONALISATION & CONTINUITY OF CARE

① PEOPLE KNOW WHEN THEY COME IN - CONFIRMED WHEN THEY COME TO THE HP.

② THEY CANNOT BELIEVE.

PERSONALISING COULD BE A CHALLENGE - EVERY WOMAN WILL RESPOND DIFFERENTLY.

(TERMINOLOGY - CHALLENGING)

CONTINUITY OF CARE

LINK TO EMBROIDERY NOTES OF PERSON

CLEARER & DETAILED INFO ABOUT ALL OPTIONS - NOT A LIST OR CHECKBOX

SHOULD BE MADE AWARE OF ALL THE CHOICES.

### ACCESS TO SUPPORT RESOURCES

OFFERED OPTION TO COME BACK & TALK

3 CONSECUTIVE MISCARRIAGES: (WHEN DO THEY GET REFERRED TO RECURRENT CLINIC)

1ST MISCARRIAGE: NO STAFF CAPACITY (NEED TO GO TO GP OR OTHER)

COUNSELLING - SUSPICIOUS OF MISCARRIAGE

TELEPHONE APPOINTMENT LINE TO REQUEST TO SPEAK TO A HP FROM THE EARLY PREGNANCY UNIT

ASK THE EXPERT

EMAIL QUESTIONS + TIMED RESPONSE

c.g. we will reply by 5pm in 2 days

### EDUCATION & AWARENESS

DOES THE GENERAL PREGNANCY PACK CARRY ANY INFO ON SYMPTOMS... E.G. BLEEDING.

CURATED INFORMATION

APP/WEBSITE WITH RELIABLE INFORMATION

MA MANAGEMENT OF MISCARRIAGE LEAFLET. PRINTED & GIVEN TO THE WOMAN.

OFFER INFORMATION ON WHAT TO EXPECT SOMETHING TO LOOK UP IN YOUR OWN TIME.

MISCARRIAGE INFO RCOG INFO/LEAFLETS.

"INFORMATION FOR YOU"

APP/INFO "WHAT TO EXPECT"

CREATING AWARENESS FOR WHAT HAPPENS WHEN YOU HAVE A MISCARRIAGE

GP SURGERIES & HEALTHCARE/PUBLIC ENVIRONMENTS NEED TO BE OPEN TO SHARE INFO/RAISE AWARENESS (CULTURAL CHANGE)

### TRAINING FOR HEALTH PROFESSIONALS

SUPPORT FOR HPs - IN PREDETERMINED FOR INFERTILITY NURSES/STAFF.

TRAINING & RAISING AWARENESS ABSOLUTELY FUNDAMENTAL WHEN CARE

PREP SUPPORT

Learn Pro - Cruise online

RCM Bereavement Network professional online

H.P. training + Support

SEPN.

JANIS Study days.

Screening conference RCM/NHS set based all HP.

Stillbirth Campaign See Practice Evidence based

SONOGRAPHER

COMMUNICATION

CREATING AWARENESS AMONG HEALTH PROFESSIONALS

### ACKNOWLEDGEMENT & REMEMBRANCE

POTENTIAL OF FORUM BEING USED TO EXPRESS ANGER (TOWARDS CLINICIANS OR SERVICES)

FORUM FOR EXPRESSION, REMEMBRANCE

A PAGE FOR REMEMBRANCE IN 'THE SANCTUARY'

MEMORY BOYS FUNDED BY SIMBA OR SANDS

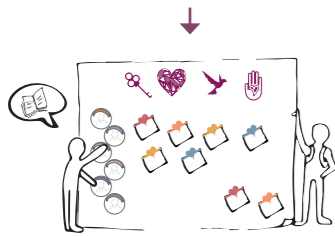
MEMORY SCRE, LAMENAS, BLANKET, FOOT PRINTS, HAND PRINT, HAIR, ETC.

EARLY LOSS - SCAN PICTURES.

SUPPORT DURING ANNIVERSARY (PREPARING PEOPLE, DELIVER THE ONLY OF A DIFFICULT TIME) + TRIGGER POINTS IN BETWEEN - DUE DATES, HOLIDAYS (XMAS), DATE

of women following m

## Exp. Lab 3



### What we did

Experience Lab 3 was a half day session held in Glasgow. Its purpose was to reunite the women who have experienced miscarriage and health professionals from previous Labs. Participants collectively reviewed and iterated the current care pathway, and the key findings to date were presented. The group then reviewed the visual summaries of the two concepts developed in Lab 2, and iterated them by building on the emerging principles/qualities of care from the previous Labs. Participants were also invited to consider how the proposed ideas would impact future care. At the end of the session, the group discussed the next steps and key actions for the project partner and the SEPN.

### Methods

At the beginning of the session, the current care pathway capturing insights and ideas for improving care emerging from all the sessions to date was presented on the wall for collective review and iteration by all participants who had contributed to it at various stages of the project.

Next, the visual summaries of the two concepts were reviewed in a focus group by all participants. Some of the health professionals shared their reflections on how some of the insights have influenced them to think differently about their practice since the previous Lab. These reflective thoughts were captured on post-its and added to the visual summaries.

For the final activity, a base map with revised stages focussing on the emotional journey informed by insights from the previous Labs (i.e., *'being prepared'*, *'space and time to grieve'*, *'hope for future and remembrance'*) was presented along with cards to capture what roles, information, resources and actions may be involved in shaping the future care around miscarriage.

