EStELC

Summary report

Engaging Stakeholders to Explore Linguistic Challenges in Communicating about Pregnancy Loss

September 2024

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Cover image shows a word cloud made from lived experience participants' written contributions

FOREWORD

It has been almost 30 years since medical literature in the UK first acknowledged that language can be an important aspect of patient care during and after pregnancy loss, with the 1985 publication in *The Lancet* of a letter asking for *miscarriage* to replace *spontaneous abortion* in clinical settings. In the intervening decades, those who have experienced pregnancy loss and those who care for them have repeatedly highlighted issues with the language used to describe, diagnose and discuss the experience. Some of this language is misogynistic and discriminatory in the blame it assigns to the bodies of women and birthing people. Some of the language perpetuates stigma associated with reproductive healthcare. Some of the language invalidates the experiences of many who lose a baby during pregnancy, especially when loss occurs at a younger gestational age. Some of the language is overly clinical and fails to account for the acutely personal grief pregnancy loss often causes. Ultimately, much of the language used around pregnancy loss seems to cause a fundamental, and often distressing, disconnect between how someone going through pregnancy loss conceptualises their experience internally, and the way that language seems to represent that experience externally.

Given the mounting evidence that losses at all stages of pregnancy are associated with significant psychological impacts, rigorous empirical research on the role of language in pregnancy loss experiences was long overdue. In 2023, the EStELC Project set out to explore this role, and to try to identify how language can best be used to support those experiencing pregnancy loss. Over the course of a year, we heard from 247 people from across the UK, who have experience of accessing and/or delivering healthcare for pregnancy loss, about how language impacted their experiences. The project's focus was directed, guided, and supported by our Expert Advisory Group (EAG). We are immeasurably grateful to all EAG members and especially to all the participants who shared their experiences with us. Without their generosity, courage, and insights, the project and its recommendations would not have been possible.

Dr Beth Malory
Project Lead, EStELC Project

A NOTE ON LANGUAGE

Before we could begin this research, we had to decide what to call it. We set out to show how fraught it can be to choose words to refer to the experience of a baby dying during pregnancy. It was therefore fitting, in a way, that it proved so difficult to find a project name that nobody would object to. Whilst *baby loss* is helpful for many, because it encompasses a broad range of experiences, including neonatal and infant death, it was not appropriate here, where our focus was on losses <u>during</u> pregnancy. *Baby loss* would also have implied that we expect all losses during pregnancy to be experienced as a baby dying. As this report highlights, this appears to be the most common way of conceptualising pregnancy loss, but it is certainly not the only one, and we did not want to choose a name that might exclude anyone from taking part.

Other options which are both widely recognisable and encompass all experiences of loss during pregnancy are scarce. I therefore chose *pregnancy loss* despite full awareness of its drawbacks (which are discussed at length in this document and the full EStELC Project report), because it was and is the best (and only) option available in the UK in 2024. I want to state clearly, though, that *pregnancy loss* is used throughout this document and the full EStELC report not with the intention of implying the loss <u>of</u> a pregnancy, but a loss <u>during</u> pregnancy.

The challenge of naming this project echoed through to the writing of its final reports, where choices likewise needed to be made about how to refer to experiences of pregnancy loss. Again, it would have been impossible to find words that nobody would object to or find difficult, so in an effort to be as inclusive as possible, I have used *baby* throughout. This reflects the preferences of most EStELC lived experience participants, many of whom found language which dehumanised their babies, such as *fetus* or *remains,* very painful. For anyone who does not find the word *baby* helpful in this context, this may be difficult, and I am truly sorry for that. It was easier to avoid using other potentially triggering terms, and it is for this reason that the word *parent* is not used, and nowhere in this report do I presuppose that only women experience, or are affected by, pregnancy loss. I have therefore used *participants* and *co-producers* to refer to those who contributed to the project. However, references to *women*, *mothers* and *parents* do occur in the report in quotations and participant testimony.

