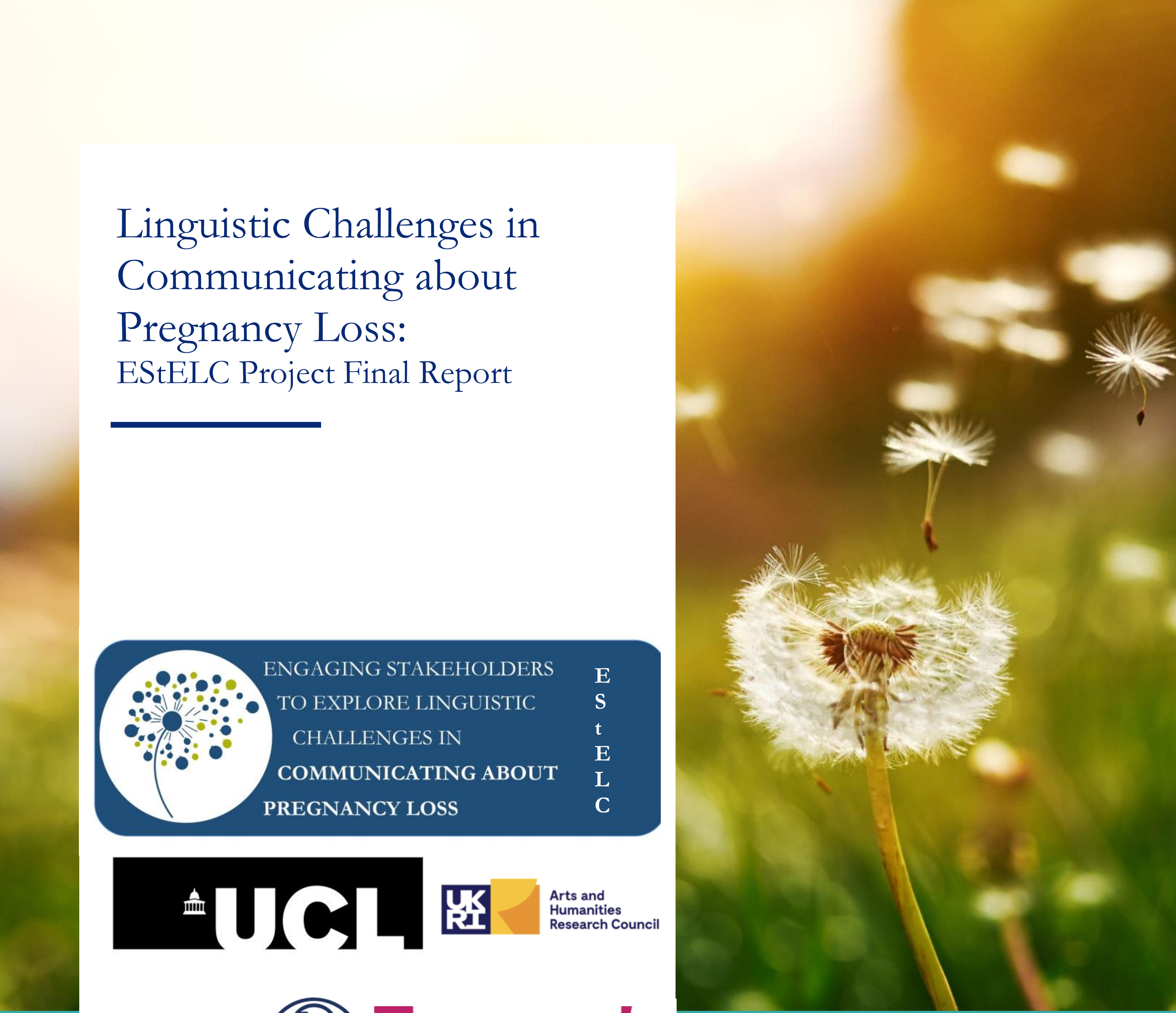

Linguistic Challenges in Communicating about Pregnancy Loss:
EStELC Project Final Report

ENGAGING STAKEHOLDERS TO EXPLORE LINGUISTIC CHALLENGES IN COMMUNICATING ABOUT PREGNANCY LOSS

EStELC

UCL

UKRI Arts and Humanities Research Council

Sands
Saving babies' lives. Supporting bereaved families.

Tommy's
The pregnancy and baby charity

September 2024

Dr Beth Malory

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Acknowledgments

This report presents a combination of primary research, expert input from across a range of relevant specialties and sub-specialties, and a review of a broad range of evidence. The primary research data cited here comes from the voices of 30 co-producers with lived experience of pregnancy loss and 10 healthcare professionals with experience of delivering care during and/or after pregnancy loss, as well as written contributions from 202 other co-producers with lived experience of pregnancy loss. Without the brave, insightful, and articulate contributions of our lived experience and health professional co-producers, this report would not have been possible, and it is thanks to their generosity in sharing their time, experiences, and their babies' stories that this report exists. Its intention is to make sure that this generosity helps to effect real change.

This report has been written by Dr Beth Malory of the Survey of English Usage at University College London, with support from Eloise Parr. The research reported here was conducted in partnership with Tommy's and Sands, and we gratefully acknowledge the support and resources offered by both charities. In particular, we thank Rachel Roberts, Dr Katharine Williams, Alice Dowden, Jeanette Nkwate, and Deirdre de Barra at Tommy's, and Mehali Patel and Ben Wills at Sands.

We also thank other charities who played a role in the project, in particular Munira Oza at The Ectopic Pregnancy Trust, Jane Fisher at Antenatal Results and Choices, Karen Burgess at Petals, and Vicki Robinson at The Miscarriage Association.

The EStELC project and this final report were strengthened immeasurably by input from an Expert Advisory Group which represented a range of disciplines, with members from professions across healthcare, academia, policy, and the charity sector. We are grateful to all members of the EAG for their role in the project, and a full list of those who contributed via the EAG is available in Appendix I. Particular thanks are owed to Ali Brett, Emily Cornish, Alex Heazell, Munira Oza, and Mehali Patel for their helpful comments and suggestions on a draft version of this report.

A note on language and presentation

In choosing a name for this project, I was confronted with an ironic (or perhaps fitting) challenge: how to refer to the experience of a baby dying in pregnancy, in a project intended to explore how best to refer to the experience of a baby dying in pregnancy? The imperative, imposed by an ethical research framework, to ensure the research purpose was as transparent as possible, made this decision slightly easier, by eliminating one obvious option: baby loss. The purpose of this project was to explore the particular experience of a baby dying before it is born, so whilst baby loss is a helpful phrase for encompassing such experiences, as well as neonatal and infant death, it was not appropriate here.

Baby loss would also, of course, have presupposed a conceptualisation of the experience as that of a baby dying. As this report highlights, that appears to be the most common way of conceptualising pregnancy loss, but it is certainly not the only one. Other options which encompass all experiences of loss during pregnancy were limited. In discussions at EStELC Expert Advisory Group meetings, we have debated bereavement, or more specifically gestational bereavement, as potentially useful alternatives, but they are not in general use and lack the recognisability needed for research recruitment. I therefore chose pregnancy loss, not without awareness of its potential drawbacks, which are discussed at length in this report (the possible interpretation that it is a pregnancy that is lost, and not a baby; the potential connotations of carelessness associated with loss), but as the best (and only) available option. For clarity, I want to state here that pregnancy loss is used not with the intention of implying the loss of a pregnancy, but a loss during pregnancy.

The challenge of naming this project was reflected throughout the writing of this document, since choices needed to be made throughout about how I referred to experiences of pregnancy loss. In an effort to be as inclusive as possible, I have used baby, since that was what the majority of EStELC participants used, and many rejected dehumanising words such as fetus and products in the strongest possible terms. I recognise, however, that this decision may pose difficulties for anyone who does not conceptualise their loss in this way, and for this, I apologise. In order to avoid using other potentially triggering terms, 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.

The struggle to name this project and to choose appropriate language to present its findings aptly encapsulates the need for it. Improvements are needed, and they cannot be made without an evidence base. This report represents the beginning of one.

The oral participant data represented here was transcribed manually, verbatim, by EStELC Research Assistant Eloise Parr. However, participant contributions have been edited minimally to optimise readability for the purpose of this report, for example by removing repetition and verbal fillers such as “um”. Written participant data is reproduced exactly, with “[sic]” added where significant differences from the written style of the report occur. In both the oral and written participant contributions cited throughout the report and elsewhere, italics are used, as is conventional in linguistics, to show when a word or phrase is the subject of discussion. Bold font is likewise used to highlight participant observations of particular relevance or importance, whether oral or written in origin.

Beth Malory, August 2024

1. Introduction

1.1 Why this project?

There is significant variation both globally and across the UK in how the English language is used to diagnose, define, and describe the states, experiences, and outcomes associated with pregnancy. This variation has resulted in increasingly heated public debate about the impact of such language, with concerns particularly being raised about the language used to describe adverse pregnancy outcomes, such as pregnancy loss, diagnoses of fetal anomaly, and challenging birth experiences. However, whilst these discussions have taken the form of clinical, academic, and lay debate, there has been little in the way of concerted effort to establish an empirical evidence base to show what role language plays in determining how people feel about their experiences, especially in the context of pregnancy loss. The purpose of this project was therefore to explore the language used to describe experiences and outcomes of pregnancy loss in a UK context, asking questions such as:

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.

In order to answer these questions, this project has recruited 290 lived experience participants and 49 healthcare professional participants and conducted thorough qualitative analysis. This report consists mainly of quotes from these participants, as well as drawing on existing literature on communication around pregnancy loss from relevant disciplines, including medicine, linguistics, psychology, sociology, anthropology, philosophy, and others.

In what follows, the project's organisation and governance will be summarised in Section 1.2, before its aims, scope, and value are outlined in Section 1.3 and background and context are detailed in Section 1.4.

1.2 Organisation and governance of the EStELC project

The UK-wide project 'Engaging Stakeholders to Explore Linguistic Challenges in Communicating about Pregnancy Loss' (EStELC) was led by University College London (UCL) in partnership with Tommy's and Sands, and a multidisciplinary, multi-sectoral Expert Advisory Group (EAG).

The EAG brought together representatives from charitable organisations, including Tommy's, Sands, Antenatal Results and Choices (ARC), The Ectopic Pregnancy Trust, Petals, and the Miscarriage Association, with clinicians, clinical academics and other academics. The EAG convened twice, at Symposia in December 2023 and June 2024. A full list of its members can be found in Appendix I.

Dr Beth Malory was the lead for the project from within UCL. She is a sociolinguist specialising in reproductive health communication. The project's Research Assistant was Eloise Parr, a PhD student in English Language and Applied Linguistics at the University of Birmingham, who specialises in metaphors around pregnancy.

1.3 Project aims, scope, and values

At the first meeting of the Expert Advisory Group at the first Project Symposium in December 2023 (hereafter, Symposium 1), 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 this, the project will seek to understand the **challenges of using language in clinical settings** around pregnancy loss

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

Figure 2. EStELC Project aims and scope.

Arising from these aims, the core values of the project were:

Listening inclusively

- The project aims to foster a respectful collaborative environment and include as many diverse voices as possible

Disagreeing well

- The project aims to facilitate difficult discussions about the sometimes competing needs and imperatives involved in choosing language around pregnancy loss, and to ensure buy-in from across relevant sectors

Following the evidence

- The project aims to oversee the establishment of an evidence base for understanding the impact of language on experiences of pregnancy loss, following a rigorous empirical model

Figure 3. EStELC Project core values.

This document aims to reflect these values throughout, by foregrounding the voices of lived experience project participants, holding space for debate, and presenting for the first time a body of empirical evidence that can help us to understand the impact of language usage in English on experiences of pregnancy loss in the UK. The methodological approach used to do this is outlined in Section 2. Before this, however, Section 1.4 summarises the pre-existing body of literature which considers the role English-language communication plays in experiences of loss at all stages of pregnancy, and highlights the significant gaps in the evidence base this project seeks to start to redress.

1.4 Background and context

There is a long history of calls for linguistic reform in the context of pregnancy loss in the UK. Most notably, it appears to have been a letter by three recurrent pregnancy loss specialists to The Lancet (Beard et al., 1985) which catalyzed the shift in clinical usage in British English from abortion to miscarriage, in relation to spontaneous loss before 28 weeks' gestation (which was then the gestational threshold for categorisation of stillbirth). This strongly worded letter called for use of miscarriage in such contexts "on humanitarian grounds", citing the distress abortion caused to patients who, they say, "always speak of 'miscarriages' unless they have had a termination of pregnancy" (1122-1123). Whilst there had been scepticism as to the role this letter played in prompting this linguistic shift (cf. Moscrop, 2013), the recent application of computational linguistic methodologies (Malory, 2022) has shown that Beard et al. were very likely responsible for catalyzing the shift away from abortion and towards miscarriage. Given that other attempts at clinical language reform in UK contexts and elsewhere have not enjoyed similar success, this is an interesting case study.

By contrast, as recently as 2011, clinicians in the US were still calling for a parallel shift from abortion to miscarriage in American clinical English (Silver et al., 2011). Asking what drove the success of Beard et al.'s (1985) call for change, and what has limited the impact of subsequent clinical calls for language reform, is therefore important for understanding the mechanisms by which the terminology of pregnancy loss can be changed when it is deemed problematic.

Against the background of calls for the reform or standardisation of pregnancy loss terminology, the past two decades have seen the publication of a body of literature, some empirical, focusing on communication around pregnancy loss from different disciplinary perspectives. This means that a body of evidence has begun to develop, which highlights the impact of communication on perceptions and experiences of pregnancy loss. Whilst it is encouraging to see increasing focus on the role language plays, there has been a troubling lack of cohesion or systematicity in this body of literature, and a lack of common purpose in exploring these issues. The one scoping review on pregnancy loss communication published prior to the EStELC project, for example, focused on only one aspect of pregnancy loss: miscarriage (Lacci-Reilly et al., 2023). This review focuses on original medical research on miscarriage and healthcare communication published in the United States during the period 2003-2023. Revealingly, it found only eleven papers which met its inclusion criteria (Lacci-Reilly et al., 2023). This review effectively identifies some existing knowledge gaps, but there is a clear need for a more comprehensive multidisciplinary review of Anglophone publications, or a complementary review focused on the UK.

Whilst little research has been conducted on language and communication around pregnancy loss, the review of the literature conducted for this project found that much has been written on this topic in recent decades, both by clinicians and in the public domain. The following sub-sections will outline the main themes of these outputs.

1.4.1. Clinicians' calls for change

As noted above and indicated by the title of Silver et al.'s (2011) paper 'Nomenclature for pregnancy outcomes: Time for a Change', the shift from *abortion* to *miscarriage* has been much slower in US clinical contexts than in the UK. Indeed, despite quantitative evidence that this shift was near-complete in the UK by the mid-1990s (Malory, 2022), an analysis of US obstetrics and gynaecology journals in the 1990s found that *abortion* remained the dominant variant (Hutchon, 1998). It is striking that in 2011, Silver et al. were still advocating for use of *miscarriage*, whilst also highlighting the need for a consistent taxonomy for clinical and research purposes.

In addition to *miscarriage*, Silver et al. (2011) also call for substitution of other labels used in diagnosing pregnancy loss. In relation to *blighted ovum*, they note that this phrase "makes no biological sense and conveys a sense of the loss being due to some inherent abnormality with the mother", whilst they also contend that "the expression chemical pregnancy [sic] implies that it was not a 'real' pregnancy, leading to anger and sometimes frustration on the part of parents" (1403). The authors also highlight "cervical incompetence" and "cervical insufficiency" as diagnostic labels which "place 'blame' on the mother" and suggest "spontaneous cervical ripening" as a substitute (1407).

The practice of highlighting multiple problematic diagnostic labels in this way, and suggesting alternatives, is also a feature of the clinical calls for reform which have been published with a focus on UK language in the last decade. In a *BMJ* blog in 2018 entitled 'Humanising birth: Does the language we use matter?', the authors identify "examples of poor communication" and suggest "alternative language" (Mobbs et al., 2018). In relation to pregnancy loss, these include "compassionate induction" for "terminate pregnancy" in cases of Termination for Medical Reasons (TFMR), and "medically complex" for "poor obstetric history" or "high risk"(Mobbs et al., 2018).

Likewise, in a comment piece in *The Lancet* in 2021, Vimalesvaren et al. set out to "call out inappropriate, insensitive, and outdated words and phrases that have been historically used in clinical practice, particularly in the intrapartum period" (859-860). To do this, they provide a table of "sensitive language" and "insensitive language" (Vimalesvaran et al., 2021: 860). In relation to pregnancy loss, they suggest "incompetent cervix" be replaced with "cervical insufficiency that can increase risk of preterm birth or pregnancy loss", and the authors "appeal to colleagues worldwide to banish such terms from their vocabulary" (860).

All the calls for substitution of problematic variants discussed in this section so far appear to come from a place of compassion, and to be made, as were Beard et al.'s in 1985, "on humanitarian grounds" (1122). However, they all also seem to arise in a vacuum of specialist linguistic expertise and empirical linguistic research, and consequently do not reflect contemporary usage, social attitudes, varying preferences of individuals with lived experiences, or large-scale research. Some, such as "compassionate induction" (Mobbs et al. 2018) are even considered highly problematic by experts with specialist insight.[1] This underscores the need for multidisciplinary consultation and empirical research before such recommendations are made.

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[1] Private correspondence with Jane Fisher, Director of Antenatal Results and Choices, 2023.

1.4.2. Calls for change in the public domain

The previous sub-section highlighted calls for reform of the diagnostic labels used in relation to pregnancy loss which have been made by clinicians, in such contexts as medical journals and medical journal blogs. This sub-section will show that this tradition of complaint, as well as the suggestion of preferred alternatives, is mirrored in the public domain, in newspapers, magazines, and non-medical blogs.

In some instances, such complaints about diagnostic terminology appearing in the public domain are written by clinicians. This is the case, for example, with a Canadian news article entitled 'It's time to stop calling pregnancy loss 'miscarriage" (Gorfinkel, 2015). In this article, Canadian physician Iris Gorfinkel argues that those experiencing pregnancy loss "largely continue to be under the false impression that the loss had been self-generated", and questions whether the word "miscarriage' could be partly to blame. She suggests "natural pregnancy loss" as an alternative which "reflects a basic understanding of what pregnancy loss truly represents".