A map of the existing organisations and platforms offering bereavement support was also shared with participants to reflect on how areas where new services/platforms could compliment and build on existing support rather than duplicate them.



### Key Findings

#### Being prepared and managing expectations

The health professionals noted that, due to a lack of public awareness around early pregnancy loss, they often find it difficult to manage expectations of the women, especially during dating scans that don't always result in a *'happy scan'*.

→ It was observed that the practices around management of miscarriage in the UK vary from other global contexts. Sometimes women who have received care in other contexts previously have different expectations from the health professionals, and could pose difficulty in building trust and managing expectations.

→ It was suggested that



greater awareness around the different possibilities and outcomes during early pregnancy and dating scans, along with a clear communication of the practice in the UK can help to prepare women and enable health professionals to better manage expectations.

#### Breaking the taboo

Participants felt another cultural barrier that needed to be challenged was the reluctance of many GP practices to display miscarriage posters in waiting areas, and the display of such information being limited to the toilets in most public spaces/organisations.

→ While spaces such as the women's toilet may help individual women in need to find the information and seek support, there needs to be information that is more

publicly available in order to change perception and break the taboo surrounding miscarriage. This can help to overcome the tendency of hiding the loss from others and to empower more women to seek emotional support.

→ It was also suggested that the SEPN can organise roadshows aimed at communities, GP practices and all community-based care providers to create awareness, and enhance access to information and care locally.

→ In addition, participants agreed that more work needs to be done to prepare our society to be well informed and sensitive towards issues related to early pregnancy. For example, participants felt that information on

pregnancy loss should be included as part of sex education training in schools to create awareness among young people and to prepare them early on.

- Many women find it difficult to take time off work after a miscarriage fearing that it will not be considered legitimate by colleagues and employers. This needs to be addressed to create a more supportive environment for working women.
- Participants noted that more shows on television, such as 'Eastenders' and 'Emmerdale', are now including miscarriage in their story lines and can help to create greater awareness and alter public perception around early pregnancy loss. Charities such as the 'Miscarriage Association' are often consulted to ensure that the message is delivered in an appropriate and sensitive manner, and

this was observed as a step in the right direction.

#### Designing a sensitive space

Early pregnancy services, ultrasound scan areas, maternity and fertility units are all linked together in most hospitals. When a woman has been diagnosed with a miscarriage during the scan, they are vulnerable and sensitive.

- Being around other pregnant women and paraphernalia related to ongoing pregnancies and babies can be upsetting following a loss.
- Some of the ultrasound rooms display developmental pictures and images of babies, which could have an impact on setting expectations, either consciously or subconsciously.
- Participants felt that if the room is used across different areas such as

the EPU, maternity and fertility services, it would be more appropriate to have visuals and information that is representative of all scenarios.

- It was proposed that there needs to be minimum considerations and guidelines for design of the space to improve sensitivity of care and provide women the choice of privacy.
- Participants recommended that the ultrasound scanning room should have an additional door which does not go back into the waiting area with other pregnant women, and a quiet space to go to after the diagnosis.



practices; and through community health care assistants. Not only would this enhance the availability of information, it would also have the added benefit of: giving reassurance; managing expectations, and preparing women for the various scenarios that may arise as a result of a miscarriage.

- It was recommended that the SEPN should take the lead on standardisation of information across Scotland.

#### Tailoring care

Providing women the choice around management of miscarriage and empowering them to be in control were identified as being key for promoting tailored and personalised care. However, due to a lack of time and availability of appointments, it becomes difficult to meet that need.

- There is a need to look at balancing the options that are made available and ensuring that the right resources are made available to provide care according to the choices made by the women.

#### 'The golden three minutes'

There are variations in the appointment time offered during ultrasound scan across Scotland. The appointment time, however, does not mean contact time with the person. One of the health professionals noted the appointment time in their hospital is usually 30 minutes, but this includes the time for taking patient history, scanning, updating scan results and related paperwork. In some hospitals, the appointment times can be even shorter. In the case of a miscarriage, this would also include making

the woman aware of different options for managing the miscarriage and, if the woman opts for surgical management, calling central booking for available appointments, doing pre-ops and gaining consent for sensitive disposal, while supporting the woman with bereavement. Consequently, most of the time is spent on the clinical and administrative requirements in the current care pathway, leaving little or no time for 'caring'.

Over the course of all the Labs, it emerged that the care received during the time immediately after diagnosis is crucial to setting the course for the overall experience of care and how women cope afterwards.

- More care in those crucial minutes after diagnosis would mean the possibility of less long-term impact on emotional well being, ability to cope with the loss and future pregnancies.
- Participants proposed the idea of the 'golden three minutes' as a key stage for providing sensitive care by breaking the bad news gently and offering woman the time and space to grasp the situation.

→ The health professional could offer a cup of tea and offer to meet the women in a quiet space after the woman returns from the toilet. This would provide some quiet breathing space for the woman and for themselves to gather their thoughts around the appropriate care plan.

- Clear and direct communication is key at this stage, for example, being explicit in acknowledging the grieving process.