INTRODUCTION
LANGUAGE MATTERS

Participant contributions to the EStELC Project make clear that language truly matters when it comes to pregnancy loss. In this context, language can, in the words of several lived experience participants, have a "huge impact" on the experience of loss and a person's subsequent mental recovery and wellbeing. Project data indicates that this is because language often acts as a proxy for the potentially very different ways of conceptualising the experience of losing a baby during pregnancy, as well as the conceptualisation of the baby themselves. Language which contravenes, contradicts, or rejects an individual's conceptualisation of their experience and baby can therefore be distressing and invalidating.

"I see clients years later who are still distressed by the language that was used" (Healthcare professional participant)

"The way I was spoken to and [m]y baby was spoken about has had a profound and long lasting impact on how I have handled the loss" (Lived experience participant)

"Words matter a lot" (Lived experience participant)

The flipside of the distressing, invalidating, or otherwise upsetting experiences we heard about during the EStELC project is that language can act as a 'key' that can be used to understand someone's perception of what has happened to them. The project data shows that language often becomes the mechanism through which someone's fraught and fragile conceptualisation of their experience and their baby is either endorsed by the outside world, or, more often, by which it is undermined or dismantled.

These findings have led us to a simple conclusion: that it is always best to ask what language someone wants you to use to discuss their pregnancy loss, rather than assume.

T H E
P R O J E C T

"The project will centre, listen to, and amplify the voices of people with lived experience of pregnancy loss" (Project aims and scope)

RESEARCH QUESTIONS

The questions the EStELC Project set out to answer were as follows:

1. What **language is being used** to describe different experiences of pregnancy loss in UK health settings?

2. What **impact is such language having** on experiences of receiving and delivering healthcare during and after pregnancy loss?

3. How do people with lived experience of pregnancy loss, or professional experience of delivering care to those experiencing pregnancy loss, **feel about the language** used?

4. What preliminary **recommendations can be made** for implementing a trauma-informed language framework for pregnancy loss in clinical settings in the UK?

Figure 1: EStELC Project Research Questions.

To begin answering these questions, written and oral contributions were gathered from participants in two research cohorts. One cohort represented people with lived experience of pregnancy loss, and the other was comprised of people whose professional role involves providing care for people experiencing pregnancy loss.

AIMS AND SCOPE

When the Expert Advisory Group first convened in December 2023, the aims and scope for the project were defined:

> 1. Above all, the project will centre, listen to, and amplify the voices of people with lived experience of pregnancy loss

> 2. Alongside (1), the project will seek to understand the challenges of using language around pregnancy loss in clinical settings

> 3. The project will work to begin establishing an evidence base that will allow progress around pregnancy loss language to be guided by evidence

In order to fulfil these aims, written and oral testimonies on the impact of language in receiving and delivering healthcare during and after pregnancy loss experiences were gathered. Lived experience participants were able to submit written contributions via UCL's REDCap survey system, answering the questions, "Why would you like to take part in this study?' and 'Are there any issues or events related to language and pregnancy loss that you would particularly like to share during this project?'. These participants were then invited to participate in a Listening and Discussion Group focused on a particular aspect of their lived experience, if they felt able to. Healthcare professional participants were also able to submit written contributions via UCL's REDCap survey system, answering the question 'Are there any issues, topics, or events related to language and pregnancy loss that you would particularly like to discuss during this project?', and were also then invited to participate in a Listening and Discussion Group with fellow healthcare professionals.