Similar sentiments were expressed in an article in the US edition of the magazine *Glamour* published online in January 2020 (Oré, 2020). Here, too, the word *miscarriage* is problematised, specifically in the context of the so-called "wave of conversation on social media" which followed the death of Chrissy Teigen and John Legend's son, Jack. Interspersed with screenshots from Twitter, the article highlights social media users' linkage of self-blame and the word *miscarriage*, citing "pregnancy loss" as a preferable alternative. The screenshots from Twitter used in Oré's (2020) piece highlight a popular groundswell of feeling concerning the language used to describe experiences of pregnancy loss, which has led journalist Jennie Agg in her book *Life, Almost* to characterise Teigen's post as "a relief valve" (2023: 18). This groundswell may reflect a cultural movement away from *miscarriage* and towards *pregnancy loss*, which appears to be manifesting in policy and public health messaging. Unlike the swift change documented to have followed the intervention of Beard et al. (1985), however, this change is occurring very slowly and in a piecemeal manner.

A more systematic approach to this model of problematising pregnancy loss terminology and suggesting alternatives in the public domain can be found in the Peanut *Renaming*

Revolution: The Motherhood and Fertility Glossary. Peanut, an app for facilitating friendships between parents, hosts this glossary on its website, with the intention of prompting a "renaming revolution", which addresses the "reality that existing terminology does not value and empower women" through pregnancy and birth (Peanut, 2023: 1). This document was compiled through crowdsourcing on social media, and thousands of women are reported to have contributed "hurtful terms they experienced"(Agatowski, 2023). In relation to pregnancy loss, the glossary suggests substitutions such as "early cervical dilation" instead of "incompetent cervix" (which is, strangely, listed under 'fertility' and not 'loss') (Peanut, 2023: 3), "early pregnancy without an embryo" instead of "blighted ovum", and "compassionate induction" instead of "medical termination" (6). The glossary was compiled with input from a small group of medical professionals and those with some linguistic training, but does not rely on an empirical model.

Before considering research on pregnancy loss language which does use an empirical model, it is necessary to discuss more official attempts to provide guidance, in the form of so-called 'consensus statements' and official language guidance.

1.4.3. 'Consensus' statements and language guidance

Given the clear sense that pregnancy loss terminology is both unsatisfactory to many and is in flux, it is unsurprising that the last decade has seen the publication of several 'consensus' statements (Delabaere et al., 2014; Johnson et al., 2020; Kolte et al., 2015). These are documents intended to provide clarity and consistency of terminology, which are produced following consultation between experts. They therefore provide a systematic overview of perceived problems with diagnostic terminology used in relation to pregnancy loss in English, as well as recommendations for terminology considered preferable. However, they are not empirical documents and tend to reflect the impressionistic observations and preferences of those involved in their compilation.

The first consensus statement on this issue in English, though not labelled as such, appears to have been published in the journal *Human Reproduction* in 2005, on behalf of the European Society for Human Reproduction and Embryology (ESHRE) Special Interest Group on early pregnancy (Farquharson et al., 2005). Farquharson et al. provide what they

term an "updated glossary" to describe "clinical events in early pregnancy", in the hope of "facilitat[ing] the introduction of a revised terminology in an attempt to provide clarity and to enhance uptake and use in literature as well as clinical assessment and documentation" (2005: 3008). It suggests alternatives such as "fetus" instead of "embryo"; "miscarriage" or "termination of pregnancy", depending on context, instead of "abortion"; "empty sac" instead of "anembryonic pregnancy" (3010), and "gestational trophoblastic disease, complete or partial" instead of diagnoses containing "mole" (3009).
With similar goals in mind and less than a decade later, a group of French clinicians published another consensus statement[2] which aims to "provide a standardised French/English terminology/glossary relating to pregnancy losses" (Delabaere et al., 2014). Its main English-language recommendations are for *miscarriage* to be used with various modifiers to reflect the taxonomy of pregnancy loss they outline. The resulting labels include "missed early miscarriage", "incomplete early miscarriage", "repeat miscarriage", and "late miscarriage".

The following year, the ESHRE Special Interest Group on early pregnancy updated its recommendations on diagnostic language, with the aim of "provid[ing] clear and consistent terminology for pregnancy loss prior to viability", and facilitating the comparison of study results between research centres (Kolte et al., 2015). In terms of specific variants, Kolte et al. recommend both "pregnancy loss" and "miscarriage" (2015: 496), in a move that apparently reflects the wider trend towards *pregnancy loss* highlighted in Section 1.4.2 above. The authors also endorse some labels discouraged by the previous ESHRE guidance (cf. Farquharson et al., 2005), such as "anembryonic miscarriage" (Kolte et al. 2015: 496).

A further 'consensus statement' was published in 2020, to provide recommendations for the delivery of unexpected news in Early Pregnancy Units and the Fetal Anomaly Screening Programme in NHS settings (Johnson et al., 2020). These guidelines were reached via a workshop of 28 interdisciplinary healthcare professionals, policy experts, charity representatives, lay experts and academics, and consultation with a wider writing group of

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[2] Though again not labelled explicitly as such Delabaere et al. (2014) reached their recommendations via literature review and "formal consensus method".

39 individuals. Recommendations in relation to pregnancy loss include substitution of "blighted ovum/anembryonic pregnancy" with "a baby who died very early on", "products of conception" with "tissue/pregnancy tissue/remains of the pregnancy", and "abortion" with "miscarriage".

Whilst not labelled as a consensus statement, the language guidelines circulated by the Royal College of Obstetricians and Gynaecologists in 2022, entitled 'RCOG Language Guide' seem to have been compiled using a similar model of consultation. These guidelines are intended "to create consistency, fairness and inclusivity" (Royal College of Obstetricians and Gynaecologists, 2022). In relation to loss, they recommend substitution of "incompetent cervix" with "cervical dysfunction", "spontaneous abortion/early fetal demise" with "miscarriage", "evacuation of retained products of conception" with "surgical management of miscarriage" and "parents who've suffered baby loss" with "parents of a baby who died".

The documents considered in this section exhibit inconsistency, highlighting a need for empirical research to establish standardised terminology. Whereas Kolte et al. (2015) recommend *anembryonic pregnancy*, for example, Johnson et al. (2020) recommend avoidance of this phrase. Much of this guidance also seems to reflect a dated concept of how language is used in this domain, with *abortion* repeatedly mentioned, despite little evidence of its continued usage in the UK in the context of pregnancy loss, and *miscarriage* presented as preferred despite the evidence presented in Section 1.4.2 that it is considered problematic by many. Since these documents lack empirical basis, they tend to reflect impressionistic observations and the preferences of those involved in their compilation, and fail to capture the degree of variation in the preferences of those with lived experience. Whilst specialist expertise is undoubtedly crucial in identifying a set of words and phrases which are likely to cause the least harm and confusion, we also need data which can enable us to understand contemporary usage and the preferences of those affected by its use. The EStELC project has aimed to combine these approaches, by utilising both specialist expertise and an empirical model, as outlined in Section 2, below. This project is also designed to account for the need to distinguish clearly between, on the one hand, contexts in which the language used should represent the specific preferences of those experiencing pregnancy loss and, on the other, contexts in which individual preference cannot be respected and standardised terminology is thus needed, such as public health information and policy documents. The need for such a distinction is discussed at greater length in Section 1.4.4.

1.4.4. Empirical research

Previous sub-sections have highlighted the many challenges posed by pregnancy loss communication and terminology, both in clinical and other specialist contexts and in wider society, and shown a clear need for rigorous, interdisciplinary empirical research to explore these challenges and provide recommendations to improve the situation. A body of empirical research is already emerging, and this report will make a significant contribution to this body of literature. These studies paint a compelling picture of the damage which ineffective, insensitive, and unclear pregnancy loss terminology can cause. However, to date there have been no attempts to pair such evidence with recommendations to provide coherent, empirically-derived recommendations for communicating about pregnancy loss.

Recent years have seen some attempt to extrapolate empirical findings to provide guidelines for pregnancy loss communication. Brann et al. (2020), for example, provide some general recommendations, such as "[r]espond to patient cues" and '[p]rovide patients with full attention"; as well as some that are more specific, for example "[a]void the term 'abortion'". Such specific linguistic prescriptions are rare; like Brann et al., (2020), Austin et al. (2021) also make communication recommendations that do not appear to be pregnancy loss-specific, suggesting clinicians should outline all options available, and be clear and avoid technical language.

Likewise, the Royal College of Midwives' Re:Birth Project Final Report (2022) notes that "findings from the Listening Groups and Voices Survey led the project team to the view that we could not support or recommend the use of any particular term over another in conversation with women, birthing people and their families", but that "[i]nstead, service user participants asked for health professionals to reflect the language they themselves used when speaking to them about their labours and births" (17). Whilst not focused explicitly on pregnancy loss, this project provides a helpful model for empirically focused language research in a related context.

Researchers providing empirical evidence as to the impacts of the obstetric and pregnancy loss terminology status quo thus seem reluctant to suggest terminology substitution in the way that clinicians and others were shown to do in Sections 1.4.1, 1.4.2, and 1.4.3. This seems to be because empirical research reflects the wide degree of variation in usage, and rarely results in clear consensus about particular words or phrases.

However, such empirical research has not yet acknowledged the importance of upholding a distinction between contexts involving mass communication, where consensus on the least damaging terminology is necessary, such as policy documents and public health information, and contexts in which language use can be more responsive to individual preference. There is a clear need for a strategy which distinguishes between such contexts; on the one hand gauging usage and preference using an empirical research model, and extrapolating these findings in the hope of finding a clear, cohesive, standardised set of terminology for pregnancy loss which can function optimally across the necessary domains; maximising clarity and minimising distress, and on the other developing a trauma-informed framework for supporting individual language preference in clinical interactions during and following pregnancy loss. The EStELC Project aims to begin establishing such a framework for interpersonal interactions in UK clinical settings, whilst its sister project SuPPL (Supporting Policymakers to Negotiate Communicative Challenges around Pregnancy Loss) aims, as will be outlined in Section 2, to find a standardised set of words that will minimize harm in mass communication.

1.5 Towards evidence-based guidance for pregnancy loss language

The fragmentary, discretely discipline-specific, focus of much of the literature highlighted in Section 1.4 may be the reason that little headway has been made in addressing the problems it identifies. This is why the EStELC project aimed to facilitate a more joined-up, cohesive approach. By bringing together a variety of stakeholders, this project harnessed and sustained multi-disciplinary attention to the problems of pregnancy loss terminology, and asked how the terminology can best serve individuals affected by pregnancy loss primarily, but also clinicians, researchers, and wider society.

The apparent need for cross-sector cooperation, if such problems are to be addressed effectively, is also the driving force behind the project's focus on words and phrases, rather than the broader narratives or cultural 'frames' which are the subject of other linguistic work in this domain (cf. Austin et al., 2021; Horstman et al., 2020; Littlemore & Turner, 2020). These narratives and 'frames' are undoubtedly often highly problematic, but without careful consideration of terminology, they will likely persist. To give an example; it may well be futile to insist that pregnancy loss should be divorced in the public consciousness from culpability, if words and phrases like *miscarriage* and *incompetent cervix* retain some level of official endorsement, remain in common usage, and give the impression of blame.

The renewed interest in the importance of communication in this context that has emerged over the last decade provides an opportunity for a holistic approach to the problems of pregnancy loss terminology, which lessens its impact on psychological wellbeing, cultural stereotypes, and clinical and research practice. It is hoped that this project will begin to facilitate such an approach.

2. Methodology

2.1 Research design

The project's methodological approach was designed to reflect its core values (see p.9) and to be iterative, inclusive, and open-minded. Our aim was to create space for the Expert Advisory Group (EAG) and co-producers with lived and professional experience of pregnancy loss language, to share their experiences and views on language in a safe, trauma-informed environment, using their own words. The qualitative research design facilitated this aim, allowing for sensitive and responsive exploration of difficult topics. The qualitative data arising from this research will also provide contextualisation for interpretation of quantitative data being gathered in a related project, SuPPL (Supporting Policymakers to Negotiate Communicative Challenges around Pregnancy Loss). Also led by Dr Beth Malory and funded by Research England, this project has used an online questionnaire to explore lived experience of pregnancy loss language at a larger scale, and its findings will be published in late 2024.

Ethical approval for EStELC project data gathering was granted in April 2024 by the UCL Research Ethics Committee (26991/001).

The EStELC project used a tripartite approach, combining input from the Expert Advisory Group with written and oral contributions from lived experience and professional experience participants, as outlined in the following sections.

2.1.1. Expert Advisory Group Symposia

Two day-long events were held at UCL to allow Expert Advisory Group (EAG) consultation and determine the direction the project should take. The first of these symposia was held in December 2023, and the second in June 2024.

13 members of the EAG attended the first project symposium, which provided an opportunity to discuss the direction of the project at its outset (see Appendix I for symposium attendance). Prior to this symposium, the project's lead Dr Beth Malory and Research Assistant Eloise Parr collated an evidence pack which was circulated to other members of the EAG. This evidence pack formed the basis for discussion during the symposium, with the goal of identifying areas of most acute challenge to be the focus of EStELC Listening and Discussion Groups. These areas of acute challenge were identified as: 1) language considered to imply blame, 2) language which either implies or denies the existence of a hierarchy of loss or grief, 3) language associated with stigma, 4) overmedicalisation and technicality of terminology, 5) cross-linguistic and cross-cultural communication, 6) the need for clear, standardised vocabulary in research and clinical contexts and 7) challenges for clinicians of communicating differently with colleagues and patients.

The EAG input informed the topic guides for Listening and Discussion Groups which were submitted to the UCL Research Ethics Committee and ultimately used in Listening and Discussion Groups with both the lived experience and healthcare professional cohorts.

10 members of the EAG attended the second project symposium, held at UCL in June 2024. This symposium provided an opportunity for the core project team to update the EAG on data collection and analysis, and to discuss the project data and possible next steps.

2.1.2. Surveys

Four separate surveys were hosted in UCL's REDCap survey system, allowing sensitive data to be uploaded directly to UCL's Data Safe Haven in encrypted form. The first two were self-screening questionnaires for prospective lived experience and health professional participants respectively, allowing prospective participants to assess their eligibility to take part quickly and easily, without prior need to submit any personal data. For prospective lived experience participants, this meant checking themselves against the inclusion criteria; having had bodily experience[3] of pregnancy loss(es) in 2021, 2022, 2023 and/or 2024. For prospective healthcare professional participants, the inclusion criteria were current employment in the UK health sector, and a professional role requiring regular interaction (>2 times per week) with people experiencing pregnancy loss, or who have experienced pregnancy loss within the last 3 years.

Participants were invited to complete the eligibility questionnaire through EAG networks, professional contacts, and social media, with partner organisations Tommy's and Sands and collaborating organisations Antenatal Results and Choices, The Ectopic Pregnancy Trust, The Miscarriage Association, and Petals playing an important role in disseminating the questionnaire and recruiting participants.

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[3] This phrase is used throughout the report to refer to the experience of losing a pregnancy or baby an individual was physically carrying in their own body. This was an inclusion criterion since clinical language was the research focus and those carrying the pregnancy are likely to have experienced most clinical interactions during and after the pregnancy loss.

Prospective lived experience participants whose screening questionnaire answers indicated eligibility were invited to submit a short form answer to the question, 'Why would you like to take part in this study?' and to email the Principal Investigator to express their interest, or to submit a contact email address via the screening questionnaire, to receive an invitation to participate in a focus group. 290 prospective lived experience participants completed the eligibility questionnaire, with most (n=237) of these individuals submitting statements about their reason for wanting to take part. These statements are the first source of primary research data used in this report.

Prospective lived experience participants who had been screened anonymously for eligibility were then invited to complete a longer and more in-depth 'grouping' questionnaire, for the purpose of being assigned to an appropriate Listening and Discussion Group, or to allow those who wanted to contribute in writing, and not during a group session, to do so.

The grouping questionnaire sent to prospective lived experience participants collected personal and demographic data and asked them to indicate which words and phrases had been used to describe their experience of pregnancy loss and their baby, as well as their preferred language. It also allowed them to add a long-form response to the prompt: "Are there any issues or events related to language and pregnancy loss that you would particularly like to share during this project?". This helped with assigning prospective participants to appropriate groups, and allowed those who wished to participate without taking part in a Listening and Discussion Group to make a substantive contribution to the project. 110 lived experience participants completed this questionnaire, and 98 of these provided statements about issues and events they particularly wished to contribute to the project. These statements are the second source of primary research data used in this report.

Mirroring the recruitment process for prospective lived experience participants, prospective health professional participants who had been screened anonymously for eligibility were invited to complete a longer and more in-depth 'grouping' questionnaire, for the purpose of being assigned to an appropriate Listening and Discussion Group, or to allow those who wanted to contribute in writing, and not during a group session, to do so. 49 healthcare professionals completed the eligibility questionnaire and, of these, 42 submitted a contact email address and were sent invitations to complete the grouping questionnaire. Uptake of this invitation was low in the healthcare professional cohort, with only 13 of these 42 individuals completing the grouping questionnaire.

The grouping questionnaire sent to prospective healthcare professional participants collected information about their professional role, as well as the language they use in the course of their duties to refer to experiences of pregnancy loss. It too allowed them to add a long-form response to the prompt: "Are there any issues, topics, or events related to language and pregnancy loss that you would particularly like to share during this project?". Of the 13 healthcare professionals who completed the grouping questionnaire, 10 submitted statements in response to this prompt and these are the third source of primary research data used in this report.

2.1.3. Listening and Discussion Groups

10 small group discussions were hosted online. 8 sessions involved people with lived experience of pregnancy loss (n=32) who had completed the screening and eligibility questionnaires and been invited to participate in a Listening and Discussion Group. Co-producers were assigned to different groups based on broad similarity of experience, resulting in 3 sessions for people with bodily experience (see footnote [3], above) of language around first trimester pregnancy loss (n=14), 1 for second trimester pregnancy loss (n=4), 2 for Termination for Medical Reasons (n=6), and 2 for stillbirth (n=8). Where questionnaire responses indicated that a co-producer had experience of two or more different types of pregnancy loss within the three years of interest, they were asked which type of group they would prefer to participate in, and assigned accordingly. 2 other sessions involved people with professional experience of providing care during and/or after pregnancy loss (n=10). One of these sessions brought together healthcare professionals involved in providing care during experiences of pregnancy loss, including two midwives, two doctors in specialty training, and a specialist pregnancy loss nurse (n=5). The other session brought together healthcare professionals involved in providing care following experiences of pregnancy loss, including specialist pregnancy loss counsellors and a Pregnancy after Loss specialist midwife (n=5).