#### Standardising information

As home pregnancy tests are becoming more prevalent and increasingly advanced, women self-refer to the EPU for dating scans, instead of the more traditional route of approaching the GP practice as the first point of contact. There is no standard information made available until they receive the early pregnancy pack following the initial antenatal appointment.

- Participants noted that there is a need to rethink what information is provided and how it is made available, so women have early access and realistic knowledge of what to expect including symptoms to watch for and potential for miscarriage.
- In addition to information provided by the hospital, other sources of information should be made available via: multiple routes; at pharmacies; with the home pregnancy test kits; at GP



- Currently, women receive a lot of information which becomes overwhelming, particularly as they could be in distress following the diagnosis. Acknowledging that the woman might be in distress and tailoring the information appropriately was mentioned as key. The information needs to be concise, tailored and provided in stages.
- Similarly, having an empathetic approach and remembering what it means to the person is also key, for example, using sensitive language and providing reassurance that there is nothing the woman could have done differently as they struggle to cope in the absence of a clear reason.
- Participants felt that taking the time to understand the patient background before the scan and asking direct questions (e.g. history on previous pregnancies/ losses, planned/ unplanned/ unwanted pregnancy) should be best practice, as this would help the health professional to tailor the communication and care appropriately.

#### Introducing a digital app

Participants expressed that not having the right information or getting a lot of information immediately after the loss could be difficult to follow when they are in distress, and can lead to women experiencing uncertainty and a lack of control. Currently there are numerous sources of information around miscarriage that women find on their own especially online, but not all of them contain verified information and may be unhelpful for women and their families.

- Participants agreed that having a reliable resource such as a digital/mobile app, as suggested in Lab 2, which would allow women to refer back to information provided by the health professionals at their own pace, as well as signpost to other relevant information would be helpful.
- The app could also help women to log questions that they may wish to ask their health professional. Participants used the example of an existing

fertility app that allows its users to log information that they would like to keep private but also get signposted to relevant public information to suggest that the miscarriage app could provide both private and public functions.

- The key requirements of the app were identified as: precise and concise information using clear and non-clinical language, dynamic and up-to-date to be able to provide responsive information in real time, and curated to ensure that the information is verified by health professionals and is sensitively personalised to meet individual needs of women, their partners and families.
- Additionally, participants discussed the value of adding a visual narrative feature similar to the storytelling tool used in Lab 1, for helping women to reflect on their experience and *'move beyond the pain'*.

- The story telling tool could be used individually for capturing personal experiences and for acknowledgement of loss. At the same time, if women choose to share it, it could help them to communicate their thoughts to a health professional or community practitioner using an alternative method.
- Participants noted that introducing a visual story telling tool would complement other resources that currently exist, which are predominantly text-based.

#### Developing community-based integrated care

It emerged that variations exist across different NHS Trust boards and hospitals in providing access to support before, and following, a miscarriage. Women don't have any formal contact with the EPU before a dating scan or an appointment, which is usually between 8-14 weeks. For many women, especially during the first pregnancy or in the case of previous miscarriages, this can be an anxious and uncertain period. There is no specific source of information or support available to them, including lack of family support as a result of people moving away from their family and social circles for jobs etc. In the event of early pregnancy symptoms or concerns, it is not clear who women could approach for support.

- Participants felt that there is a need for a community-based practitioner, such as a health and wellbeing assistant, who is trained specifically in early pregnancy care to act as a dedicated contact for women in the community.

- The health and wellbeing assistant could be trained to provide appropriate information around early pregnancy as well as have counselling skills to provide emotional support and signpost to appropriate specialist services based on need, especially prior to the woman being assigned a midwife.

Similarly, there is no standard pathway for following up on the woman's emotional wellbeing after miscarriage and, due to resource constraints, it is difficult for the EPU staff to follow up with every woman. Health professionals may contact the woman via phone or letter, and offer a rescan. However, some women do not want to come back for a scan and there are no alternative ways to track how they may be coping with the loss. The eight-week waiting period required for tests following a miscarriage can leave the woman without any support, leading to more uncertainty and anxiety. The GP may be informed about the results of the diagnosis and subsequently after miscarriage findings from the tests of the pregnancy tissue are sent to them.

However, women do not see the GP as the right source of emotional support in this context. The hospital was also not considered to be the right environment for follow-up by participants, due to the potential trauma related to the experience of loss, adding that a community setting could be beneficial for supporting emotional well being.

- Participants proposed that having a health and wellbeing assistant in the community who will work alongside staff from the EPU and GP practices as

part of a care team could ensure continuity of care and support for all women.

- The health and wellbeing assistant may also be able to spot signs of complex grief in women early and signpost them to additional counselling support if required thereby reducing the risk of women experiencing long lasting emotional problems.
- Although not all women may need additional support, it will offer women the choice of a single point of contact for care close to home before, and following, the miscarriage.
- This could help to overcome some of the challenges currently related to: long waiting times for seeing a specialist midwife or counselling staff, and criteria for women to be seen for counselling/specialist services only after three or more recurrent miscarriages that leaves others with no support.
- One of the participants also noted that as a telephone contact for the 'Miscarriage Association', she often finds that most of the calls she receives are from women who are/want to be in control (*'copers'*). Having a dedicated resource will help to identify women who may not be actively seeking help but are in need of support and an offer of timely care.