> I would love to make an impact so others don't have to experience such pain in the language or lack of trauma informed practice around baby loss' (Lived experience participant)

> "[I want to talk about the] **importance of using the same language the patient (or client) uses**. For example many people use the phrase 'born sleeping', others use *baby loss*. But both these can cause distress in their own way for some other people" (Healthcare professional participant)

Some participants' reasons for taking part, contributed via UCL's REDCap survey system

PARTICIPATION

During the project, we heard from 339 participants; 290 of whom had lived experience of pregnancy loss, and 49 of whom were healthcare professionals involved in caring for people during or after experiences of pregnancy loss. Most participants submitted written contributions, outlining how language had impacted their experience of receiving or delivering pregnancy loss care (see Figure 2). 42 of these participants also took part in small group Listening and Discussion (LD) sessions (see Figure 3), where they discussed at length the role language played in their experiences. 10 LD Group sessions were held in 2024. 8 sessions involved people with lived experience of pregnancy loss occurring between 2021 and 2024 (n=32), and 2 sessions involved people with professional experience of providing care during and/or after pregnancy loss (n=10).

Recruitment for the lived experience cohort was highly successful, with hundreds more people expressing interest in participating in LD Groups than the project was able to accommodate. This attests to the need for this research, and for attention to be paid to the importance of language in experiences of accessing healthcare during and after pregnancy loss. Recruitment for the healthcare professional cohort was much more challenging. The higher level of interest from prospective lived experience participants in LD sessions and difficulties in recruiting professional participants resulted in an increase in LD sessions devoted to lived experience (8, rather than the projected 6) and a corresponding decrease in LD sessions devoted to professional experience (2, rather than the projected 4). This has resulted in fewer insights than expected from healthcare professionals, but has allowed a greater level of in-depth participation by more lived experience participants.
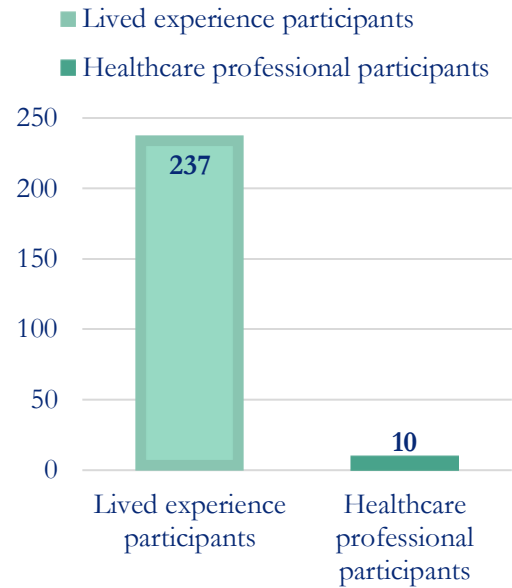

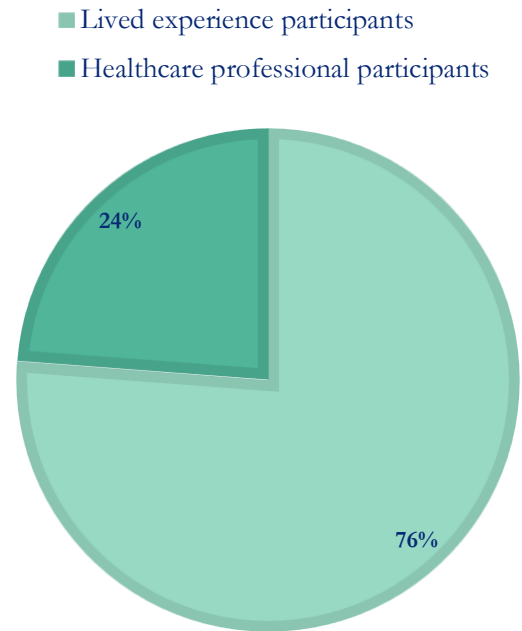Figure 2. Written participant contributions numbers.

Figure 3. Listening and Discussion cohort proportions.