Listening and Discussion Group sessions were ‘moderated’ and guided loosely by the facilitator, Principal Investigator Dr Beth Malory, but discussion was allowed to flow freely providing it remained on-topic and focused on language and pregnancy loss. Two topic guides were prepared; one for lived experience Listening and Discussion Groups and one for healthcare professional Listening and Discussion Groups. These were used only to ensure that all central topics for a given Group were discussed, unless intervention was needed because discussion was not flowing freely. This happened in only one session.

During lived experience Listening and Discussion Groups, participants were asked about the terminology used to refer to their experience(s) of pregnancy loss and their babies, by healthcare professionals, and about how this made them feel, as well as their preferred language, and any relevant language used outside of healthcare settings which they had strong feelings about. During healthcare professional Listening and Discussion Groups, participants were asked about the language they use with people who are experiencing or who have experienced pregnancy loss and with other clinicians, the factors which determine the kinds of language they use, and any changes they had witnessed during their careers.

2.2 Participant information

2.2.1 Lived experience cohort

Lived experience participants who submitted the grouping questionnaire mostly identified themselves as being aged between 25 and 34 (n=53), followed by 35 to 44 (n=51) and 18 to 24 (n=5). 2 participants declined to provide information about their age.

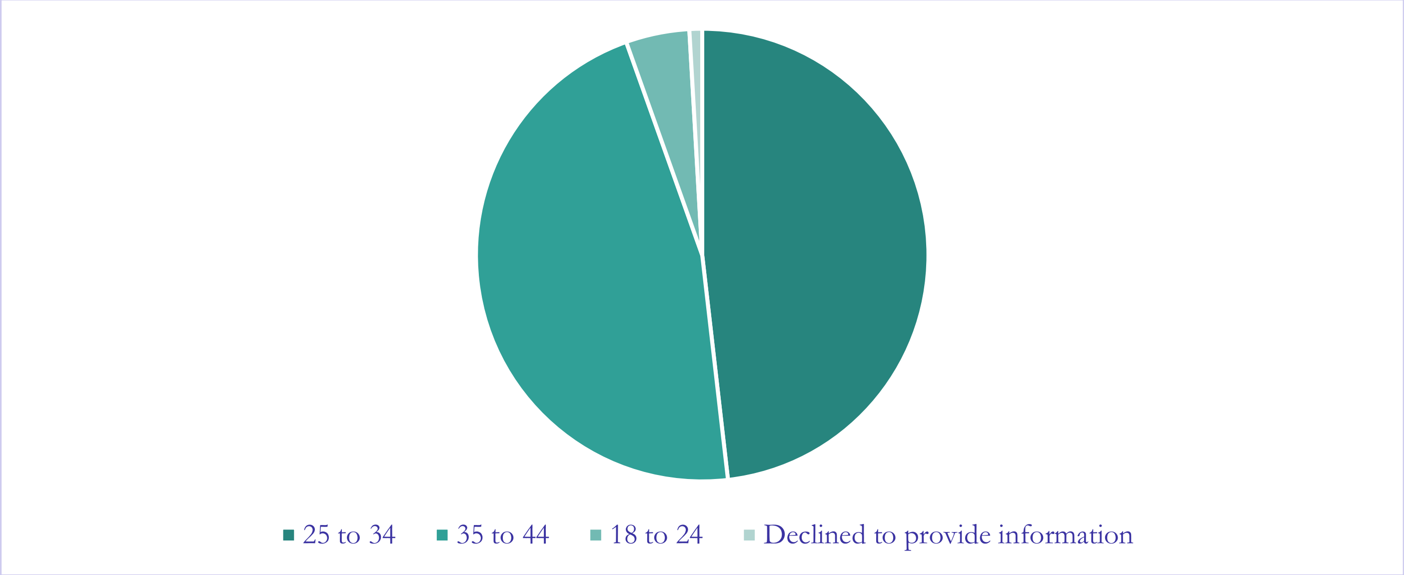

Figure 4. Age distribution of participants who completed the grouping questionnaire.

All but 2 of the participants who completed the grouping questionnaire identified their gender as 'woman' (n=108). Of these 2, one identified their gender as 'non-binary' and the other declined to provide information about their gender identity. Of the 32 lived experience participants who took part in Listening and Discussion Groups, 31 were women and 1 was non-binary.

98.12% of participants (n=101) identified themselves as heterosexual. 4.55% identified themselves as bisexual (n=5), and 1.82% as lesbian (n=2). A single participant identified with the descriptor 'A sexuality not listed here', and another declined to provide information about their sexuality.

Given the disproportionate rate of adverse pregnancy outcomes amongst Black and Asian ethnic groups and those from deprived socioeconomic backgrounds (Knight et al., 2023), recruitment efforts were focused particularly on attempting to ensure representation for these communities. This was achieved by reaching out to charity and grassroots organisations focused on inequalities in maternity care, and by prioritising prospective participants from these communities for Listening and Discussion Group places. Ethnic group classifications were taken from the 2021 Census.

Unfortunately, success with the first of these strategies was limited, with 82.73% (n=91) of participants who completed the grouping questionnaire identifying their ethnic group as 'White: English, Welsh, Scottish, Northern Irish, or British, Irish, Gypsy or Irish Traveller, Roma, any other White background'. Only 3.64% (n=4) of participants at this stage identified their ethnicity as 'Asian or Asian British: Indian, Pakistani, Bangladeshi, Chinese, any other Asian background', and only 1.89% (n=2) identified as 'Black British, Caribbean or African: Caribbean, African, or any other Black, Black British, or Caribbean background'. 5.46% (n=5) of grouping questionnaire participants identified their ethnicity as 'Mixed or multiple ethnic groups: White and Black Caribbean, White and Black African, White and Asian, any other Mixed or multiple ethnic background'. 1.89% identified themselves as 'Other ethnic group: Arab, any other ethnic group' (n=2) and one participant declined to provide information about their ethnicity.

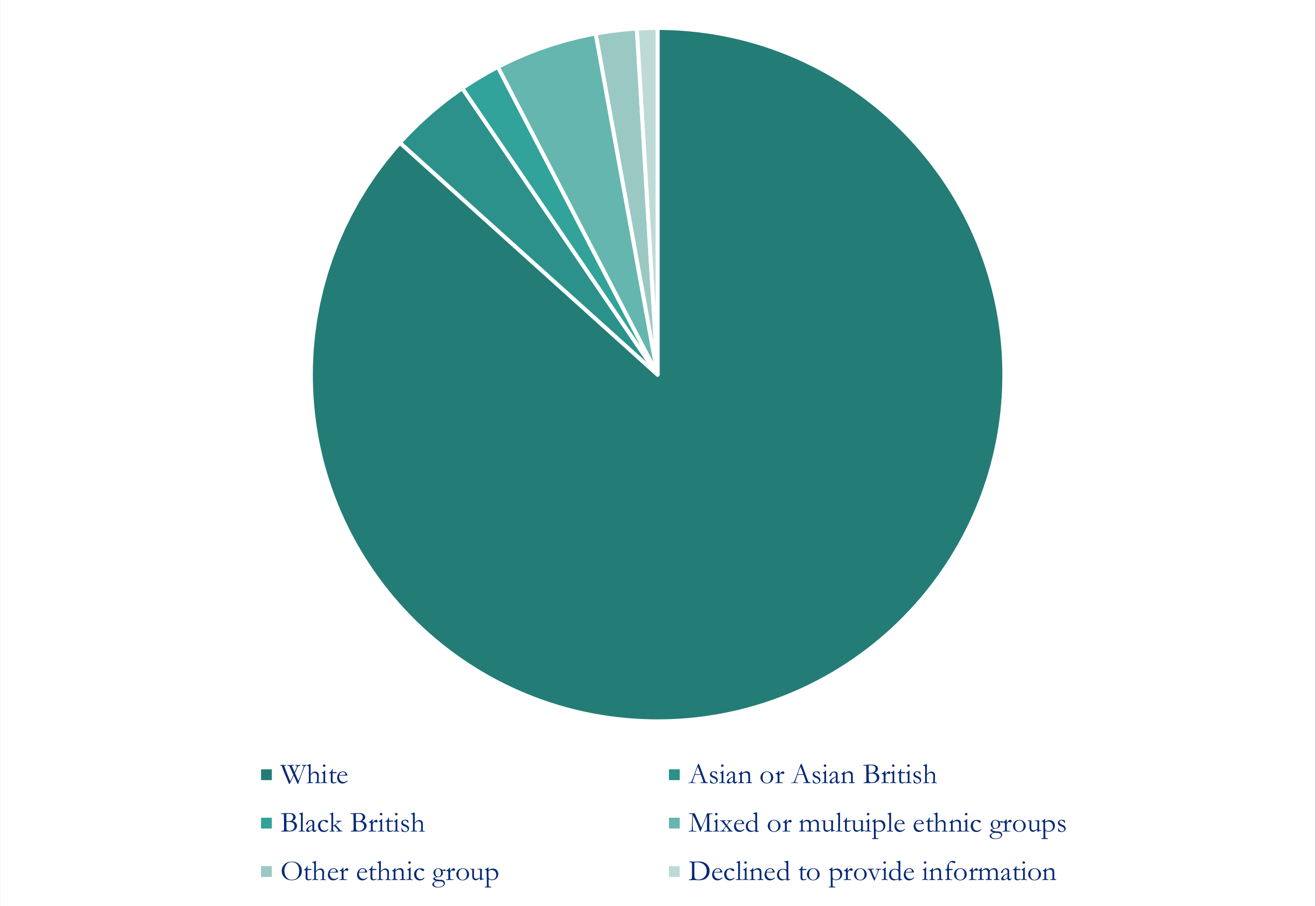

Figure 5. Ethnicity data of participants who completed the grouping questionnaire.

Prioritising representation at Listening and Discussion Groups for lived experience participants of colour was a slightly more successful strategy. Of the 32 participants in the lived experience Listening and Discussion phase, 9.38% (n=3) had identified their ethnicity as 'Asian or Asian British: Indian, Pakistani, Bangladeshi, Chinese, any other Asian background', and 6.25% (n=2) had identified as 'Black British, Caribbean or African: Caribbean, African, or any other Black, Black British, or Caribbean background'. 9.38% (n=3) of Listening and Discussion Group participants had identified their ethnicity as 'Mixed or multiple ethnic groups: White and Black Caribbean, White and Black African, White and Asian, any other Mixed or multiple ethnic background', 3.13% had identified themselves as 'Other ethnic group: Arab, any other ethnic group' (n=2).

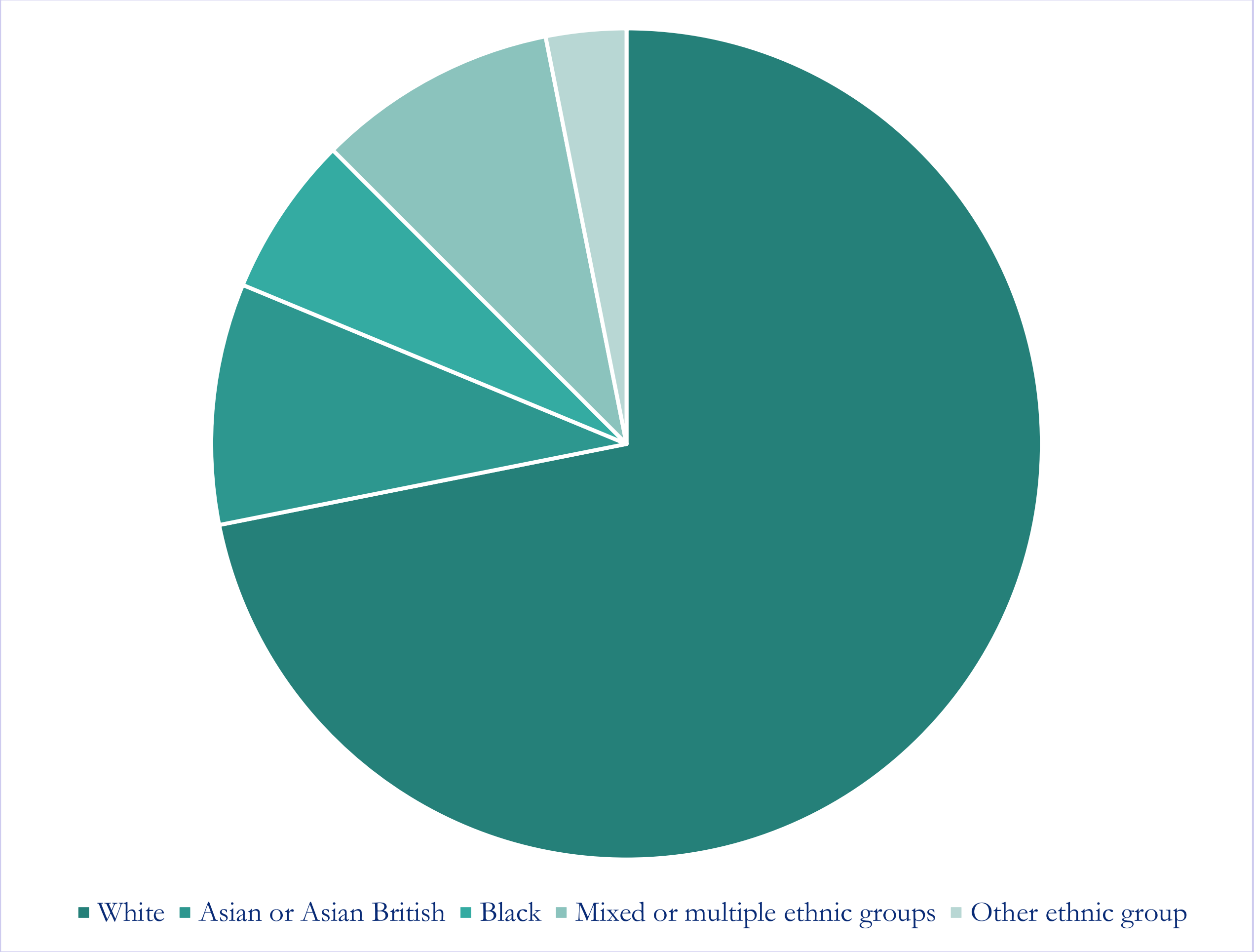

Figure 5. Ethnicity data of participants in Listening and Discussion Group sessions.

Whilst these numbers demonstrate some success in ensuring greater participation during the Listening and Discussion phase than in the survey phase, future research in this area will need to do more to ensure adequate representation.

Demographic data was not collected from healthcare professional participants, who were required only to indicate their professional background. Representation of different specialties and sub-specialties in the Listening and Discussion phase was outlined in Section 2.13, above.

3. Findings

3.1. Language matters

There is a growing body of evidence that highlights the importance of patient-centred communication, 'reflective listening', and showing compassion in clinical settings; both in the context of pregnancy loss and more broadly (Brann & Bute, 2017; Meluch, 2022; Royal College of Midwives, 2022). Despite a lack of focused research, there is also some empirical evidence that language can be harmful in clinical settings involving pregnancy loss, as well as many anecdotal reports (Beard et al., 1985; Johnson et al., 2020; Smith et al., 2020). Outside clinical settings and in society more broadly, there is likewise evidence that some words and phrases play a role in perpetuating cultural taboos, misguided notions, and problematic narratives around pregnancy loss (Littlemore & Turner, 2019, 2020; Smith et al., 2020).

These findings were corroborated by both the lived experience and healthcare professional participants in this project; many of whom stressed the crucial importance of language. This was articulated particularly clearly by one healthcare professional who provides counselling after pregnancy loss with the charity Petals:

> 'We, and I'm thinking of Petals, we [have] limited [counselling] sessions and **you have to spend a lot of time trying to unpick the language (…) which actually interferes with the…with supporting them with the loss**, you know actually (…) there's time has to be spent on that piece of education, which actually that then is time away from other bits of therapy they could benefit from (…) If we didn't have

> to spend that time…you know, we could spend potentially four or six sessions, [and] **we haven't got a lot of sessions, and if two or three of them are spent on unpicking the language, then that's even less with that couple or person**. So then that impacts thinking about what's the impact [of the loss itself]. [Language] has this ripple effect and it's a matter of undoing the language because maybe it's not considered or thought about [in healthcare settings]' (Healthcare professional participant H002.1, from a Healthcare Professional Listening and Discussion Group on pregnancy loss aftercare)

Mirroring this testimony, many lived experience participants identified language as a factor which affected or even determined the emotional experience of their loss:

> 'I **found the words used by others in the aftermath of my pregnancy so important and really had an effect on how I dealt with the situation** and my feelings' (Written contribution W075, from lived experience eligibility questionnaire)

> '[T]he **language used by people involved in and around baby loss can have a huge impact on the mental health** of those who are grieving' (Written contribution W208, from lived experience eligibility questionnaire)

> '**Using the wrong language can really, you know, can really affect someone** and I think especially for women who've gone through pregnancy loss, we take so many things on (…) we probably get triggered by a lot of things (Lived experience participant F003.3, from a Listening and Discussion Group on First Trimester Loss)

One participant was clear that both the language used to describe their experience and their baby were critical factors in determining their emotional response:

> 'I feel that 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 (…) **I've found that the way people talk about my baby has a huge impact on my emotional response**' (Written contribution W274, from lived experience grouping questionnaire)

In some cases, lived experience participants spoke of particular incidents or of individuals whose use of language had stuck out as problematic and had long-lasting psychological impacts:

> 'The language varied and sometimes was insensitively clinical, sometimes it was just insensitive. I found that **the worst language was used by the surgeon that became involved in my care**. I am a healthcare professional myself and was shocked at times. It **contributed significantly to my emotional and mental distress.**' (Written contribution W301, from lived experience grouping questionnaire)

> '[T]he **language used when we spoke with our consultant** after a missed miscarriage was discovered at our 12 week [sic] scan **had a profound impact on our experience**' (Written contribution W047, from lived experience eligibility questionnaire)

Such testimonies as these, which identify language as a significant factor in the experience of pregnancy loss, were echoed by corresponding statements from the healthcare professional cohort:

> '[M]any mothers are upset by the way their pregnancy loss is referred to by medical staff and this can cause issues with grief for a long time. **I see clients years later who are still distressed by the language that was used**' (Written contribution W002, from healthcare professional grouping questionnaire)

> 'I mean [I've seen] lots of really strong reactions, so where it's like…I mean, even (…) like terms like *retained products* is one. *Products* is a…often a really sticky kind of word. *Fetus* is very, for some people very triggering. If they've had a termination and they've had to have an injection, then the paperwork will also potentially say *feticide* on there, or *infanticide*, and that's (…) that can really be hurtful. **Hurtful is the word. And, yeah, I think it's often just that they're the words that really, really stand out'** (Healthcare professional H002.1, from a Healthcare Professional Listening and Discussion Group on pregnancy loss aftercare)

The reports of language impacting experiences of pregnancy loss shared during the project were not, however, universally negative. Some lived experience participants emphasised the power language has to mitigate the emotional impact of pregnancy loss, as well as to exacerbate it:

> '**Words have a lot of impact, we have had both positive and negative experience of this** over the last few months since our baby died' (Written contribution W014, from lived experience eligibility questionnaire)
>
> 'Words hold power and during my experience **the way I was spoken to and things were spoken about in a medical setting had a profound effect both negatively and positively**' (Written contribution W027, from lived experience eligibility questionnaire)
>
> '**Language used can help or hinder loss parents significantly**' (Written contribution W018, from lived experience eligibility questionnaire)

Such testimonies demonstrate that good language practice around pregnancy loss can have a positive impact on the experience of families, just as poor language practice can have a negative impact. Identifying what constitutes such good and poor language practice in these contexts is one goal of this project, and preliminary recommendations based on the empirical evidence presented here will be made in Section 4. These recommendations are primarily based on testimonies relating to negative experiences, since recruitment was achieved via self-selecting sampling and many lived experience participants reported being motivated to take part by negative experiences. Indeed, only 1 of the 237 participants to submit statements as part of their eligibility questionnaire wrote exclusively about positive experiences of language in relation to their loss. By contrast, all other lived experience participants who contributed across the different media reported negative experiences with language during or after their pregnancy loss. Many among these explicitly identified language as a driving factor in exacerbating trauma:

> 'Wording is so important. **Words matter a lot. They can really help you deal with a traumatic event, or they can make it like even more traumatic** if they're careless about it' (Lived experience participant S001.2, from a Listening and Discussion Group on Stillbirth)

> 'The **language used during my first pregnancy loss was horrific and inappropriate. This led to increased trauma** around my loss' (Written contribution W236, from lived experience eligibility questionnaire)

> 'A variety of different language [was] used (…) Some of it made our experience a lot easier and made us feel human whereas **others really made a[n] already traumatic experience worse'** (Written contribution W038, from lived experience eligibility questionnaire)

The following sub-sections will explore in detail the factors which were identified by participants as determining whether language was positively or, more often, negatively, received. Often, as will be explored in Section 3.2, the determining factor was whether the language used by others, and particularly clinicians, to describe a pregnancy loss experience aligned with someone's preference.