#### Training and supporting a multidisciplinary care team

There are a number of health professionals involved in providing care for women during early pregnancy and who women come into contact with in the event of a loss.

However, it emerged that health professionals may have varied levels of training related to providing support around miscarriage. For example, dating scans may be undertaken by sonographers or midwives based on the hospital set up. Participants observed that sonographers tend to remain silent while scanning or discuss observations with colleagues if they spot any concerns without having any direct communication with the women, which can increase anxiety. Midwives were observed to have a different demeanour, communicating with women during the scan and making them comfortable.

- While having a multidisciplinary team of staff for early pregnancy was considered positive by all participants as each professional brings a different perspective and expertise, it was proposed that all staff coming into contact with women during early pregnancy need to receive training around communication and soft skills.
- Participants also highlighted that the way in which the news of miscarriage is delivered to women can have a profound impact on how they cope with the grief. In this regard, it was proposed that the 'breaking bad news' training for health professionals should include specific scenarios related to miscarriage (e.g. during Objective Structured Clinical Examinations/ OSCEs). Organisations such as the 'Miscarriage Association', 'SANDS' and the 'Child Bereavement UK' currently offer consultancy or training services for health professionals, and

there are opportunities to link these with the formal curriculum for training health professionals.

- The participants proposed that women who have experienced miscarriage should be involved in the training sessions, in a similar way as with the Labs, to embed real life experiences and learning.
- The training should be delivered through practical sessions focussing on difficult diagnosis and various scenarios of breaking bad news, and prepare healthcare professionals to:
  - acknowledge the loss; show empathy; use sensitive language (e.g. referring to the 'baby', not 'foetus' when talking to women), and support women to grieve. If staff are not adequately prepared to do this sensitively at the point of diagnosis, moving away from a 'checklist culture', it can have a negative impact on the women and their experience of services later on.

Similarly, participants highlighted the importance of peer support of health professionals in order to be able to provide high quality care for women following miscarriage. For example, one of the participants shared that it is best practice while performing ultrasound scans to seek a second opinion from colleagues when three scans in a row are diagnosed with miscarriages. In addition to ensuring that the diagnosis is accurate, it also helps to overcome the negative impact of 'compassion fatigue' when staff have to continuously deliver bad news. Another participant

shared that as a result of being involved in the previous Lab they had introduced a '9 at 9' huddle where nursing staff come together for 9 minutes at 9 am as part of their daily practice, to share concerns and priorities. This is recorded and shared with all staff in the unit, so each patient's needs are understood by the whole group and they could ensure better continuity of care.

- Peer group support and validation of best practice can have a positive impact in creating a supportive working environment for health professionals and in turn, impact the quality of care provided.
- Participants also noted that junior members of staff would benefit more from the tacit knowledge around softer skills such as communication gained from experienced staff as opposed to a formal learning resource.
- It was observed that existing digital resources such as 'LearnPro' are perceived as a chore and may not be the right platform to introduce further training around miscarriage.

#### Marking the loss with remembrance artefacts and rituals

Women do not often have any physical artefacts for remembrance following miscarriage, unlike in later losses or stillbirths where providing memory boxes and similar practices are more common in most hospitals.

- Participants suggested that all women should be offered a letter acknowledging the loss along with a copy of the scan.



- One of the health professionals pointed out that this will require a change in work practice. Currently, women are offered a printed copy immediately following the scan. Some women opt not to have the printed copy, and health professionals are unable to save a copy on the ultrasound machine. So if a woman asks for the photo later, especially

following a loss, there is no way to recover the scan copy. It was suggested that the standard practice should be to save a printed copy in the patient notes to prepare for such situations.

Memorial services are held in many hospitals and these were seen as an opportunity for people to gather and share experiences, and enable them to cope with the loss. However, participants noted that there are variations across hospitals as they may be led by various people, e.g. chaplain, midwives or undertakers.

- An audit of these memorial services by the SEPN was recommended to capture the different services currently offered, and enhance them by sharing good practices across Scotland.
- Similarly, it was also highlighted that a variety of remembrance ceremonies and platforms are hosted by organisations such as the

'Miscarriage Association' and local charities, and health professionals should be made aware of them to be able to signpost services appropriate to the individual.

- It was suggested that having a catalogue of all remembrance ceremonies including digital platforms and symbolic places such as local cemeteries or spaces for grieving baby loss (e.g. 'The Sands Garden') will help health professionals to offer tailored information/ advice to women based on what is relevant to each individual's situation.



“There’s a perception you need to pick yourself up and get on with it. Nobody admits that you have to grieve. And it’s almost like you need permission to grieve.”

- Research participant

## Overall Findings

All the key findings from the Labs are synthesised into three visual summaries:

→ Key qualities of care based on key themes emerging from the personal stories of miscarriage shared by women.

→ Map of current experiences of care captured from the perspective of women who have experienced

miscarriage and health professionals providing care at different stages of the care pathway.