FINDINGS 'DIFFICULT' LANGUAGE

"If the language isn't sensitive or considered, then it's just like a big fat arrow that says, 'Yeah, you're to blame'." (Healthcare professional participant)

Alongside establishing that 'bad' language practice can be detrimental, a core goal of the project was to identify what constitutes 'good' and 'bad' language practice in the context of pregnancy loss in clinical settings. A number of themes emerged, including the following:

Technical language

Lived experience participants told us that technical language was not always comprehensible, especially when English was not their first language. Many also said clinical terminology seemed cold or cruel:

"You can't understand what is happening... when they told me the baby died...they didn't say, 'The *baby* died', they said, '*Products of conception*'...it would be better to know that my baby died"

"We had somebody talk about the *fetal demise* and that seemed like a really clinical, strange way of saying it"

Blaming/stigmatised language

Lived experience participants told us that language like *miscarriage* and *incompetent cervix* implies blame. Others with experience of Termination for Medical Reasons (TFMR) reported avoiding *termination* due to stigma:

"[T[he word *miscarriage* to me implies that you did something wrong, that you mis-carried your baby"

"I've shied away from using *termination for medical reasons* [because I know people who] have very strong beliefs around termination generally and the fact that...[it] shouldn't be allowed"

Hierarchical language

Lived experience participants reported difficulties with language around hierarchies of grief. Some participants preferred language that imply such hierarchies, whereas others rejected such language:

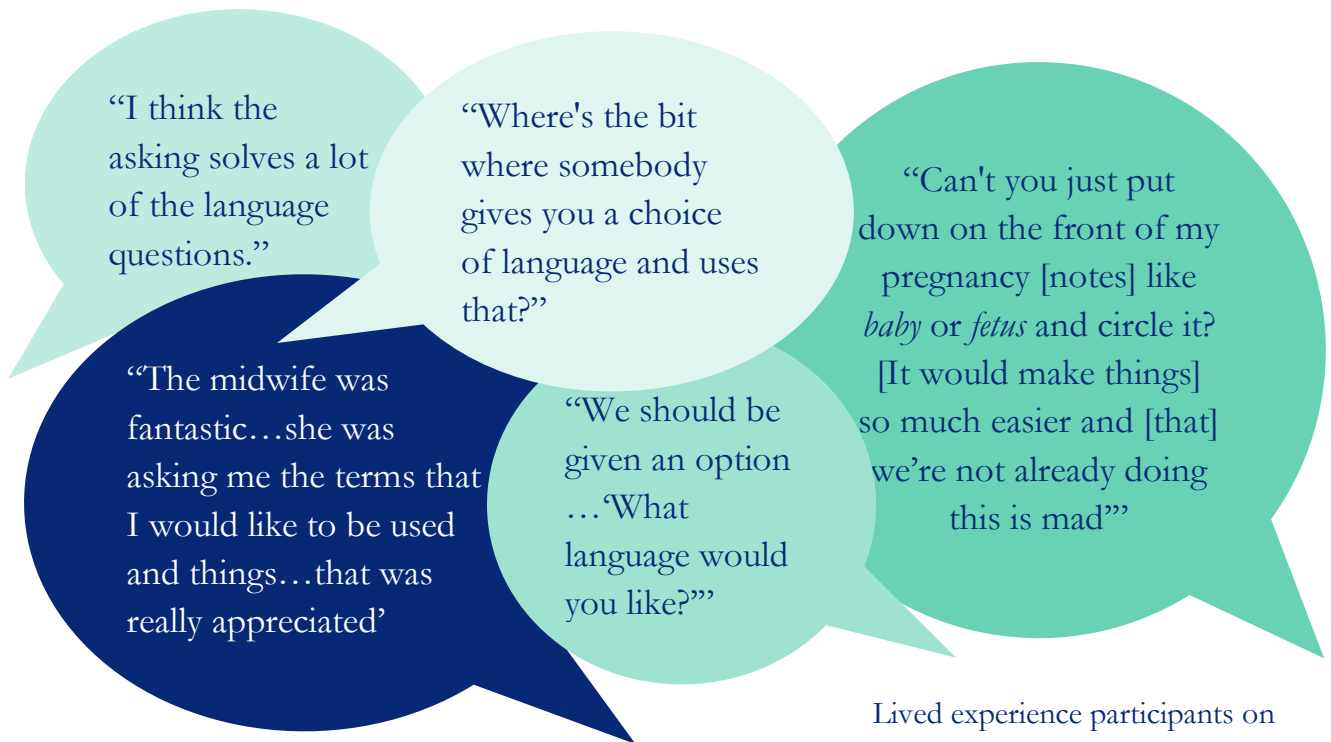'There is no hierarchy of grief. If you've lost a baby, you've lost a baby in my opinion"