Thus far, this section has highlighted the significant degree to which language matters in pregnancy loss care, and the important role it plays in determining how those with lived experience evaluate the care they received. The data collected during the project also enabled the identification of specific factors which appear to exacerbate linguistic difficulties during pregnancy loss. Many of these related to comprehension and the importance of ensuring that information about the pregnancy and experience of loss were conveyed in a way that could be understood. For example, one lived experience participant discussed their neurodiversity and highlighted the particular importance of trauma-informed practice for people with mental health challenges or neurodevelopmental differences:

> 'I am **neurodivergent and have Auditory Processing Disorder which impacted how I understood the information I was given around my miscarriage**. 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' (Written contribution W142, from lived experience eligibility questionnaire)

Many participants also highlighted difficulties in understanding medical terminology which was presented without being fully explained. Other challenges presented by use of medical jargon are discussed in Section 3.2, but it suffices here to demonstrate that such language is not always comprehensible to those receiving care:

> 'I found some of the **medical terminology was used without a clear explanation**, **which could have been frightening** - e.g. we were told our genetic testing revealed a 'primary transfucation' [sic], which is not an easily understood term with no immediate explanation of whether this was a 'good' result or not' (Written contribution W322, from lived experience grouping questionnaire)

> '[W]ith ***ectopic*****, it's like the most alien sounding**…like, "What the hell is *ectopic* and what's *pregnancy*…what's *PUL*, like *Pregnancy of Unknown Location*?". And I just didn't understand, and they said, "[Y]ou've got cells, you've got a baby growing but we just can't find where it is", **so all that was so confusing to me**" (Lived experience participant F003.2, from a Listening and Discussion Group on First Trimester Loss)

> 'I lost my baby following damage done to my cervix at a previous c-section [sic] when I had had no issues during my first pregnancy. I was told at the booking for my second pregnancy that **I was "high risk for preterm birth" based on the cervical damage. I interpreted this as a potential 30-36 week delivery**. The actual reality was that I was at high risk for losing my baby before they would be able to survive which **felt distinctly different to what the message had been**.' (Lived experience participant T001.2, written contribution from grouping questionnaire)

These three participants who experienced difficulties in comprehending communication about their care all highlight the impact technical language had on their experience: making it more "frightening" or "confusing", or failing to adequately communicate the risk of an adverse outcome. All these lived experience participants identified English as their first language, but it is also vital that we consider the risk of linguistic challenges for people for whom English is an additional language. This is true both for individuals receiving and providing healthcare. The testimony of one lived experience participant for whom English was an additional language highlights the additional scope for challenges that such a linguistic background provides:

> **'During the scan I did not understand what the "empty sac" really meant and was given false hope to wait a few more days**, and I would rather have preferred direct truthful answer and an in-depth explanation.' (Lived experience participant F002.3, written contribution from grouping questionnaire)

This participant was given an inadequate explanation of the ultrasound finding that the baby had stopped developing earlier in the pregnancy, and was "given false hope" that the pregnancy could continue. Another participant for whom English was an additional language also reported difficulty in comprehending what she was being told when the phrase *products of conception* was used, since this was at odds with her understanding that her baby had died:

> '[T]hey're asking all the questions and **you can't understand what is happening** still. At the same time, and there was like a *product of conception*, there wasn't any baby and it was also like, "What? What's happened with this *product of conception*?", because **at the point when they told me the baby died…so, they didn't say, "The *baby* died", they said, "*Products of conception*"**. So yeah, I think for me, it would be better to know that my baby died' (Lived experience participant F002.4, from a Listening and Discussion Group on First Trimester Loss)

The additional layer of potential complexity that is added to the linguistic experience of receiving care during and after pregnancy loss for those who use English as an additional language is not the only consideration, however. As one participant noted, where terminology in English is actually more palatable than the equivalent in their first language, they may feel differently about the English word or phrase:

> '[B]ecause English isn't my first language, it's…I'm doing the double job every time I, I'm reading (…) because yeah, **I'm like translating things into my mother tongue and things and ironically in English *miscarriage* is more OK** (…) than the word that's used in my mother tongue which basically translates into English…would be something like 'self-abruption of the baby', like 'self-evacuation of the baby', which I was never OK with, even when I was just a small child and I heard this, this, this kind of word…I was like, "What? How do you call this this way? It's just really weird and ***miscarriage* is kind of like more explainable** to me because I kind of like dissect the word and I do understand where it comes from and it more resonates with me but **I would agree with [F002.1] that it's not the best term'** (Lived experience participant F002.3, from a Listening and Discussion Group on First Trimester Loss)

This participant is responding to strong criticism of *miscarriage* by another participant (for whom English was also an additional language) by "agree[ing]…that it's not the best term" but highlighting that "*miscarriage* is more OK" than the equivalent in her first language. By contrast, another participant for whom English was an additional language felt the opposite way about miscarriage:

> **'**English isn't my first language (…) I was born here but (…) Farsi, I'm Iranian, is my first language**. Everywhere where you hear *miscarriage* it's always *miscarriage of justice*, *miscarriage of this***. It sounds like something has gone really (…) and like it's like when people talk about *miscarriage of justice* **they're always talking about the people that are to blame,** like injustice' (Lived experience participant F002.1, from a Listening and Discussion Group on First Trimester Loss)

Differing language norms in different community contexts in the UK must also be considered an important factor in seeking to understand the role language plays in the lived experience of pregnancy loss. One participant highlighted the tendency within her community for all experiences of loss during pregnancy to be labelled *miscarriage*, and the impact of this on her wellbeing following the stillbirth of her daughter:

> ‘In the Black African community, I don't think years and years ago they used the word *stillbirth* so they will…I have had someone that's, you know older, from Africa say, “You had a *miscarriage”*, which the two are not the same (…) from the older generation (…) I could go on about this ‘cause it’s so bad and I think they know that, of course, back then babies did pass away and but they just always say, **call it all *miscarriage* and that's something that really bothers me of course. So it it basically diminishes and minimises do you know [name]’s life**, so yeah something that needs to… I would say like the older generation needs to be spoken to about [this] more. I don't know if this is spoken about in churches and community groups and support groups, but it needs to…yeah it's not getting any better’ (Lived experience participant S002.2, from a Listening and Discussion Group on Stillbirth)

In terms of clinical language, one healthcare professional participant highlighted a tendency for words no longer considered acceptable for many native British English speakers to be used by researchers using English as an additional language (EAL), due to differing standards of acceptability and varying usage in different Anglophone countries:

> ‘[W]hen papers are written by researchers whose first language is not English I think [*abortion*] is still a term used to describe pregnancy loss or spontaneous pregnancy loss but I think they do frame [that] as a *spontaneous abortion* rather than you know just *abortion’* (Healthcare professional participant H001.4, from a Listening and Discussion Group for healthcare professionals)

Whilst the experiences of those with English as an additional language is not the principal focus of this project, such testimony shows a clear need for research considering the experiences of EAL speakers in UK healthcare settings. The need for such research in the specific context of care during and after pregnancy loss will be considered in Section 4.

The comprehension difficulties reported by native English speakers and EAL users of English highlight a fundamental linguistic challenge for healthcare professionals. This challenge, and the ensuing responsibility to ensure clarity and comprehensibility in explanations of what is happening or has happened, was summarised thus by a healthcare professional participant:

> 'It's about education isn't it (…). It's telling the patient about what [something] means and explaining it**. I think that's what you can do in those situations to kind of bridge it, by saying it and [making sure] patients understand what that means**. Then they understand (…) what's happened (…) I think often if we can just, if we literally just take the time to explain it essentially and explain, you know, "You've lost a pregnancy, or baby, and this means this…"' (Healthcare professional participant H001.2, Listening and Discussion Group)

However, as will be explored in the following section, even where issues of comprehension were not reported, many lived experience participants expressed that language around their loss had been difficult or challenging in some way.

3.2. Difficult language

As was outlined in Section 1.4, there has been concern for decades that those experiencing pregnancy loss in Anglophone settings are affected by use of problematic language in relation to their experiences. However, as was also made clear there, only a handful of recent studies have explored how often terminology considered problematic is used, and since most are US-focused, their findings are not straightforwardly applicable to a UK context. In the last decade, for example, it has been repeatedly demonstrated that US-based individuals experiencing pregnancy loss before 20 weeks prefer *miscarriage* or *pregnancy loss* to *spontaneous abortion* (Brann et al., 2020; Clement et al., 2017; Clement et al., 2019). This is a frustratingly self-evident finding in a country where *abortion* has, for the most part, been successfully eliminated in clinical contexts relating to pregnancy loss since the 1980s (Beard et al., 1985; Malory, 2022). The difference in British and American English in this context limits the applicability of such findings to a UK context, where participants would not be expected to have been routinely exposed to *abortion* in the context of spontaneous loss. A related issue with these studies is that when research participants are exposed to a highly stigmatised word like *abortion* (Malory, 2023), it also risks a prejudicial response whereby other variants seem less problematic by contrast.

Whilst insights as to the preferences of research participants in studies such as these must therefore be approached with caution, they provide the only recent data on this topic and must be considered. The finding of Clement et al. (2019) that US "[p]articipants most frequently chose 'miscarriage' as their preferred diagnosis term (n=79 [54.5%]), followed by 'early pregnancy loss' (n=49 [33.8%])" is especially interesting, given the apparent preference of many writers discussed in Section 1.4, both in the UK and US, for *pregnancy loss*.

With few studies exploring language usage and preference in relation to pregnancy loss in recent years, and none presenting findings which are straightforwardly applicable to a UK context, we are forced to look back to 2005 to consult the last empirical study of terminology use in pregnancy loss contexts. This was when Cameron & Penney (2005) conducted a case note review and survey in Scotland, to assess usage of four so-called "inappropriate terms": *abortion*, *blighted ovum*, *incompetent cervix*, and *pregnancy failure* (314). Their findings reflect "low levels of inappropriate terminology usage by health professionals" (Cameron & Penney, 2005: 314), but note that *pregnancy failure* was "an exception", "heard by approximately 1 in 7 women" (314) surveyed. The authors also report that "[r]elatively high levels of usage of 'abortion' were found in case records, with 1 in 10 hospital records containing this term" (314). Ultimately, they conclude that "[i]n order to meet national recommendations on terminology for early pregnancy loss, clinicians should not only say 'miscarriage' but also write it" (314).

That there has been little or no substantive research on this topic in the UK since 2005 underscores the importance of the EStELC project. Its findings suggest, unfortunately, that almost 20 years after Cameron & Penney (2005) conducted their research, all of the "inappropriate terms" they investigated are still being used in clinical settings in the UK. Those and other words and phrases used to diagnose and describe experiences of pregnancy loss were identified as problematic, both by lived experience and healthcare professional participants in EStELC. Some of these were linguistic items identified as problematic in other previous research, literature, or in public discourse. For example, the "updated glossary" to describe "clinical events in early pregnancy", published in the journal *Human Reproduction* in 2005, the same year as Cameron & Penney's research, on behalf of the ESHRE Special Interest Group for Early Pregnancy (Farquharson et al., 2005), suggests alternatives such as "fetus" instead of "embryo"; either "miscarriage" or "termination of pregnancy", depending on context, instead of "abortion"; and "empty sac" instead of "anembryonic pregnancy" (3010).

Farquharson et al. (2005) therefore suggested almost 2 decades ago that words such as *abortion* be abandoned in favour of what they perceived to be less hurtful or insensitive words and phrases. However, participants in the Listening and Discussion Group attested to the fact that all of these, like those "inappropriate terms" identified by Cameron & Penney (2005), were still being used during the study period of 2021-2024. EStELC participant data also underscores the ongoing perception of insensitivity, and the hurtful nature of these words. For example, *abortion*, identified by both Cameron & Penney (2005) and Farquharson et al. (2005) as "inappropriate", was described by one very distressed participant as the word used in the context of medical management for first trimester loss:

> 'The woman who I was discussing my procedure with kept referring to it as an *abortion* (…) **but I wasn't having an abortion [crying] my baby [crying] was already gone**' (Lived experience participant F001.5, from a Listening and Discussion Group on First Trimester Loss)

Lived experience participants who had experience of TFMR also identified *abortion* as a word that was used to describe their experiences, and which, together with *feticide*, they found very challenging:

> '[I]n the end, they technically **died with a procedure called a *foeticide* [sic], which is a hard word. This was referred to as an *abortion*** on my paperwork' (Written contribution W260, from lived experience grouping questionnaire)

> 'During my loss later on at almost 24 weeks, **I hated the term *feticide*** which is what we had to do before being induced. **I hated any reference to the word**

> ***abortion***.' (Written contribution W319, from lived experience grouping questionnaire)

The difficulties presented by the word *feticide* were also highlighted by several healthcare professionals:

> '***[F]eticide* is a difficult word** in which all of my years working in this field I personally struggle to hear the words and know **every patient that has had sadly experienced this procedure find the word deeply distressing**.' (Written contribution W007, from healthcare professional grouping questionnaire)
>
> 'Patients of mine who have requested notes and have been encouraged to open their notes have been absolutely blindsided and had no idea of that word [*feticide*]. Like, they've been told the baby needs an injection through the heart and that makes sense…but **it's so traumatic when that word is brought home because there's a lot of…I would say guilt, feelings of guilt, or something. And when you use a word as strong as that, it's absolutely horrendous'** (Healthcare professional H002.4, from a Healthcare Professional Listening and Discussion Group on pregnancy loss aftercare)

As will be highlighted in Section 3.2.3, participants who have not been exposed to the word *feticide*, or who do not recall any such exposure, reported no issues with the framing of the injection they received to stop their baby's heart.

Likewise, *fetus* was experienced as problematic. Often, this was associated with dehumanisation of the baby, which will be discussed in Section 3.3, but it was perceived to be especially inappropriate where a shift occurred from humanising language such as *baby* before the death and *fetus* after they had died:

> 'When we were in that limbo waiting stage to see what happened, it was **"baby this, baby that". The minute [name]'s heart stopped, "the fetus hasn't developed properly or the growth of the fetus…"** (…) and it, it was **that shift that really**

> **messed with my head**” (Lived experience participant M001.1, from a Listening and Discussion Group on Second Trimester Loss)

Several of the substitutes for these words and phrases which were proposed by Farquharson et al. (2005) were also experienced as similarly problematic by many participants, however. *Miscarriage, termination of pregnancy, biochemical pregnancy* and *empty sac* are all such alternatives suggested by Farquharson et al. (2005) which were identified as challenging by lived experience participants. *Miscarriage* is also the word recommended in the language guidelines published by the Royal College of Obstetricians and Gynaecologists in 2022, entitled ‘RCOG Language Guide’, as an alternative to *spontaneous abortion* or *early fetal demise;* by Delabaere et al., (2014) in their French/English pregnancy loss glossary; by the updated ESHRE consensus guideline (Kolte et al., 2015); by the more recent consensus on delivery of unexpected news in obstetric ultrasound (Johnson et al., 2020), and by the Peanut *Renaming Revolution Glossary* (2023). It is striking that whilst *miscarriage* is thus widely recommended, it is so problematic for lived experience participants. For many of those who reported problems with *miscarriage*, its connotations of blame were invoked.

> ‘**I've always, like, hated - even before it happened to me - always hated the word *miscarriage* because it sounds, like, quite blamey**’ (Lived experience participant F001.2, from a Listening and Discussion Group on First Trimester Loss)

The connotations of culpability associated with miscarriage will be discussed in depth in Section 3.2.1. Even where no specific reasoning was provided, however, *miscarriage* proved one of the most widely unpopular words in the entire EStELC dataset:

> ‘**I also don't like the term *miscarriage* (…) I don’t think anybody really likes it**’ (Lived experience participant M001.3, from a Listening and Discussion Group on Second Trimester Loss)

This unpopularity is also reflected in popular discourse, as outlined in Section 1.4.2, where articles and discussions about *miscarriage* have arisen with increasing frequency over the last decade (Gorfinkel, 2015; Lindemann, 2018; Oré, 2020; Agg, 2023). However, there is little indication that this widespread acknowledgment of *miscarriage* as problematic has so far translated into any kind of meaningful change or even impetus towards change. Moreover, when used with the modifier *missed*, as it frequently is to refer to the intrauterine death of a baby in the first trimester of pregnancy, *miscarriage* was also identified as problematic because of the perception that *missed* compounds the implication of fault and blame:

> 'My first loss was also a missed miscarriage (…) it's obviously a massive shock because yeah **you have missed it** (…) but yeah **the *missed miscarriage* is like a horrible, horrible terminology'** (Lived experience participant, from a Listening and Discussion Group on First Trimester Loss)

Whilst the use of terminology which implies fault or blame will be discussed further in Section 3.2.1, it is important to note here that *missed miscarriage* was associated with significant levels of distress amongst lived experience participants with experience of receiving such a diagnosis.