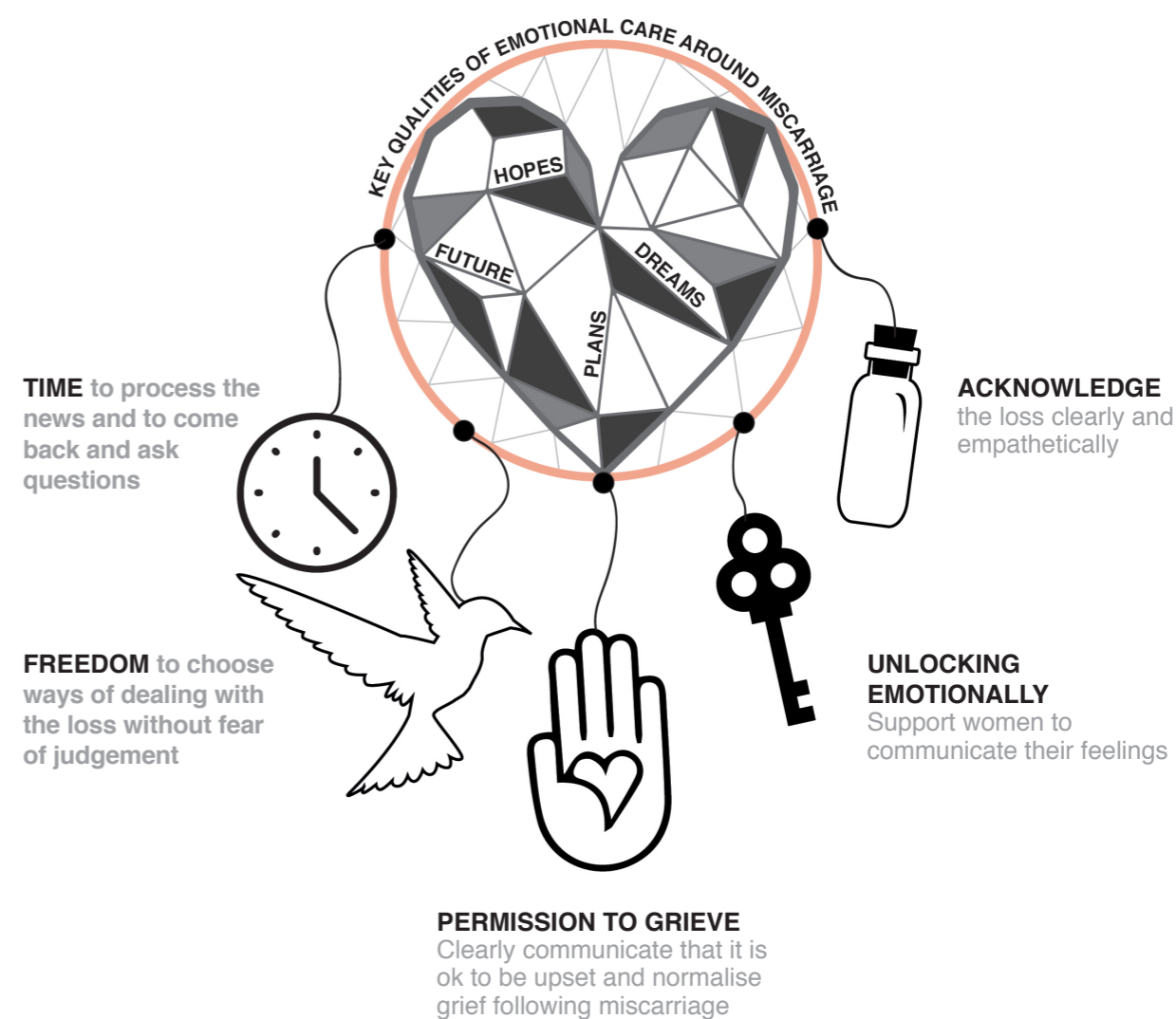
→ Concepts and framework for future care focussing on enhancing emotional wellbeing, based on ideas emerging from the Labs.



### Qualities of care

The visual presented here brings together the key qualities of care around miscarriage that emerged from the personal experiences of the women who participated in the Labs.

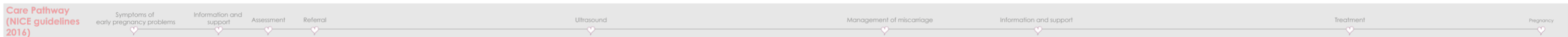
The symbols and their meanings were chosen by the women to represent the common links between their individual experiences.