'I'm not totally happy with the word *stillbirth* and I think my reason is because it encompasses such a range of loss, and I always really feel like I need to tell people... how late we lost [name]"

CONCLUSIONS
RESPECTING PREFERENCE

Whilst themes emerged from the project dataset, the EStELC project data highlights the impossibility of finding a set of words or phrases that nobody will object to. Many people prefer to refer to their *baby*; others prefer *fetus* or *embryo;* some like *pregnancy loss*, and others feel that it implies the loss <u>of</u> a pregnancy and not a baby, or that *loss* implies negligence and thus responsibility. The only way to avoid the use of 'difficult' language, then, is to use personalised language around pregnancy loss, wherever possible.

The full EStELC report discusses several strategies for ascertaining what kind of personalised language to use in a given context. 'Reflective listening', involving mirroring the language someone uses, is one way to do this. Framing 'difficult' language to mitigate the impact of exposure to it is another way to do this. Based on the findings of this project, though, we recommend actively eliciting preference on an individual basis wherever possible, to avoid mistakes and make clear your awareness that language matters in this context.

"I think the asking solves a lot of the language questions."

"Where's the bit where somebody gives you a choice of language and uses that?"

"Can't you just put down on the front of my pregnancy [notes] like *baby* or *fetus* and circle it? [It would make things] so much easier and [that] we're not already doing this is mad'"

"The midwife was fantastic…she was asking me the terms that I would like to be used and things…that was really appreciated'

"We should be given an option …'What language would you like?'"

Lived experience participants on the need for preference elicitation

RECOMMENDATIONS

The EStELC Project makes 4 recommendations for healthcare practitioners to bear in mind when discussing someone's experience of pregnancy loss with them:

1   Be **AWARE** that language matters

2   If in doubt, **ASK** about language preferences

3   **ALLEVIATE** the impact of difficult language using framing strategies

4   **AVOID** challenging or undermining stated language preferences

These recommendations acknowledge the clear importance of language in experiences of accessing healthcare during or after pregnancy loss, prioritise the preferences of individuals, and highlight the importance of mitigating the impacts of 'difficult' terminology where its use is unavoidable.

FUTURE WORK

The EStELC Project was limited in terms of the time and resources available to it. As such, this report represents the findings of relatively small-scale research and a self-selecting sample. Despite these limitations, the project has shown a clear need for the development of a trauma-informed framework for supporting individual language preference in clinical interactions during and following pregnancy loss

FORMAL MECHANISMS FOR ELICITING PREFERENCE

Whilst the EStELC Project recommendations are aimed at individual clinicians who may consider implementing active preference elicitation, future translational work to develop a national framework to support this approach may be key to ensuring that this evidence-based recommendation is implemented as widely as possible. As one EStELC participant in the healthcare professional cohort highlighted, small-scale initiatives which do this are already in place, including via the 'Know our Story' document described below, which is used within the Royal Berkshire NHS Foundation Trust. Research to optimise this kind of approach, as well as the national rollout of such an initiative, could embed evidence-based best practice on language around pregnancy loss across the UK healthcare system.

"One thing we try to do with pregnancy after loss is that we sit with families and ask them to tell us their stories in their own words. We say, 'We've got this digital record of your story but it's our version, so can you tell us?' And we have a document called 'Know our Story', which we worked with families to produce, where they can fill it in and say, 'Please can you say this? Please don't say this. This will hurt me, please avoid this.' And it's been a really helpful communication tool." (Healthcare professional participant)

ACKNOWLEDGMENTS

CONTRIBUTING ORGANISATIONS

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