Farquharson et al.'s (2005) suggestion of *termination* is widely reflected in contemporary usage in the context of pregnancy loss, in the phrase *Termination for Medical Reasons (TFMR)*. This was also identified as challenging phraseology by a number of lived experience participants who had experienced TFMR:

> '***Termination* invokes quite a strong number of feelings doesn't it** (…) I do specifically remember when the TFMR was discussed I remember thinking, "Ooh that's quite…". I remember that bit being the bit that I probably latched onto a little bit, thinking, "Oh my God that's quite…". **It sounds quite…aggressive** is probably the word I would use' (Lived experience participant T001.1, from a Listening and Discussion Group on TFMR)

> 'When I went back in at the beginning, at the booking [appointment for] this pregnancy, **my last pregnancy, which I very much consider to be a loss, rather than a kind of…termination…was referred to as a *termination***. I'm not…**I find that quite challenging** but (…) I suppose, you know, that your, the midwives, are looking through your history and they're looking at the medical terminology that they see on the screen. So they see, you know, "pregnancy (2020), you know,

> delivery by C-section; pregnancy (2022), termination'" (Lived experience participant T001.2, from a Listening and Discussion Group on TFMR)

As will be outlined in Section 3.2.2, discussion around use of *termination* focused on stigma and the linguistic overlap, but desire to uphold a distinction in reality, between TFMR and the termination of unwanted pregnancies:

> 'There was one lady in particular who was very angry about that because she…she had to make that really difficult choice and **she wanted the other words *termination for medical reasons* on that piece of paper where she's gone home with a piece of paper that [only] says *termination*'** (Healthcare professional H002.1, from a Healthcare Professional Listening and Discussion Group on pregnancy loss aftercare)

Despite Farquharson et al.'s (2005) suggestion that *empty sac* be used instead of *anembryonic pregnancy, empty sac* was also highlighted as a phrase strongly associated with negative experiences and emotions for lived experience participants. Many of these participants across different Listening and Discussion Groups reported feeling that *empty sac* implied their baby had never existed:

> '[I]t's the **most horrible term** because like then you think, "Oh, **is like, nothing even there**?"' (Lived experience participant F001.2, from a Listening and Discussion Group on First Trimester Loss)

> '[I]t **sounds almost like it wasn't there** (…) even though they did say that they believed it was (…) [I]t **just makes you feel a bit crazy**, almost, that you thought you were pregnant, you saw the tests, positive tests, you get all the symptoms, and at that point it wasn't there and it's just, yeah, it was quite a shock and yeah I don't like [*empty sac*]' (Lived experience participant F001.3, from a Listening and Discussion Group on First Trimester Loss)

> '[T]he thing that they used was *empty sac,* which was a bit (…) I felt like a failure, that I didn't…it's **like I imagined it in my head that we had the baby and that we**

> **fell pregnant but now we have something empty, something nonexistent and it's like a nothing I tried to carry**, so that [language] didn't help at all' (Lived experience participant F002.3, from a Listening and Discussion Group on First Trimester Loss)

As Jennie Agg notes in *Life, Almost*, "unhelpful, obfuscating language" such as *chemical*, *blighted* and, in this case, *empty sac*, gives the impression "that these earliest losses are a form of phantom pregnancy, rather than a physical reality" (2023: 80). This inevitably contributes to the disenfranchised grief commonly associated with experiences of first trimester loss, that will be discussed in Section 3.2.5. Similar views were likewise expressed about phrases such as *products of conception* and *pregnancy tissue* during lived experience Listening and Discussion Groups:

> 'I went into the day unit in the hospital, into [the] gynaecology section and there was **absolutely no mention of my baby being a baby at all. Straight from the go it was um the *products of conception, products,* or *tissue*'** (Lived experience participant F001.4, from a Listening and Discussion Group on First Trimester Loss)

> 'I found the language used by NHS staff in my two baby loss events to be **terrible such as calling my misscarrage [sic] a *product*'** (Written contribution W023, from lived experience eligibility questionnaire)

Similar feelings were reported to be associated with *chemical pregnancy* which, as noted above, was recommended in the form *biochemical pregnancy* as recently as Farquharson et al. (2005):

> 'They used the language like *chemical pregnancy* which was…yeah, **really difficult (…) there was an undertone that it wasn't really real**" (Lived experience participant F003.4, from a Listening and Discussion Group on First Trimester Loss)

> **'**I hated the use of the **word "chemical"… which almost made the pregnancy feel like a figment of my imagination**' (Written contribution W251, from lived experience grouping questionnaire)

The suggestion by Farquharson et al. (2005) that *biochemical pregnancy* should replace *preclinical embryo loss* may have resulted in the popularisation of the phrases *biochemical pregnancy* or, more commonly, *chemical pregnancy*. In a contemporary context, however, there seems to be growing recognition that such phrases are "not very helpful for patients" (Professor Nick Macklon, quoted in Agg, 2023: 72). Indeed, both *biochemical* and *chemical pregnancy* were universally unpopular with lived experience participants, who also reported feeling that the modifiers *biochemical* and *chemical* belittled and invalidated the loss(es) they had experienced:

> 'When I talk about my experience…it's very important for me to emphasise that it **wasn't say something very small and insignificant even though it's called a *biochemical pregnancy* the last two times it's literally the perspective of losing another person**' (Lived experience participant F002.3, from a Listening and Discussion Group on First Trimester Loss)
>
> **'The second one was a chemical pregnancy and [there] is this** real horrible language around chemical pregnancy. I feel personally feel like they think it's just something that was never meant to happen 'cause **it was so short in the time of pregnancy that it's OK and it's actually not'** (Lived experience participant F003.5, from a Listening and Discussion Group on First Trimester Loss)

One of the phrases associated with pregnancy loss which is most often cited as problematic, and was indeed highlighted as such by Cameron and Penney (2005) almost two decades ago, is *incompetent cervix*. Widespread recognition of the problematic nature of *incompetent cervix* is attested by the fact that its avoidance is advocated by Johnson et al. (2020), Vimalesvaran et al. (2021), the RCOG (2022), and the Peanut *Glossary* (2023).

Despite the obviously longstanding and widespread awareness that *incompetent cervix* is experienced as problematic by those with lived experience of preterm cervical shortening or opening, however, all EStELC lived experience participants (n=6) with this experience reported hearing this language in healthcare settings during the study period of 2021-2024. As will be explored in Section 3.2.1, like *miscarriage*, *incompetent cervix* was strongly associated with connotations of blame and failure. Participants also highlighted the semantic specificity of the word *incompetent*, and its strong association with ineptitude:

> 'What a completely ridiculous word, because ***incompetent*** **implies, you know, that's what you say to someone when you're about to sack them** (…) it's not a**…**it's not a useful word to use for people' (Lived experience participant M001.3, from a Listening and Discussion Group on Second Trimester Loss)

Despite a prevailing sense from the literature discussed in Section 1.4 that problems posed by language in relation to pregnancy loss are associated primarily with pregnancies of shorter gestation, several lived experience participants across different Listening and Discussion Groups also reported challenges with the words *stillbirth* and *stillborn*. The reasons given for this differed, and will be explored in relation to the themes they represent in later sections:

> 'I think it **implies (…) that you have a medical reason for this stillbirth** whereas we don't, we never found out why it happened' (Lived experience participant S001.3, from a Listening and Discussion Group on Stillbirth)
>
> '**I didn't like them using *birth* for [name] (…) that created trauma for me**, because I found like I…you know [older child] he was fine, he was born, we got a birth certificate for him. We only ever got a death certificate for [name] so I just didn't like the use of *birth*' (Lived experience participant S001.2, from a Listening and Discussion Group on Stillbirth)
>
> '**My baby didn't have a life (…) He died. So I really struggled with the terminology of *stillbirth*** because (…) I looked into it, the definition of it was, you know, the birth of a baby and like it was life, new beginnings and stuff which is yeah…it's not. I don't like it' (Lived experience participant S002.3, from a Listening and Discussion Group on Stillbirth)

As will be discussed in Section 3.2.5, 'umbrella' terms which can be used to discuss all experiences of loss during pregnancy proved divisive, with some EStELC participants rejecting the implication that all such experiences can be considered equivalent and others strongly advocating that they should be. The term *pregnancy loss*, chosen for use in this study for the reasons outlined above in the Note on Language (p.4), was criticised by 2 participants. For example, one participant who was not based in the UK and was therefore ineligible to take part in the Listening and Discussion phase of the project wrote that:

> 'I **didn't suffer a 'pregnancy loss', my baby died. This is baby loss. Not 'pregnancy loss'. My baby was so much more than just 'a pregnancy'.** People obviously don't want to cause hurt or further stress to anyone, but it's so easily done, as above' (Written contribution W179, from lived experience eligibility questionnaire)

Whilst this participant was technically not eligible to take part, they gave consent for their views to be included here because they feel so strongly that *pregnancy loss* does not adequately reflect their experience and that of their baby. The imperative for language to align with each individual's sense of their experience will be discussed in Section 3.2.4, and the impossibility of finding universally acceptable language to refer to experiences which are often associated with extreme grief and trauma will be addressed in Section 3.3.

It is also necessary to consider the role of cultural norms, however, and the frequency with which individuals are likely to be exposed to different words or phrases in their cultural context. In the instance above, the criticism of *pregnancy loss* may reflect differing linguistic norms between Anglophone countries, and there is a need for research which considers how *pregnancy loss* is being used, in the UK and beyond. In the UK, as discussed in Section 1.4, *pregnancy loss* seems to have gained momentum as 'umbrella' terminology, which is perceived to be more sensitive than other ways of talking about experiences of loss during pregnancy, in recent years. This was reflected in discussions in the Listening and Discussion Groups for healthcare professionals about their usage in encounters with patients:

> **'**I **do tend to find myself talking about *pregnancy loss* rather than *miscarriage*** and I don't know if that is, you know, more or less acceptable for patients but that's just something that I've noticed myself doing. I don't know if there's any sort of

> subconscious bias or anything like that towards the word *miscarriage,* even though I don't particularly find it offensive' (Healthcare professional participant H001.1, from a Listening and Discussion Group for Healthcare Professionals)
>
> **'*Pregnancy loss* is much more comfortable to use at the moment,** like and again it's not a conscious thing but I think with patients it just felt kind of natural to move towards**…**I don't really know when it happened or if it was always there but yeah ***pregnancy loss* (…) it's softer somehow'** (Healthcare professional participant H001.2, from a Listening and Discussion Group for Healthcare Professionals)

These perceptions were echoed by lived experience participants:

> 'I think ***pregnancy loss* is a lot more kinder and has a bit more like gravity to it'** (Lived experience participant F001.2, from a Listening and Discussion Group on First Trimester Loss)

The 'umbrella' purpose of pregnancy loss, which encompasses different types of experience, was also discussed in positive terms by some:

> 'I generally **prefer the term 'pregnancy loss' because my own experiences varied so much - ectopic pregnancy and missed miscarriage** - and sometimes it seemed like my ectopic didn't 'count' as a loss because it was technically different to a miscarriage' (Written contribution W206, from lived experience grouping questionnaire)

However, questions remain as to how applicable *pregnancy loss* is considered in describing the experiences of those who have had a loss in later pregnancy. The second criticism of *pregnancy loss* in EStELC project data arose during a Listening and Discussion Group, when a participant distinguished between their different types of experience (in the first and second trimesters of pregnancy), and the applicability of *pregnancy loss* in each:

> ‘I don't think I like *second trimester pregnancy loss* because it's not appropriate I mean (…) it’s **not a loss is it, it is a baby dying** and to call it a pregnancy…doesn't, you know, that's… well I guess I've had a fair number of times with medical professionals like referring to it as a *pregnancy*, whereas it's not it's *babies* and whereas my really early ones I'm happy to call my *pregnancy losses*. To me, it makes sense, **like I lost the chance of being pregnant whereas the twins were definitely not, yeah, not a loss of pregnancy. It was a loss of two humans**’ (Lived experience participant M001.3, from a Listening and Discussion Group on Second Trimester Loss)

Here, as in the other statement objecting to *pregnancy loss* above, criticism of *pregnancy loss* seems to arise from the interpretation of the phrase as implying that the *loss* is of the *pregnancy*, rather than a loss during pregnancy. This is experienced as a form of dehumanisation and, as will be discussed in depth in Section 3.3, dehumanising language was experienced negatively by a large number of participants. With only 2 statements from participants objecting to use of *pregnancy loss*, it is difficult to draw conclusions on this, but it is clear that further research on this topic is needed; both to establish how such umbrella terms are perceived and to chart their use both in recent history and in different parts of the world.

Having established in the previous section, 3.1, that EStELC participants consistently reported language to be a difficult aspect of their pregnancy loss experience, this section has highlighted words and phrases identified by participants as problematic in some way and noted some patterns that can be observed. These patterns, identified via thematic coding during the qualitative analysis of the EStELC dataset, will be examined in greater depth in the sub-sections which follow; beginning with blame and culpability in Section 3.2.1.

3.2.1. Blame and culpability

The notion that certain diagnostic terms for pregnancy loss are linked with self-blame and cultural myths about culpability has gained ground in the last decade. As noted in Section 1, above, this is a connection made by Iris Gorfinkel, for example, who argued in a 2015 Canadian newspaper article that those experiencing pregnancy loss “largely continue to be under the false impression that the loss had been self-generated". Gorfinkel questions whether the English word *miscarriage* could be "partly to blame for these false impressions". Likewise, in a 2018 article *in The Guardian*, Katy Lindemann pointed out that:

> Our language of pregnancy loss is so wedded to the notion of failure, unintentionally attributing blame: "failed pregnancy", incompetent cervix". To a grieving mother, desperate for answers and quick to blame herself, even the term 'miscarriage' suggests her own inability to carry, as though she has somehow neglected her baby.

Jennie Agg, in her book *Life, Almost*, similarly suggests a causative relationship between language and her specific experience of self-blame following recurrent first trimester losses:

> No wonder we have such a scrambled picture of cause and effect. Perhaps the first barrier to true understanding of miscarriage is a linguistic one. Because, for all that some of the UK's best specialists can tell me, following the best available evidence, there is no inherent weakness or fallibility in my body that should hinder its ability to carry a baby. Yet, all the same, I can't shake the feeling that pregnancy is something I am just not very good at (2023: 144)

Such sentiments were also echoed in the project data, as summarised by this healthcare professional participant whose role involves counselling people who have experienced pregnancy loss:

> 'When we're at the receiving end, of taking in clients for baby loss work, they do feel…the women, often particularly women, feel that they are to blame. That they've done something wrong. **There's a guilt there. So, any of the language that presses into that is basically painful 'cause it… sort of feels like that [is implied] then from a medical point of view**. […] **If the language isn't sensitive or considered, then it's just like a big fat arrow that says, "Yeah, you're to blame".** Yeah, that's how people receive it and that just makes their, I think, their journey harder' (Healthcare professional participant H002.1, from a Listening and Discussion Group on pregnancy loss aftercare)

This powerful idea of language as a "big fat arrow that says, 'Yeah, you're to blame'" is the focus of this sub-section. The perception that pregnancy ends in success or failure is a pervasive cultural concept and is often mirrored in the language we use. This was, indeed, highlighted by the Re:Birth project (2022), which considered how language around labour and delivery impacted birth experiences. In the final Re:Birth report, the Royal College of Midwives team concluded from their empirical research into the language of labour and birth that it is hard to avoid engaging with "difficult language", including what they term the "failure/incompetent words". They thus found that, although the project did not set out to explore such words, they consistently became relevant during focus groups. This led them to conclude that when this kind of "problematic language was used by others around them, this exacerbated an already challenging experience" (Royal College of Midwives, 2022). Like those of Re:Birth, the findings of this project highlight that, almost two decades after Cameron & Penney found that the word *pregnancy failure* were "heard by approximately 1 in 7 women" in their Scottish study (314), discourses of failure continue to be common in relation to pregnancy. This is an aspect of their lived experience that many participants reported as problematic:

> 'I really **hated "failing pregnancy". I felt like it made me feel like a failure in a way I didn't until it was used**' (Written contribution W264, from lived experience grouping questionnaire)
>
> 'I have often felt that the language surrounding pregnancy loss needs reviewing, words like *miscarriage, incompetent cervix, placenta insufficiency* [sic], have such strong blame connotations and **make a woman feel like she has failed in some way'** (Written contribution W233, from lived experience eligibility questionnaire)

The same could be said of many words, phrases, and narratives that we use around pregnancy loss, including *pregnancy loss* itself. In 2011, Australian feminist sociologist Catherine Kevin published a paper which used the quotation 'I did not lose my baby…my baby just died" in its title, highlighting that questions of culpability apply too to this phrase *pregnancy loss*, despite its apparently broad acceptability (see Section 1.4). Whilst most participants used *loss* to describe their experiences, project data also reflected the less common perception that *loss* has connotations of negligence or carelessness. Several lived experience participants objected to the implication that they had *lost* their baby, in the sense of not knowing where it was:

> ‘I don't like it when people say, “[F002.1] lost the baby”, 'cause I feel like they’re saying that I lost it, like I don't know where it was. **I know where my baby was. I didn't lose my baby.** So I know some people might be OK with that but I actually don't like it’ (Lived experience participant F002.1, from a Listening and Discussion Group on First Trimester Loss)

> ‘[A] lot of people use the language like, “Sorry for your loss”, and (…) I didn't really appreciate it ‘cause again **I haven’t lost anything. I definitely knew where my baby was**’ (Lived experience participant S002.3, from a Listening and Discussion Group on Stillbirth)

These strikingly similar sentiments from different Listening and Discussion Groups focusing on different types of experience suggest that this is unlikely to be an idiosyncratic response to *loss*, and may instead reflect a wider experience in relation to that phrasing. Others explicitly linked the use of words related to *loss* to the implication of blame or negligence:

> ‘I really hated when people said, "I'm sorry for your loss". I didn't lose something, my son died. **"I'm sorry for your loss" makes me feel like I am responsible**’ (Written contribution W288, from lived experience grouping questionnaire)

One lived experience participant distinguished between the verb *lost* and the noun *loss,* as in *pregnancy loss*, however. Participant F002.1, who is cited above as saying, ‘I don't like it when people say, “[F002.1] lost the baby”’, went on to say that:

> ‘Pregnancy loss sounds like a noun (…) but, **“You lost”, it’s like you’ve actively lost**, **it feels like the responsibility is on me**’ (Lived experience participant F002.1, from a Listening and Discussion Group on First Trimester Loss)

As has already been highlighted, both *incompetent cervix* and *miscarriage* were widely unpopular amongst our lived experience cohort because of their perceived implication of blame. Those who had heard or seen *incompetent cervix* in the context of their care perceived a clear link between the diagnostic terminology and self-blame:

> 'Some women just have a weaker cervix, you know, there's no shame in that either. Your body is just made the way it is and all of us as women, **I think, have a terrible, you know, tendency to blame our bodies for various things**. But I think particularly in relation to baby loss or miscarriage, there is a lot of, you know, mulling over what…well, why did this happen to me, or what did I do wrong?' (Lived experience participant T001.2, from a Listening and Discussion Group on TFMR)

> 'I don't like **those terms [*weakened cervix* or *incompetent cervix*] 'cause it makes me feel as if…like the fault lies with me** and (…) **those types of words kind of added to my experience of feeling like shit, basically, that it's my fault** (…) It's just not nice and (…) for baby loss I just don't think that word [*incompetent*] should be used at all' (Lived experience participant M001.2, from a Listening and Discussion Group on Second Trimester Loss)

This implication was also highlighted by several healthcare professionals:

> '[I]t's not something that I would use, I would want to…**I think it suggests a little bit of blame there doesn't *incompetence***? But it is the way that I would use [language when] discussing with clinicians' (Healthcare professional participant H001.2, from a Listening and Discussion Group for Healthcare Professionals on providing care during pregnancy loss)

> **"[*Incompetent* is] just a terrible word, isn't it? Because, you know, a woman, as a person is told that their body is *incompetent*… It just feels like that is a personal thing. I think anything that has any element of blaming a body** or a person just feels really…um. Yeah, so *insufficient* feels more…um, less (…) blaming. [It] is just that the cervix doesn't hold that, and you know it's one of those things, rather than that you're not doing something right. So yeah, that's definitely a personal choice, but I think it is all my team. Nobody would use *incompetent* or *deficient* or anything' (Healthcare professional participant H002.3, from a Listening and Discussion Group for Healthcare Professionals on providing pregnancy loss aftercare)

The first of these quotations highlights a tension between H001.2's personal sense of discomfort with *incompetence,* and their recognition of its association with blame, but also their sense that it is necessary to continue using it with colleagues. This speaks to a significant challenge in reforming how language is used around pregnancy loss, since diagnostic language must not only be optimised for sensitivity in patient-facing interactions, but also for comprehensibility and transparency in clinician-to-clinician communication. This tension is negotiated by H002.3 and, she notes, her team, by use of *insufficient* instead of *incompetent*. In an example of variation which reflects the huge degree of discrepancy across the body of literature discussed in Section 1.4, *insufficiency* has been suggested as an alternative to *incompetence* by some (e.g. Vimalesvaran et al., 2021) but identified by others (Johnson et al., 2020; Silver et al., 2011) as problematic in the same way as *incompetence*.

Cervical incompetence and *incompetent cervix* are obviously problematic phrases, therefore, but they nonetheless continue to be used, both in clinical contexts and beyond. In clinical contexts, this speaks to a need for standardised, unambiguous terminology that can be used effectively and efficiently in high-pressure, time-poor contexts. Beyond clinical settings, as the name of the support group 'Incompetent Cervix UK' on Facebook highlights, the benefit of such long-established, if highly problematic, terms is that they are widely recognised and understood, and therefore searchable in digital contexts.

As with *incompetent cervix*, there was a clear consensus amongst lived experience Listening and Discussion Group participants across different sessions that *miscarriage* implies failure and blame:

> 'I've always like hated, even before it happened to me, always hated the word *miscarriage* because it sounds quite blamey…'cause it's like **"oh the women didn't carry the baby properly, your body mis-carried it", like you did something wrong, like you know, even like it was in your control. That your body just kind of failed**' (Lived experience participant F001.2, from a Listening and Discussion Group on First Trimester Loss)

> '[T[he word ***miscarriage*** **to me implies that you did something wrong**, **that you mis-carried your baby**' (Lived experience participant S001.4, from a Listening and Discussion Group on Stillbirth)

> '***Miscarriage*** **has a connotation that me carrying the baby (…) my carriage of it, I would say, is what is, what has gone wrong**' (Lived experience participant T001.1, from a Listening and Discussion Group on TFMR)

As noted above, this is a sentiment that has been raised publicly in a variety of contexts over the last decade, from the news and magazine articles cited in Section 1.4.2, above, to the viral 2018 Instagram post by former *Dawson's Creek* actor James Van Der Beek, in which he argued that "we need a new word" to replace *miscarriage*. For Van Der Beek, "'Mis-carriage', in an insidious way, suggests fault for the mother – as if she dropped something, or failed to 'carry'" (quoted in Agg, 2023: 142). The problematic nature of *miscarriage* in terms of its synonymity with failure was likewise raised by a project participant:

> '[T]he word miscarriage in the thesaurus **is synonymous with failure so when somebody says, "[F002.1] miscarried", in my head, I hear, "[F002.1] failed**"' (Lived experience participant F002.1, from a Listening and Discussion Group on First Trimester Loss)

Something which has been less commonly discussed previously but which emerged as a strong pattern from the EStELC dataset was a sense that culpability is also implied by the diagnostic terminology *missed miscarriage*, which is used to describe an intrauterine death occurring in the first trimester of pregnancy, without outward signs or symptoms:

> 'I've been in counselling and stuff, um, and I feel a lot of blame towards myself and I think, and I think, **the language around missed miscarriage adds to that blame** (…) It was kind of like, **felt a lot like, 'you've missed it, you must've seen something happening',** when I went in for my scan and the- and they said…they kept on saying, over and over and over again, "oh no, did you not have any symptoms? You must have had symptoms", and **then explaining it's a *missed miscarriage* and that I'd missed it. That language has really stuck with me**.

> I've heard someone since and I never heard this at the hospital, someone else has used this terminology to me, about *silent miscarriage* and I felt like I would have liked that language to be used instead, at the hospital, because that more aligns with what my experience was' (Lived experience participant F001.1, from a Listening and Discussion Group on First Trimester Loss)

> 'It's obviously a massive shock because yeah, **you have missed it (…) missed miscarriage is like a horrible, horrible terminology**' (Lived experience participant F001.2, from a Listening and Discussion Group on First Trimester Loss)

> '[I]t was a missed miscarriage and (…) afterwards you know (…) there was some **guilt, "so I missed it" (…) it was a big thing, wave of guilt, you know like "I missed it**"' (Lived experience participant F002.4, from a Listening and Discussion Group on First Trimester Loss)

These testimonies make clear that the participants understand *missed miscarriage* to mean a pregnancy loss that they have personally missed, interpreting this as a direct insinuation of fault. Likewise, *empty sac*, a phrase used to describe anembryonic pregnancy, where a pregnancy is detectable via ultrasound but only the pregnancy sac and not its contents can be seen, was also considered to imply fault:

> '***[E]mpty sac*** **is really emphasises like, "Oh, I failed**, I could have conceived a normal baby or embryo", or whatever' (Lived experience participant F002.3, from a Listening and Discussion Group on First Trimester Loss)

Similarly, *blighted ovum*, another phrase used to describe anembryonic pregnancy, was also identified as problematic. However, this was not language that any lived experience participants reported hearing in healthcare settings:

> 'A friend had had what she called a *blighted ovum* before…***blighted ovum*****, it's just horrible. It sounds like something that happens to a crop**' (Lived experience participant F001.2, from a Listening and Discussion Group on First Trimester Loss)

Blighted ovum is a phrase that has been problematised consistently in the body of literature on pregnancy loss language discussed in Section 1.4. As Silver et al. (2011) point out, the phrase "makes no biological sense" (1407) because it implies a fundamental flaw with the ovum has caused the issue, when research suggests that in fact an "apparently empty pregnancy sac did contain an embryo at one time, but that the embryo was reabsorbed very early in its development" (Regan, 2018). Moreover, as Silver et al. (2011) also point out, *blighted ovum* misogynistically "conveys a sense of the loss being due to some inherent abnormality with the mother" (1407). As Jennie Agg notes, such implicit blaming is "a sly kind of medical misogyny…one that props up an idea that women's bodies alone are responsible for the fate of a pregnancy" (2023: 150). Thus, Agg suggests that "the idea that [anembryonic pregnancy] is…a failing rooted in the woman's body thanks to a 'rotten' egg…is not based in biological reality. It is misogyny, handed down through language, not physiology" (2023: 79). Although not a representative sample, it is therefore encouraging that none of the EStELC project participants had been exposed to *blighted ovum* during their experiences in healthcare settings.

Themes around blame and guilt also arose strongly in contributions around experiences of Termination for Medical Reasons (TFMR):

> 'I lost due to TFMR in 2023 **(…) the way I was spoken to, made me feel responsible for my daughters [sic] death**' (Written contribution W130, from lived experience eligibility questionnaire)

> 'In Penelope's[4] case, no matter what choice we made she wouldn't have been OK anyway. So, I feel like my level of guilt is maybe a bit less but **I think adding that word *termination* makes me feel guilty if that makes sense**. Like I…I don't like I generally I also just don't like say [*termination*]. I just wouldn't say it to someone if I was explaining what happened I wouldn't use that that phrase [*Termination for Medical Reasons*]' (Lived experience participant T002.1, from a Listening and Discussion Group on TFMR)

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[4] Participant T002.1 wished for Penelope's name not to be anonymised.

For some participants, such feelings of guilt prompted the decision to avoid the word *termination* and develop alternative ways of describing their experience:

> 'I think that's probably why I prefer the phrase *compassionate induction*, because for me there is still, as you know…**Everyone I speak to tells me not to be, but I am very, very guilty so I think that's why I sort of sway towards finding that easier to use than to say *termination*'** (Lived experience participant T002.2, from a Listening and Discussion Group on TFMR)

As noted above, this phrase *compassionate induction* has been suggested repeatedly as an alternative (Mobbs et al., 2018; Peanut, 2023) to TFMR, but experts including Expert Advisory Group member Jane Fisher of the charity Antenatal Results and Choices (ARC) have expressed concern that it could perpetuate stigma. Clinicians at the first EStELC project symposium also pointed out that *compassionate induction* does not clearly encapsulate all possible experiences of TFMR, in a way that may exacerbate difficulties in communicating about such experiences and indirectly contribute to perpetuating stigma. The association with stigma of some words and phrases used to diagnose and describe experience of pregnancy loss, or the perception that such language has stigmatised connotations, was another pattern which emerged strongly within the EStELC dataset, and it is to that theme which we now turn in Section 3.2.2.

3.2.2. Stigma

Recent years have seen a marked increase in awareness of the stigma and societal taboo associated with pregnancy loss; both in the public domain, with campaigns such as Tommy's 'Breaking the Silence' and Sands' 'Finding the Words', and empirical research such as that conducted by Littlemore & Turner (2020). Much has also been written lately on the "social awkwardness" of pregnancy loss (Andipatin et al., 2019) across different cultures, as well as the fact that different cultural norms pose different difficulties for those experiencing pregnancy loss (Tommy's, n.d.). Moreover, given the disproportionate rate of adverse pregnancy outcomes amongst Black and Asian ethnic groups and those from deprived socioeconomic backgrounds (Knight et al., 2023), there is an urgent need for research exploring the experiences of pregnancy loss communication for these groups. As Lacci-Reilly et al., (2023) note in relation to Black, Indigenous and People of Colour (BIPOC) groups in the United States, particular attention needs to be paid to "cultural considerations and discrimination in the healthcare setting" in such communication-focused research (6).

More exploration is also needed of the ways in which media, both traditional and social, contribute to the stigmatisation and/or destigmatisation of pregnancy loss. Empirical research to date indicates that traditional media may perpetuate problematic conceptions of pregnancy loss. Martin (2023), for example, finds that although there has been a notable increase in public discourse about experiences of pregnancy loss, news stories often perpetuate heteronormative and male chauvinistic narratives, and sensationalise experiences of pregnancy loss. Whilst much more research is needed to confirm these findings, they remain relevant to any consideration of cultural narratives around pregnancy loss.

The role social media plays, as a forum for opinion-sharing about pregnancy loss terminology, was discussed in Section 3 in relation to the "wave of conversation" (Oré 2020) which often follows a major news story about a celebrity who has experienced pregnancy loss. The death of Chrissy Teigen and John Legend's son Jack at around 20 weeks of pregnancy represents a particularly significant instance of this phenomenon, since Jack's gestational age ignited debate about the applicability of the term *miscarriage* in the second trimester (see also Section 3.2.5). Further public discussion ensued when Teigen clarified in 2022 that she now conceptualised her experience as "an abortion to save my life for a baby who had absolutely no chance", in the aftermath of the US Supreme Court's decision to overturn Roe vs. Wade ('Chrissy Teigen Says She Has Come to Realise She Had an Abortion, Not a Miscarriage', 2022).

The issue of stigma is, of course, particularly salient in relation to experiences of pregnancy loss which are perceived as associated in some way with choice or decision making, such as TFMR. As will be clear from the following participant contributions, terminology is often perceived to create or sustain this association:

> '**I've shied away from using *termination for medical reasons* I have to say**. I think it can be…I think the word *termination*, unfortunately, it can invoke a number of different emotions can't it, for different people and **there are people who I know have very strong beliefs around termination generally and the fact that, you know, you shouldn't be allowed at all, you know, so I've shied away from that**' (Lived experience participant T001.1, from a Listening and Discussion Group on TFMR)

> '**The word *termination* just, for some reason, doesn't sit right for me**. And so much that I was at the doctors like fairly recently and I could see it, you know like on the…they have your highlights on the side of the screen? There was sort of like an **exclamation mark with *termination* next to it, like highlighted and in red** (…) I think there is ultimately a choice involved [but] for us it felt like there was no choice but to go down that route**. So yeah [the word *termination*] um personally doesn't sit comfortably with me for some reason. But again, I think that's our experience…but I also grew up in a Catholic household and went through Catholic schools, who have sort of drilled in from a very young age** that you know…so I think it's it depends on your personal experience with that language and so on' (Lived experience participant T002.2, from a Listening and Discussion Group on TFMR)

This feeling, that *termination* is a word loaded with stigma, was also echoed by healthcare participants:

> 'Lots of women have said to me, "But then I had to say straight away, you know, when I came round [from anaesthetic], **the first thing I said to whoever the medical staff was at the time is that I didn't…I really wanted this baby"**. You know, that…they don't want to be judged, that they…they wanted the baby. And if I'm thinking about **the language around termination specifically it's a broad brush** isn't it? Everything's under that umbrella and there can be the ending of a pregnancy for a number of reasons, but it feels like there's a really apologetic explanation that has to come tumbling out, sometimes, of women who feel that the negativity of that word (…) for them, it's almost saying that (…) **"You've had an**

> **abortion. You didn't want to have this baby, and you weren't, you know, whatever, whatever then else they think around that'"** (Healthcare professional participant H002.5, from a Listening and Discussion Group on pregnancy loss aftercare)

This professional participant highlights the fear of judgment that accompanies awareness of stigma for many who dislike the word *termination* or the phrase *termination for medical reasons*. One participant also flagged the stigma associated with *termination* as a motivation to continue using the word to describe her experience, to raise awareness that TFMR is healthcare:

> '**I find myself, since everything that is happening in America with Roe vs. Wade being overturned, I've actually found myself using the word *termination* a lot, in order to make sure people know** that…I'm like, "Termination isn't…", and it makes my skin crawl when people are like, "Oh, well, better make sure you wear protection!". I'm like, "Termination is…I've literally had three for two wanted pregnancies! **This was all in the name of healthcare for myself and for my family and, compassionately, for my baby at Christmas**. I couldn't have got pregnant again with the second baby if I hadn't had the surgical termination, because I was so ill after the medical termination the first time!". So, like I find it, you know…if I hadn't had a surgical termination after the medical one it would've taken me…who knows when my body would have expelled you know what was left of that first pregnancy and then I wouldn't have been able to get pregnant so soon. So, if you are "pro-life" or pro- whatever (…) I find it really difficult when stuff like that is online (…) and as much as it's, you know, it is my body and it is my choice, I'm still like, "That is a massive part of healthcare [for people] who are trying to have families!" I'm trying (…) to have a family' (Lived experience participant T002.3, from a Listening and Discussion Group on TFMR)

This participant, T002.3, had mixed feelings about another participant's suggestion of *compassionate induction* as a phrase to replace *TFMR*. On the one hand, she said that she would have liked the word *compassionate* to be used to describe her experiences:

> ‘I actually think your use of the word *compassion* is really lovely (…) **personally I'd like *compassionate*’** (Lived experience participant T002.3, from a Listening and Discussion Group on TFMR)

Highlighting the potential risk of perpetuating stigma around termination by giving the impression that termination of pregnancy only occurs in the context of unwanted pregnancy, however, she reiterated her determination to continue using *termination* to describe her experiences to others:

> ‘I still think [I will use] the word *termination* for other people. And I know it's not my job to educate people but I'm mouthy and I'm going to say it, so **I'm just going to help people to see it as like, this is someone who is really trying to have a family [so] maybe I need to not think about it as, “Oh, it's just some daft girl who doesn't, you know, take her morning after pill”. Like, no that is not it at all. It's a medical tool that needs to be you know, enacted.** So, personally I'd like *compassionate* but when I get out in the world I’ll start using [*termination*] everywhere to get people to listen to me’ (Lived experience participant T002.3, from a Listening and Discussion Group on TFMR)

For the participant who suggested *compassionate induction*, its foregrounding of the baby’s best interests made it preferable to TFMR:

> ‘I've entered into to some mental health support afterwards – so I was diagnosed with PTSD – and it's the terminology that the trauma-informed maternal services, that they've been using with me. And it just seems much kinda…it seems, **for me it sounds softer, it feels softer. And that idea of it being, like, compassionate makes it seem like, you know, it wasn't us thinking that we couldn't cope with [name]** and so on. It was actually just…just the situation put onto us’ (Lived experience participant T002.2, from a Listening and Discussion Group on TFMR)

This contribution makes clear that *compassionate induction* is a phrase being used by healthcare professionals in the UK, and highlights the importance of thinking carefully about how such a phrase, which faces opposition from many experts, is used. For T002.3, the challenge of accommodating such preference as expressed by T002.2 whilst also retaining the clarity and transparency of TFMR could be mediated by using *compassionate* not as a substitute for TFMR, but alongside it:

> 'I **feel like [*compassionate]* takes the sting out of me and my husband feeling guilty**. We were compassionate, we made …I feel like I will say, "We made a compassionate choice and decided to have a Termination for Medical Reasons." I think that's the phrasing I would use' (Lived experience participant T002.3, from a Listening and Discussion Group on TFMR)

Looking beyond T002.3's own usage, this may be a strategy that could be useful more broadly. This highlights that the solution to the 'difficult language' under discussion here is likely not always to be substitution with another word. This is, as will be discussed at length in Section 4, likely to be impractical and ineffectual in many cases. However, where a word has been flagged as consistently problematic, the EStELC dataset highlights the crucial importance of careful framing of information, in order to mitigate negative effects.