# Current experience of care around miscarriage

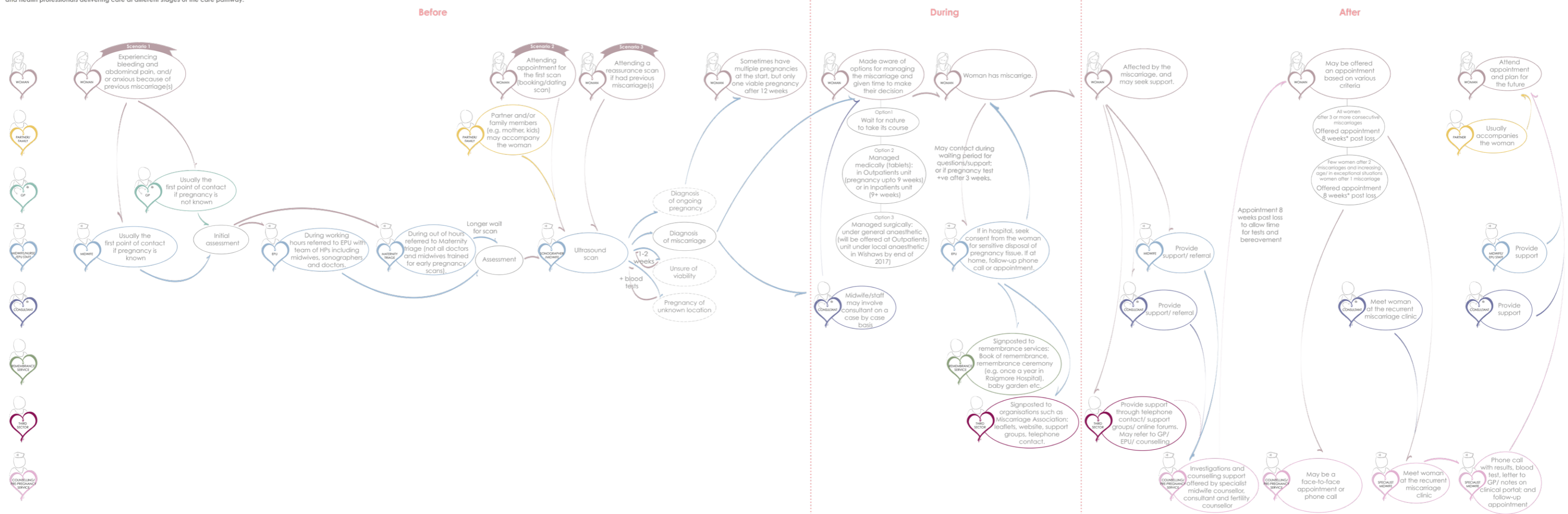
The map captures the various stages of a woman's journey of accessing care, along with the

people, activities and resources involved in each stage. Key moments where there is a gap in current care and opportunities for enhancing support are highlighted along with supporting insights and quotes from the participants.



### Care experience

Experience captured from the perspective of women who have experienced miscarriage and health professionals delivering care at different stages of the care pathway.



### Key moments

Increasing awareness on early pregnancy loss and training health professionals is key for being prepared/managing different scenarios and outcomes.

Even if they've got heavy bleeding (...) it doesn't always lead to miscarriage. So we have to be as unbiased and informative, and that's what you want - is honesty.

How will you address the pregnancy? It's a big challenge; what would you say?

### Insights

I had no information, nothing.

Time soon after diagnosis is crucial for bereavement support and sets the tone for rest of the care journey.

.. that really short period of time, it seems like forever. And you are hypersensitive. Or have been in shock.

More compassion here, and less counselling needed (in later stages).

Emotional support should be made available early on, along with a tailored care plan to ensure appropriate care for the individual.

.. acknowledging that miscarriage means different things to different people..

Your heart feels (...) just all cracked and you don't know what to do. That's how it feels, that's what they (care providers) have to - not fix, that's not their job - but to manage.

The loss should be clearly acknowledged and women need to be prepared for triggers in the future (e.g. due dates or anniversaries).

I think people don't acknowledge things because they are scared it upsets you.

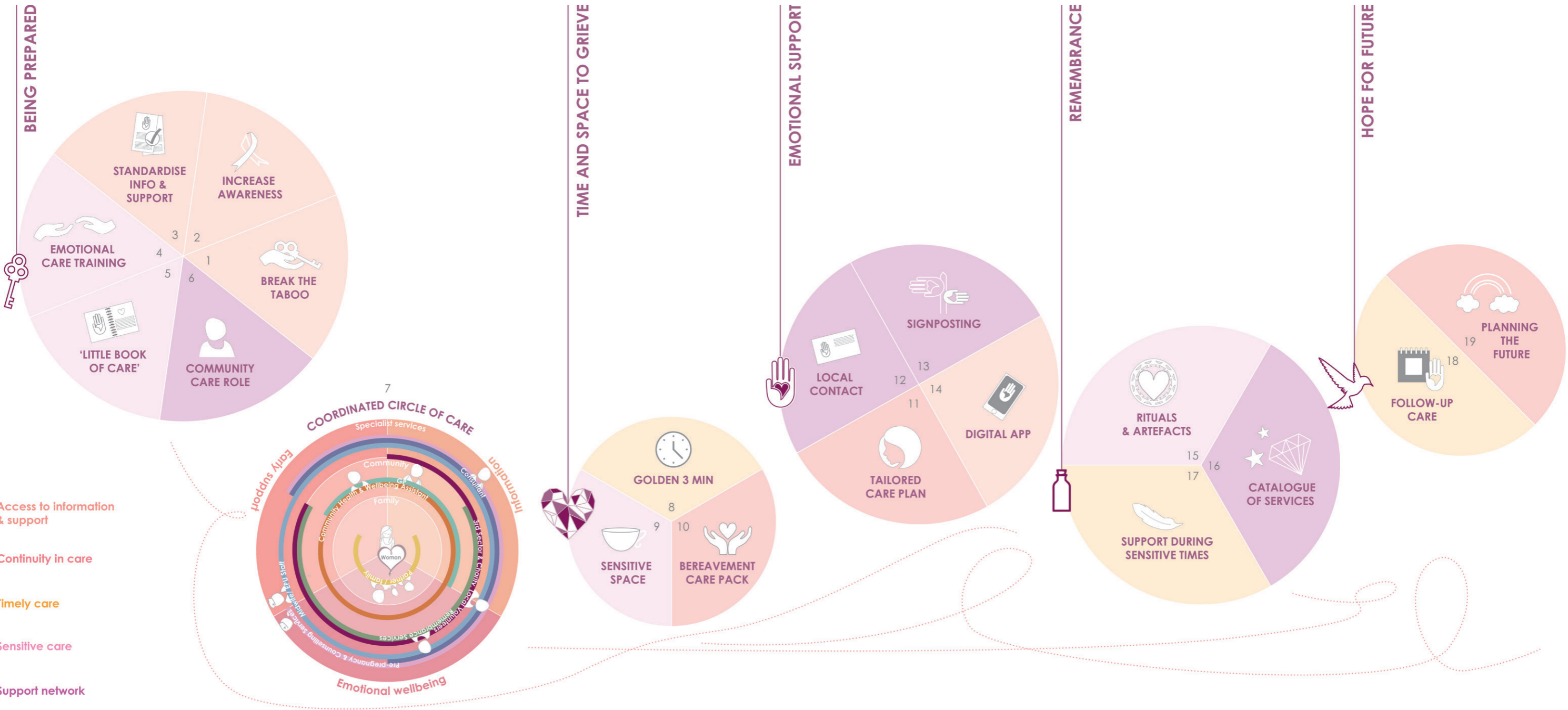
There's a perception you need to pick yourself up and get on with it. Nobody admits that you have to grieve. And it's almost like you need permission for it to grieve.

All women should have the choice to access support for bereavement, planning future pregnancies and counselling.

Miscarriage can be very isolating. You may be surrounded by lots of people ... but even those people who love them (the women) dearly are not getting it. And that's why women need this extra support (...) in whatever form it is ...

# Future care around miscarriage: Enabling emotional wellbeing

Key concepts



Concept summaries

1. Break the stigma and encourage people to talk about miscarriage and how it impacts women and families through posters in public spaces and workplaces, info on early pregnancy in sex education curriculum in schools and popular media such as TV.

2. Increase general awareness on early pregnancy & miscarriage, and on how to seek support by clearly describing the info & pathways to access support specific to the UK: 'when to seek support', 'who to talk to', 'what to expect from the care' etc.

3. Standardise information & access to support across Scotland through legislation, sharing practices & creating capacity within health & social care.

4. Train & support a multidisciplinary care team to provide sensitive care. Focus on enhancing communication skills around 'breaking bad news', 'counselling skills' for providing emotional support to women in distress, showing compassion & etiquette around managing grief by showing empathy & sensitivity.

5. Create a book of guidelines on how to provide emotional care, focussing on key principles & concepts emerging from this project, to train care staff & develop future care.

6. Create a new role for a community health & wellbeing assistant specialised in early pregnancy care.

7. The health & wellbeing assistant would offer early intervention & ongoing info & support closer to home for all women in the community, working collaboratively with primary & secondary care staff.

8. Ensure time & space for women to grasp the situation. Use sensitive language when breaking bad news. Acknowledge the loss.

9. Provide choice of exiting scan room using private door. Offer a cup of tea, & meet woman in a quiet space.

10. Introduce soon after the loss to support women & families to cope through the different stages of grief.

11. Provide health professionals time & tools to map individual needs. Offer choice around support & precise info appropriate to each stage. Support women to make informed decisions.

12. Provide contact details for a local support person in the community (e.g. Miscarriage Association volunteer, health & wellbeing assistant). Present info on local charities & support groups in a simple, concise way.

13. Ensure health professionals & women have most up-to-date info & support. Make pathways to access info & support across multiple organisations & platforms visible & accessible.

14. Introduced on diagnosis of miscarriage, for women to find info & support in their own time, using simple non-clinical language. Include option to contact staff, view videos, & visual tool to capture personal stories.

15. Provide women copies of scans (if they had scans before the miscarriage) & a letter acknowledging the loss from the hospital. Share good practices & standardise memorial services across Scotland.

16. Prepare & offer support to women to cope with grief during sensitive periods such as due dates, anniversaries & holidays. Empower women to make personal choices around remembrance.

17. Create a catalogue of all services offered by hospitals, communities and the third sector. Make it accessible & highlight all ceremonies & platforms relevant to the woman, including physical, digital & symbolic spaces for remembrance.

18. Mark a date in the calendar to follow-up with all women following miscarriage through EPU team/ midwife/community health & wellbeing assistant & signpost women to further support if needed.

19. Provide realistic & honest information & empower women to identify personal care needs & support to plan the future. Respect the woman's freedom to choose.



Overall insights from the project highlight that each woman's experience and their way of coping with the loss following miscarriage is unique. A linear care pathway is inadequate for providing care and support that is tailored to each individual. Additionally, current pathways focuses on the stages following the loss and in the later stages of the journey for providing emotional care. The insights from the project, however, emphasises the need to prepare women before and focus on emotional care during the early stages of loss.

Based on these insights, the visual (p.44) captures the five key areas focusing on emotional wellbeing in the future:

## Recommendations



The findings from the project will be shared with the project partners and the Scottish Early Pregnancy Network (SEPN). The findings can be made available to other relevant stakeholders in the government, NHS, social care, third sector and the wider public. Key actions for the SEPN and opportunities for developing future projects have been highlighted in the report, including: auditing bereavement and remembrance services and sharing of good practices;

### →Being prepared

Synthesis of insights and ideas about breaking the taboo around miscarriage (P.33), increasing awareness (P.17, 28), standardising information and support (26, 35), training around providing emotional care (P.17, 28, 37), a book with guidelines for care (P.35, 37), introducing a community care role and a coordinated approach to care (P.37).