3.2.3. Framing

Many contributions to the EStELC dataset, from both lived experience and healthcare professional participants, highlighted the importance of communicative framing as a way to lessen the impact of 'difficult language' that needs to be used in contexts of pregnancy loss. This was a subject of much discussion in the Listening and Discussion Group for healthcare professionals involved in pregnancy loss aftercare. Here, there was an acknowledgment that the need for transparent clinical and technical language in contexts such as postmortem reports is often at odds with the need to communicate sensitively with bereaved families:

> 'There are certain things **we just can't get away from in terms of terminology, clinically. But we can do something about how we express that** and give…but again, there we are subject to what people will allow us to do in that […] I have sent postmortems out to people, thinking, "I really hope you're OK," but you've asked and even tried to say, "Can we do this together?" and so it is complex. I think it can be complex for a midwife and for a health professional, wanting to do the right

> thing, wanting to avoid causing any more distress, and yet sometimes not being able to completely avoid that even with the best intention' (Healthcare professional participant H002.3, from a Listening and Discussion Group on pregnancy loss aftercare)

Here, participant H002.3 stresses the importance of healthcare professionals' role in reframing documents which may otherwise be jarring or distressing. This echoes Littlemore & Turner's (2019) findings on the importance of bereavement midwives' mediating role between the clinical and social domains of pregnancy loss. Another participant in the same Listening and Discussion Group emphasised, however, that this may in large part be a question of resources, rather than know-how or training:

> 'Part of the […] work we do at Petals will be to prepare someone for the fact that [the postmortem report] is going to be clinical and to make sure that they approach the meeting a certain way, to request an in-person meeting, you know, with a consultant or someone who knows what they're talking about is really helpful. **And if they get the time there, it doesn't really matter what the language in the clinical report is, if they feel that that's been presented to them in a really caring and thoughtful way and time has been sought out of busy, busy schedules to enable, you know, someone to sit with them specifically to talk about what's happened**. And I think that that goes a long way in terms of trying to explain the clinical language. So, I think we know what works in that area, as long as there's the resource available to do that, that can really, really help' (Healthcare professional participant H002.1, from a Listening and Discussion Group on pregnancy loss aftercare)

This idea that "it doesn't really matter what the language in the clinical report" is like, providing the overall experience is patient-centred and empathetic was also reflected in some lived experience participants' reflections on framing around words and phrases they found difficult, and the ways in which healthcare professionals prepared them ahead of exposure to difficult language and supported them through initial exposure:

> 'Something that was really helpful actually [was that] we had a bereavement midwife who went through the postmortem with us and **she did prepare us that a lot of the language they would use in that was would we would find upsetting and we did because it was very clinical** and it would talk I don't think they used the word *fetal demise* but they did talk about factors that could try to determine when he'd died and they were quite graphic and not something we particularly wanted to think about' (Lived experience participant S001.3, from a Listening and Discussion Group on Stillbirth)

Likewise, in the context of a Listening and Discussion Group on TFMR, one participant spoke at length about the efforts that had been made to "talk around" difficult language "in more gentle terms":

> 'The team that I was working with and the language that they used was very gentle, so albeit **they did refer to…to our situation as a *Termination for Medical Reasons* – which I immediately, as soon as I heard that I must admit started to cry straight off – they did kind of talk around that in more gentle terms,** I would say, around, you know, what that would be like and specifically related to things like you know, "Baby," or [name] I should say, we called him [name], "He won't feel any pain there would be no…", etcetera. So, I think for me although initially (…) like I say, **I must admit that phraseology took me back a bit and they did then kind of explain what that meant. And it was very rarely referred to, I would say, actually after that**. They told me that's what it's called, but [it was] very rarely that anyone really referred to that.' (Lived experience participant T001.1, from a Listening and Discussion Group on TFMR)

This testimony highlights the importance of framing in mitigating negative effects of difficult language during the experience of pregnancy loss, and not just in its aftermath. In such contexts, participant T001.1 also emphasised the importance of healthcare professionals avoiding use of difficult language wherever possible. She noted that the word *feticide*, noted above as a word which caused distress to other participants, had not been part of her conscious experience, with *injection* used instead to refer to the injection used to stop her baby's heart.

Perhaps reflecting participant H002.3's emphasis on the availability of resources to facilitate framing, positive experiences of framing difficult language reported during the EStELC project related exclusively to experience of pregnancy loss occurring after 20 weeks. References to framing or reframing efforts in earlier pregnancy in the project data were, by contrast, universally negative. Many of these related to recommendations from clinicians that the personhood of the baby lost be reframed:

> 'When I found out my baby had no heartbeat **the consultant said to me - think of it like a manufacturing production line and your body is getting rid of defective product**.' (Written contribution W309, from lived experience grouping questionnaire)

> 'I found it very difficult when my GP said to me, after my second miscarriage, because **I kept saying, "My baby died," 'cause in my mind, you know, my baby died. And he kept saying, "You might find it easier if you frame it as not that your baby died but that your pregnancy ended**"' (Lived experience participant F002.1, from a Listening and Discussion Goup on First Trimester Loss)

Such denial of the personhood an individual has assigned to their baby, as is clear from both these participants referring to "my baby", means that clinicians' suggested reframing represents a misalignment between the language being used and the concept of their baby an individual has. As will be explored in the following sub-section, this kind of discrepancy between the way someone conceptualises, and therefore describes, their experience and/or their baby and the way others do so, is the reason that many words are identified as 'difficult' by EStELC lived experience participants. In many of the instances discussed in Section 3.2.4, however, such discrepancies seem to result from someone else not knowing how a lived experience participant conceptualises their experience and/or baby, and how they wish to use language. The attempts by clinicians described above, to reframe the experience in a way that contravenes a patient's clearly-stated preference, is an example of particularly bad practice, which should be avoided at all costs.

3.2.4. Misalignment between external language and internal experience

Across all the lived experience Listening and Discussion Groups, there was widespread recognition amongst participants that language became a problem in clinical settings when the words and phrases used by healthcare professionals did not align with the individual's sense or understanding of what was happening or what had happened. This is, for example, the case with the word *termination* in experiences of TFMR, since it was considered by several participants to indicate the existence of choice where, as one participant is quoted below as saying, "this would never be my choice".

> 'It was a loss of a baby that I wanted and so, that was the struggle for me around the language that was there, **of saying *termination* when actually it feels like the choice was not there**' (Lived experience participant T001.2, from a Listening and Discussion Group on TFMR)

This was also reflected in discussions of the word *choice* itself:

> 'People **find it incredibly triggering, the word *choice*, definitely**. Incredibly triggering, because I guess you're left thinking, "well this would never be my choice, this situation has never been my choice, so it's not really a choice", so yeah that is, it is a challenge' (Lived experience participant T001.1, from a Listening and Discussion Group on TFMR)

In one Listening and Discussion Group on TFMR, this led to a discussion between participants about whether *decision* might be less objectionable than *choice* in clinical settings when TFMR is being discussed:

> 'I'm stumbling a bit because I feel like in some ways in those heightened times of emotion it's going to be very difficult to use a single word or you know a single phrase that's gonna make anyone feel better (…) **I probably would replace the word *choice*, definitely. I think a *decision*, I think yeah, it's a *decision* that in some cases needs to be made for sure**' (Lived experience participant T001.1, from a Listening and Discussion Group on TFMR)

This apparent preference for *decision* over *choice* was likewise reflected in the narrative which this same lived experience participant used to describe how she communicated with family, friends, and colleagues about what had happened:

> "'We had our twenty-week scan. There was some issues within that that meant that, we needed to really make a decision…", and it was a decision**, I did use the word *decision*, actually, "around whether or not continuing with the pregnancy was the right thing to do for [name], and for us as a family." (…) I really used, used those terms, *decision* definitely actually, about whether or not continuing the pregnancy was the right thing to do for [name] and my family**, and I said, "Ultimately we've um we've decided that we don't think it's the right thing to do"' (Lived experience participant T001.1, from a Listening and Discussion Group on TFMR)

Other participants who had experience of TFMR, however, used the word *choice* without difficulty, and showed no apparent preference for *decision*. Given the small sample size in this study, the impact of these words may be a useful thing for a future study to explore.

Participants who objected to use of *abortion* also highlighted the difficulty of language presupposing a choice where none was felt to exist:

> 'When I was medically discharged, the pill they gave me was obviously the abortion tablet. And I remember the midwife didn't tell me that, but it was in a leaflet I read and that was bad (…) I remember reading the words on the leaflet when they kind of explained what was going on (…) and I remember thinking, **"But I'm not choosing this. This is not… I'm not taking this because it's a choice", and, and it did make me feel very guilty, even though my brain knew that I had to do it (…) it's the guilt like, "I'm taking this". I haven't, they didn't use the word [abortion] which I'm really thankful for but I…I did still read it** (Lived experience participant F002.2, from a Listening and Discussion Group on First Trimester Loss)

Participants also reported concern that words which did not align with their experiences may fail to convey adequately to others the trauma of what they had been through:

> 'I can't stand people thinking that both a) the first miscarriage and b) the TFMR were just…you know that scene, I don't if you've seen it, in Fleabag where the sister goes off and has a miscarriage in the toilet and comes back to brunch? Now I'm sure that happens to people, it's horrific in the series anyway. **But that's what people imagine, "Oh you go to the toilet, you weed and there was some blood? I'm so sorry**"' (Lived experience participant T002.3, from a Listening and Discussion Group on TFMR)

Some also highlighted the role that language which does not align with their experience can play in invalidating their experience:

> 'A lot of the healthcare professionals that we were involved with referred to it as ***passing baby*** **(…) a lot of it was, "Passing little one, you'll pass your little one", as though there wasn't the labouring part, like you know you sort of just pass like a clot (…) But, you know, it's completely diminished the whole experience that I would have to labour [name] and give birth to a baby** and it's almost it's found it then tricky when I've afterwards when I've like referred back to that *labour* um and *giving birth* to him it almost makes me feel like I can't say that I've *given birth* to him almost' (Lived experience participant T002.2, from a Listening and Discussion Group on TFMR)

For some participants, it was this desire to emphasise the gravity of the experience that directly motivated their decision to choose certain words or phrases:

> 'We describe it in in our house as *baby loss* because that is what it is. And I think when you describe it as a *miscarriage* or an *ectopic* or whatever the terminology is in relation to that particular baby loss, people go "Oh, well it's medical". And actually, if you say, "We've lost three babies", or, "We've lost five", however many it is, it makes people sort of sit back and go, "Oh, actually that is a really big deal and actually I (…) now understand why it's such a massive thing for you, sorry" (…) And

> I think I think for me that's something that's really changed because I think I used to use quite, you know, medical terminology in relation to it because I felt like that was the right thing to do and actually then having subsequently been like, **"No, it's baby loss and I have lost three babies", people really respond very differently 'cause they're like, "That is a really big deal" and because it sort of conveys the gravity of what you've been through'** (Lived experience participant F001.3, from a Listening and Discussion Group on First Trimester Loss)

Likewise, others' use of language which reflects someone's conceptualisation of the experience can be affirming and helpful:

> 'I have had some professionals use **terminology like *loss*, *mourning, baby, grief* and they truly made me feel understood'** (Written contribution W325, from lived experience grouping questionnaire)

> '[T]he **right words at the right time have helped** massively' (Written contribution W083, from lived experience eligibility questionnaire)

For some participants, finding language which reflected or validated their experience could also be a transformative experience:

> 'I myself had to really accept this term [*pregnancy loss*]. I couldn't at the beginning 'cause I felt like we'd made the choice [to have a TFMR and to] **call it a *pregnancy loss*…I didn't feel like I was allowed to be included in that group of women who had suffered from a pregnancy loss**. Until, weirdly the bereavement midwife, she said, "No, you are. It's a pregnancy loss", and I felt really validated then (…) once someone had said that to me, then I also felt that (…) I was allowed to be a bit more sad about it, as it was referred to as a *pregnancy loss'* (Lived experience participant T002.3, from a Listening and Discussion Group on TFMR)

> 'I remember reading on one of the charity websites somewhere, not sure if it was Tommy's or Miscarriage Association, but **one of them referred to, like, what had**

> **happened as my *baby dying* and I hadn't thought of it that way because of the way all the medical terms were used. I know technically maybe they never lived but I had seen their heartbeat at one time and to me it felt like they'd died.** Like, that feels to me the same as someone else in my family dying and so yeah, I don't think the word *death* is actually used a lot in the medical community for miscarriage, but I did think of it more as a death' (Lived experience participant F001.4, from a Listening and Discussion Group on First Trimester Loss)

Whilst it may seem straightforward to allow individuals to label their experiences in a way that feels right for them, however, this can present both practical and ideological challenges. In particular, the project's dataset contains evidence of relatively widespread desire for gatekeeping around particular terminology, and a need for some experiences of loss to be distinguished from others. These challenges will be considered in Section 3.2.5.

3.2.5. Disenfranchised grief and hierarchical conceptions of loss

Socially unrecognised bereavements have been discussed for decades, in relation to the concept of 'disenfranchised grief'. The originator of this phrase, Doka (1999) defines this as "the grief experienced by those who incur a loss that is not, or cannot be, openly acknowledged, publicly mourned or socially supported" (37). In the paper which introduced the concept of 'hierarchies of loss', Robson & Walter (2013) reject the "binary assumption that grief is either enfranchised or disenfranchised", instead arguing that "the social norms about the legitimacy of bereavement are not binary (yes-no), but are scalar or hierarchical" (97). Robson & Walter (2013) therefore propose a tool for "identifying hierarchies of loss" (113). They concede, however, that "there may be certain losses that are entirely unrecognised socially, such as miscarriage or elective abortion [sic]" (109).

Middlemiss & Kilshaw (2023) adapt this framework to the specific context of miscarriage and TFMR, in order for such "experiences which fall outside assumed norms [to] be included and examined" (2). They find that "there are indeed hierarchies of loss based on some persons being afforded more social legitimacy in their reaction to loss", but also that "the factors which hierarchise loss are more complex and diverse than simply the closeness of relationship to the deceased" (2).

Middlemiss & Kilshaw's (2023) analysis highlights that "aspects of the foetal body such as gestational time" influences the hierarchisation of pregnancy loss" and that some individuals "recognise and use hierarchies of loss in agential ways, sometimes to convey the impact and bolster the social status of their own loss, sometimes to assert the legitimacy of the foetal being or baby that died" (15). This was reflected in the dataset for this project. Several participants who had experienced full- or near-term stillbirths, for example, felt strongly that the gestational age of their baby was a fundamental aspect of the experience that they wanted to emphasise in the language they used:

> '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 that…how late we lost [name]** and how much of a person he is and was. And I sometimes feel like when you…they just go, "You had a stillborn", it just detracts every human part of that. And like, "Do you realise how developed he was? Do you realise how far along we were in this process? Do you realise, you know, that there are babies born 14 weeks before him and they survive and they're fine?" Like and that's not…yeah we just kind of gloss over it as this term' (Lived experience participant S001.3, from a Listening and Discussion Group on Stillbirth)

> '**I agree with the terminology *full term stillbirth* because I think *stillbirth* is also used for late miscarriages sometimes too**. And I think I agree I want people to know that I carried my baby and I grew that baby until they were ready to be born' (Lived experience participant S002.3, from a Listening and Discussion Group on Stillbirth)

As Middlemiss & Kilshaw's (2023) analysis highlights, however, the challenge with anything, including language, that seeks to validate feelings such as these is that it would simultaneously invalidate the experiences of others, many of whom already "do experience hierarchies as social constraint, in some cases as disenfranchised grief" (15). In response to the previous quotation, another participant made the following reply:

> ‘I feel **quite sensitive about [*full term stillbirth*] being used, as in I want people to use [*stillbirth*] with [name]. She was on the earlier end, she was 25 weeks and five days** and not, admittedly, not medical professionals but other people I know have said that it's not a birth, that she wasn't a person because it was so early. And well it sure felt like a birth to me! I was in labour for 17 hours, I had to have an epidural, my milk came in afterwards. To me, that's a birth. She…she had passed viability week, meaning that had she not already lost her heartbeat there was a, admittedly small, chance that she could have survived. So to me, it's a birth’ (Lived experience participant S001.1, from a Listening and Discussion Group on Stillbirth)

As the references in the above quotations to “late miscarriages” and “viability week” highlight, the hierarchy perceived by some lived experience participants to exist within experiences of stillbirth are mirrored and exaggerated in the dichotomy between miscarriage and stillbirth. In the UK, this legal threshold is 24 weeks’ gestation, and this threshold and its equivalents in other countries are associated with a tendency to equate younger gestational ages to lower psychological impact. As Kraus (2022) notes, in general “for physicians, the emotional impact of stillbirth tends to be experienced, and therefore perceived, as a much greater calamity” (238). As Kraus indicates, this hierarchy is legitimised in many global territories by the dichotomy between miscarriage and stillbirth. After the ‘viability’ threshold, many legitimising rituals are facilitated, encouraged or even mandatory, such as ‘memory-making’ (Hennegan et al., 2015), photography (Oxlad et al., 2023), parental leave, registering the stillbirth (Hodson, 2022), and holding a funeral. However, whilst technically possible following loss before 24 weeks, such rituals are often not facilitated, or are even discouraged in cases of loss prior to the ‘viability’ threshold. In the case of parental leave, the 24-week stillbirth threshold has been described as an “arbitrary cliff edge”, creating a “stark injustice” (Hodson, 2022).