### →Time and space to grieve

Synthesis of insights and ideas about 'the golden 3 min' of care (P.17, 26, 35), a sensitive space (P.34) and bereavement care pack (P.26, 36).

### →Emotional support

Synthesis of insights and ideas about creating a tailored care plan (P.17, 26, 35), accessing local support (P.27, 37), signposting to relevant groups and platforms (P.27, 28, 36) and a digital app (P.27, 36).

### →Remembrance

Synthesis of insights and ideas about rituals and artefacts (P.38), catalogue of all services (P.39) and support during sensitive times (P.18, 27, 37).

### →Hope for the future

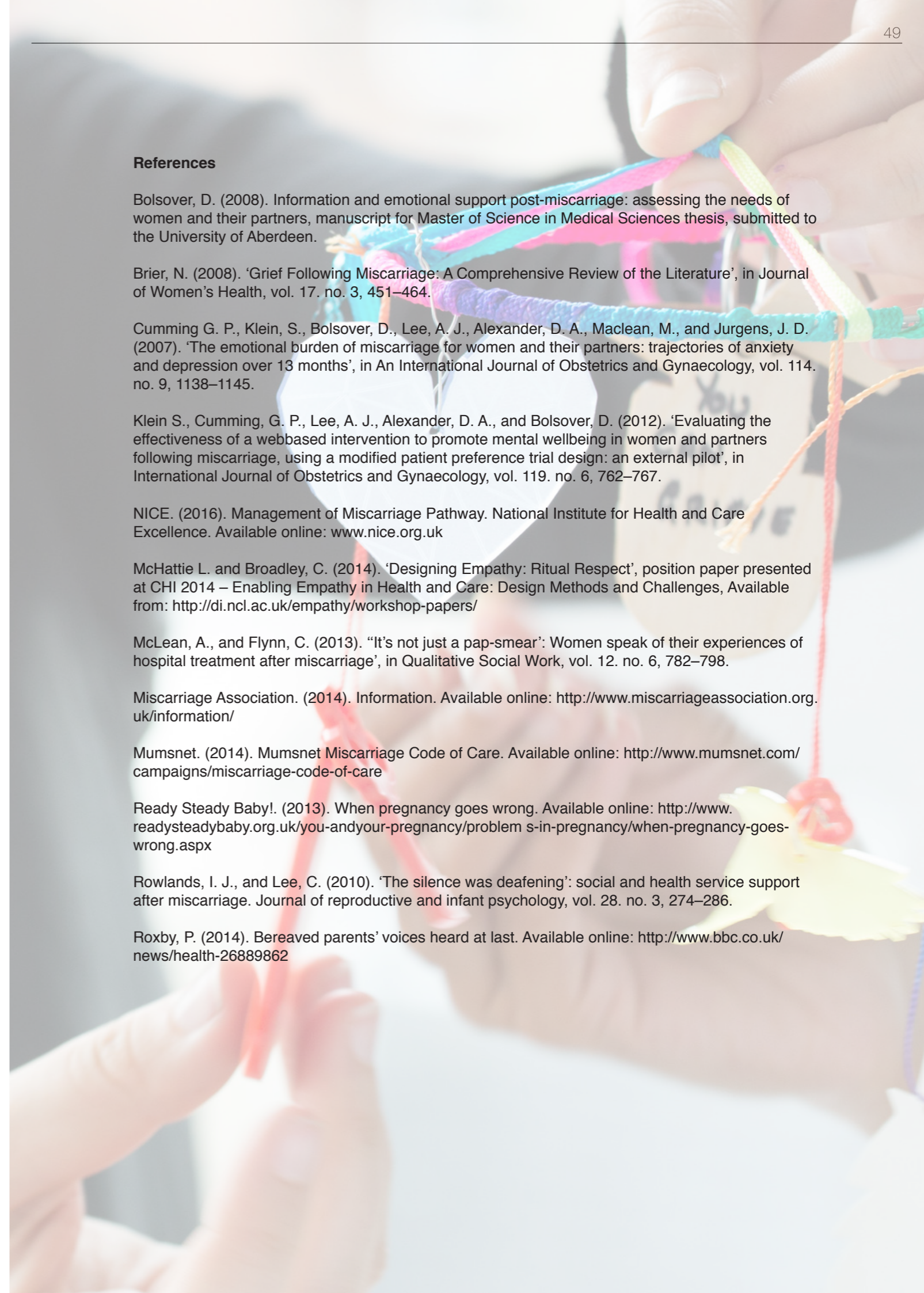
Synthesis of insights and ideas about follow-up care (P.27, 37) and planning the future (P.26)

standardising information and access to care across Scotland; creating awareness and upskilling the communities through roadshows and training programmes; and creating guidelines for emotional care. A number of concepts for the future emphasise the need to create capacity and develop the necessary infrastructure to support the shift from a clinical linear model of care to focus on emotional person-centred care. It is important to address

this systemic and cultural shift in order for digital platforms and tools to be able to play a meaningful role in enabling care.

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