Silver et al. (2011) likewise describe the distinction in US law between pre- and post- 20-week loss as “arbitrary”, as well as “unfounded” (1406). They argue that “the pathophysiologic events that precede births between 16 and 20 weeks are not significantly different from those preceding births after 20 weeks, manifested by cervical softening and effacement caused by infection or decidual hemorrhage or both” (1406-1407). Silver et al. argue that on this basis, “it makes no biological sense to draw an artificial line at 20 weeks of gestation. These births share pathophysiology and recurrence risk and should be described using similar terminology" (2011: 1407). Such arguments highlight the difficulty of disaggregating the need for legislative clarity, clinical and research precision, and cultural sensitivity.

In terms of cultural sensitivity, sociological research in the UK has shown that the dichotomisation of pre- and post- 24-week loss and the associated vocabulary *miscarriage* and *stillbirth* poses particularly acute challenges to those experiencing pregnancy loss between 20^{+0} and 23^{+6} weeks of pregnancy in the UK. Use of *miscarriage*, though reflective of the legislative and medical definition, can in such contexts be perceived as invalidating, as well as inadequately preparing families for the realities of labour and birth at such gestations (Smith et al., 2020). As Smith et al. (2020) note, at such a gestation, "the distinction between the terms 'miscarriage' and 'stillbirth' is not trivial. The term miscarriage focuses attention on the woman's body failing and denying fetal personhood" (872).

Miscarriage has also been noted to cause friction among communities of bereaved parents, particularly in the context of losses occurring after 15/16 weeks; where rejection of the term *miscarriage* to describe second trimester loss can be perceived as a comment on the validity of grief and trauma following first trimester loss (Malory, 2021). As Meluch (2022) notes, "when the way a traumatic diagnosis is communicated feels invalidating, it can make the entire medical experience feel undermined". Especially in the hinterland between legislative and medical definitions of miscarriage and stillbirth, terminology poses significant risks of this kind, and this is reflected in the lived experience contributions to the EStELC project. Lived experience participants who had experienced their loss in the second trimester of pregnancy all strongly rejected the word *miscarriage* not just on the basis of its implication of blame, discussed in Section 3.2.1, but because it did not distinguish their experience from those in the first trimester:

> 'I think the word *stillbirth* for the twins is the appropriate term…**to call those babies at 22 and 23 weeks a *miscarriage* just seems completely ridiculous** (Lived experience participant M001.3, from a Listening and Discussion Group on Second Trimester Loss)

> 'I struggled with that, [with] ***miscarriage*…I didn't think that it described what I went through (…) our baby that we met and saw**. I don't think it described, and I'm not minimising miscarriage at all, because I know personally in my family, my sisters have been through miscarriages and I'm not minimising at all. I just didn't think that *miscarriage*…it was in between a *stillbirth* and *miscarriage* I felt and so I like to refer to my loss as a *second trimester loss'* (Lived experience participant M001.2, from a Listening and Discussion Group on Second Trimester Loss)

> '**The word *miscarriage,* I hate it. [Name] was a baby.** He was tiny, I held him in my hand, he had ten toes and ten fingers. Just gorgeous. But the *second trimester loss* sits better with me than a *miscarriage* like you said, not downplaying it but that is not what happened to me in my head' (Lived experience participant M001.1, from a Listening and Discussion Group on Second Trimester Loss)

In several instances where EStELC participants had experienced both first and second trimester losses, they explicitly distinguished between the applicability of a word like *miscarriage* for their earlier and later experiences:

> '**I've now had two actual miscarriages you know and it's really different… it's just not the same and to put that in the same category as delivering…like, you know, going into hospital and delivering babies [at 17 weeks]**. It's just…it doesn't make any sense, [that] is on a completely different plane (…) I guess what's important is (…) you don't want to kind of come to a situation where people in first trimester miscarriages don't feel like that's taken seriously 'cause it's "only a miscarriage"' (Lived experience participant M001.3, from a Listening and Discussion Group on Second Trimester Loss)

Here, participant M001.3 distinguishes what she considers to be "actual miscarriages" in the first trimester of pregnancy, with "going into hospital and delivering babies" at 17 weeks. However, she highlights that the effect of making this comparison might be that "people [experiencing] first trimester miscarriages don't feel like that's taken seriously". Others who compared personal experiences of losses in the first trimester and at later gestations stressed the physicality of the experience and the concrete separation from the baby who had died:

> 'Not to belittle anybody that's suffered miscarriages at all…I mean I've had missed miscarriages, a 10 week [one], as well as ones at 8, 6, 7 weeks. **But I think for me maybe because there's not a baby, a baby I can hold onto**…[the experience is less traumatic]' (Lived experience participant S002.3, from a Listening and Discussion Group on Stillbirth)

Some participants compared their experiences of second trimester loss with the first trimester losses of others close to them:

> 'My friends have had different losses at different times, and none of them second trimester like mine. **But certainly, [with] first [trimester loss], I think the difference is for them [they are] losing the future, losing the…you know the thought of what you might have. Whereas I think, for me, the distinction in this case is losing something physical**. Actually having to hold something or in this case [name] and then having to leave that, having to leave him behind in the hospital, walk out with the box instead of walking out with your baby. It's just things like that and I think [that is] probably the distinction…the physical aspect is probably what I'd say, you know, the physical differences that that you have to do' (Lived experience participant T001.1, from a Listening and Discussion Group on TFMR)

Here, this participant, T001.1, distinguishes between what psychotherapist Julia Bueno has labelled the 'child in mind' (2019) and the physicality of "actually having to hold" a baby and "having to leave [them] behind in the hospital". Whilst we must be extremely cautious of the risk of further disenfranchising the grief of those who experience types of pregnancy loss that do not involve this type of physicality, the physical experience of holding and leaving behind a baby was highlighted repeatedly as a cause of acute trauma for many EStELC participants; many of whom reported that this trauma was exacerbated by language which they felt did not distinguish between experiences which are and are not physical in this way.

On the flipside, however, it has been noted that "the absence of an embryo, of a *body*, can be particularly tormenting, as if it makes it a different, lesser category of miscarriage" (Agg 2023: 73), meaning that any language which upholds a physical distinction may do greater harm than good.

The overriding impression gleaned from many participants who had lost babies in the second trimester was therefore that it was inaccurate and inappropriate to label their loss as *miscarriage*, since this word did not reflect the physicality of the experience and the gravity of what they had been through. This sense that the word *miscarriage* likewise does not adequately reflect the gravity of the experience of losing a baby in the first trimester was also reflected in the EStELC dataset, however:

> '**I feel like [*miscarriage*] downplays it,** and I think lots of people think, "It's just an early miscarriage", or (…) that many people have miscarriages, and I think people have that sort of mindset of, "Oh, at least it's early!" and that kind of thing (…) I think that's my worry sometimes with *miscarriage'* (Lived experience participant F001.1, from a Listening and Discussion Group on First Trimester Loss)

Many participants who had lost a baby during the first trimester of pregnancy also explicitly rejected a hierarchy of grief which associates longer gestations with a higher level of grief or trauma:

> '**There is no hierarchy of grief. If you've lost a baby, you've lost a baby in my opinion**. Like that that's another language [issue]…that I've heard, that when people have said, **nurses have said, "I had someone recently who was much further along than you", as if well I should be [thinking myself] lucky then, 'cause I'm 10 weeks and not 20 weeks**. I think [people think] there's a hierarchy of loss' (Lived experience participant F003.2, from a Listening and Discussion Group on First Trimester Loss)

> 'I did find when people say, "Oh, oh, you miscarried", **the first thing people say is, "How far gone were you?" It doesn't matter how far gone you were!**' (Lived

> experience participant F003.1, from a Listening and Discussion Group on First Trimester Loss)

In some cases, as for participant M001.1, the hierarchising impact of the 24-week threshold had been made explicit in interactions with others. For M001.1, these interactions were in the context of employment, where she was given the impression that she was not entitled to use the word *stillbirth*:

> 'I chose [*stillbirth*] as well until I had people telling me it wasn't. [Name] was born um he may have been born sleeping but he was born; he was *stillborn* (…) I emailed work saying, "This happened and I'm currently in hospital (…) in a bereavement ward 'cause my baby is going to be born sleeping". **And it was like, "Your baby is not a baby yet, it's not here yet so it's just a miscarriage** or it's just this, it's just that"' (Lived experience participant M001.1, from a Listening and Discussion Group on Second Trimester Loss)

This kind of linguistic gatekeeping highlights how pervasive hierarchical thinking around pregnancy loss is in UK society, as well as how closely tied it is to the 24-week legislative threshold. This has trickle-down effects on those who experience loss occurring at much younger gestational ages. It has been clear from this section and the one prior that such sharp divisions as those which exist in legislative and medical definitions in the UK and US do not always reflect the conceptual frameworks of those experiencing pregnancy loss. Kraus (2022) highlights the differences in the pregnancy loss narratives of healthcare professionals and those with lived experience; arguing for the importance of "emphasising the value of even the earliest loss" in clinical practice (238). Jennie Agg, however, notes that this is not usually how clinicians behave in reality, reflecting a "hierarchy in terms of how healthcare professionals value miscarriages, devaluing losses that occur before a scan can be done" (2023: 182). Agg cites Professor Nick Macklon, who notes that:

> One of the reasons we assume women should handle a 'biochemical' pregnancy better than, say, a miscarriage after an early scan, is because of the importance that professionals place on saying, "Look, I can see a foetal heart". When that gets lost, it's no longer just an affair for the couple; other people have given it a certain value, which in a biochemical pregnancy hasn't happened yet (quoted in Agg, 2023: 182)

This, too, was reflected in the EStELC project's dataset, where people who had experienced pregnancy loss in the first trimester clearly felt that their distress, grief, and trauma were not acknowledged or understood by those involved in their care:

> 'I **just thought there was no compassion**, and it was very much a case of, "Well it's just a case of this, this is what it is". And even when it was a case of, "We're going to take the second fallopian tube," even then, "You're going to be infertile", there **was no [cries] awareness of what that meant'** (Lived experience participant F001.3, from a Listening and Discussion Group on First Trimester Loss)

This perceived lack of compassion persists despite evidence of high levels of Post Traumatic Stress Disorder following a loss during the first trimester of pregnancy (Farren et al., 2016). One healthcare professional participant acknowledged the different "level(s) of care" that might be received after a 6-week loss, versus that following a 22-week loss:

> 'In terms of **like is there a hierarchy or not…I think we like to think there isn't but I think certainly when I've spoken to other clinicians there is [one]**…"OK you've had a six week loss, really sorry about that", you know and the level of care that they can offer is quite different to a 22 week loss and the way we would talk about it I think changes, you know, that the…even just maybe subconsciously the way you think about it, the way I would, not care for that patient, but like the level of care you perhaps put out to that patient is different, the amount of time they might spend in the hospital would be different (…) I think there is, you know, it's quite a varied experience isn't it, in that (…) they're not having the same experience those two women, 6 weeks and then the 22 week loss' (Healthcare professional H001.2, from a Listening and Discussion Group on providing care during pregnancy loss)

Kraus (2022) ultimately recommends healthcare professionals listen to the individual and affirm the loss, to avoid the use of depersonalised and biased language. Unfortunately, however, as highlighted in Section 3.2.4, experiences of loss earlier in pregnancy were often experienced negatively by lived experience participants for these reasons. Ultimately, the dataset reflects the need for empathetic, patient-centred communication regardless of gestational age at the time of loss. An important consideration in this regard is how technical clinical and medical jargon should be used in patient-facing contexts, as is discussed in the following sub-section.

3.2.6. Technical clinical/medical vocabulary

Use of medical jargon has been shown repeatedly to have negative impacts on patient wellbeing in the context of pregnancy loss (Brann et al., 2020; Meluch, 2022). In reporting the responses of participants with lived experience of pregnancy loss to prerecorded videos of clinicians delivering the news of a loss, Brann et al. (2020) note that participants discussed their dislike of medical terms like "fetal tissue, contents or parts" when referencing the baby (Brann et al., 2020). Likewise, Lacci-Reilly et al.'s (2023) scoping review found that patients "overwhelmingly" prefer healthcare professionals to use patient-centred communication and that "overmedicalised" language can lead to communication barriers and confusion in pregnancy loss contexts. This in turn can impact the levels of informed consent, something that was found to improve patient experiences of care significantly. Lacci-Reilly et al. conclude that "the ability to express empathy through words is crucial for achieving patient-centered care" (2023: 5) and that "[t]he language used in the healthcare setting around pregnancy loss has led to the discursive medicalisation of miscarriage." (5).

The concept of "discursive medicalisation" of pregnancy loss (Lacci-Reilly, 2023: 5) also appears elsewhere in social science literature. Van Der Sijpt (2010) highlights a tendency for pregnancy loss to be discussed through a medical lens, which ignores the social complexities of the experience. Medicalised terminology is likely to play a role in this. From a psychological standpoint, Andipatin et al. (2019) examine the medicalised framing of experiences of pregnancy loss, and the hegemonic role of biomedical discourses in constructing societal understandings of pregnancy loss. These findings were reflected in the contributions of lived experience participants to the EStELC project:

> 'The **language most clinicians use around baby loss is cold and not empathetic, the last thing loss parents need is to be clinically spoken to** and brushed away' (Written contribution W057, from lived experience eligibility questionnaire)

> 'I have heard the same clinical terms over and over again, that stuck with me as part of the trauma of miscarriage. Each time they tell you how it will feel and what to expect but **do not use caring language and have clearly not experienced it themselves so makes the process very cold and cruel**' (Written contribution W148, from lived experience eligibility questionnaire)

In both these cases, the participants did not volunteer particular ways of speaking that they had found "clinical" and "cold", but other lived experience participants did highlight certain terms as upsettingly clinical, for example *demise*:

> 'We had a couple of people who used words that we found quite upsetting, so (…) **we had somebody talk about the *fetal demise* and that seemed like a really clinical**…I dunno, **strange way of saying it**. And one of the midwives used quite similar terminology the day we were we were coming home without [name]' (Lived experience participant S001.4, from a Listening and Discussion Group on Stillbirth)

> '[The] Early Pregnancy [Unit] scanned when the baby was still alive but the heartbeat was very irregular and **the language behind that was so barbaric**, like thinking back to it (…) I just didn't know what was happening then a consultant… she came and she went**, "Right 50/50 demise, come back in 10 days", and that was it, "50/50 demise**"' (Lived experience participant F003.5, from a Listening and Discussion Group on First Trimester Loss)

In some cases, as was also highlighted in Section 3.2.5, participants felt that use of clinical language had failed to adequately prepare them for the reality of their loss:

> 'They just used the word *tissue* (…) you know, they say, "**You're going to pass the *pregnancy tissue*." When actually, you know, what I actually saw was (…) my small baby in its sac**' (Lived experience participant F003.3, from a Listening and Discussion Group on First Trimester Loss)

The data gathered also reflected the findings in Section 3.2.3 on framing, as well as Littlemore & Turner's (2019) emphasis on the importance of bereavement midwives' mediating role between the clinical and social domains of pregnancy loss. EStELC findings also corroborated Kraus's (2022) observations on the "objectivity that often plagues the practice of medicine" and the need for "focus, listening and compassion" in place of medical jargon (240):

> 'Medical terms can feel clinical and harsh to many. **It's important to balance accurate medical terminology with empathetic and sensitive language**. Language can significantly affect mental health. Terms that acknowledge the grief and validate the loss are important in helping individuals process their emotions.' (Written contribution W316, from lived experience grouping questionnaire)

As was explored in Section 3.2.3, framing can play a significant role in creating this 'balance', and of mitigating the impact of clinical or medical language in the context of pregnancy loss. Lived experience participants reported significant challenges especially where they perceived a shift to occur in the language used in relation to their pregnancy or their baby, from language perceived to validate their experiences or humanise their baby, to more clinical or technical language:

> 'Some were really kind and compassionate and others made me feel not just dismissed but as if my baby was not someone who could be spoken about and like my experience was purely clinical**. And the difference in my treatment from my emergency scan when our baby was alive versus the way I was treated that evening and the next day by the hospital when they had died was huge.** I think consistent care and an agreed lexicon for loss is really important in ensuring women and their babies receive equal dignity throughout their pregnancy and loss/bereavement care' (Written contribution W216, from lived experience eligibility questionnaire)

> **'I was shocked when speaking with the consultant that the word 'product' was used**. We found out I had a missed miscarriage at our 12 week scan and it was a total shock. I had had a routine midwife appointment at 9 weeks and 'baby' was said and I was asked about plans for birth, and yet 5 days after a shock realisation that I had a missed miscarriage, the consultant referred to 'product''.' (Written contribution W273, from lived experience grouping questionnaire)

> 'The **language definitely changes from baby to yeah, not a baby, the moment you lose it**' (Lived experience participant F002.3, from a Listening and Discussion Group on First Trimester Loss)
>
> '**Straight away they stopped (…) saying like, "Your baby," or anything. It was, "Your pregnancy,"** and it was all like, "You're OK but the pregnancy might not be continuing." (…) The language definitely changed' (Lived experience participant F001.4, from a Listening and Discussion Group on First Trimester Loss)

However, sensitivity cannot be the only consideration when thinking about clinical terminology in relation to pregnancy loss. There is also an imperative to ensure that pregnancy loss terminology can provide clarity and precision in legislative, clinical, and research domains, as well as ensuring clarity and sensitivity in patient-facing clinical settings and the wider cultural domain. One healthcare professional participant emphasised the considerable challenges of striking this balance:

> 'If somebody is having a termination for medical reasons, the word *feticide* is a legal requirement to write. If you write *injection* then you your form will be rejected because it could be any injection, could be a water injection (…) and so because that form needs to be signed by two clinicians…it is part of a legal requirement. But I think (…) almost like people can cope with a lot as long as there's a bridge between them, and so we find um we…we…my hospital is a really old hospital and we sometimes have to people have to navigate space and go through an antenatal clinic in order to get to a bereavement sort of suite which is really not ideal but if we say, "I'll meet you and I'll walk with you through", that…mostly people find that completely OK and I think it's the same with language. We will always we have families who request postmortems being sent out and will often try- it's their information, so it's not ours to gatekeep but we'll often try very hard to say, **"Do you think we'd be able to do that with you, together, because the language is…that can be very hard to read on your own, in your bed at night, you know, when you're…But could we do that with you?". Some people will say yes and some people will say no (…) but offering to be the bridge between**

> **the legal clinical terminology and someone's…I guess people's hearts and then that that feels the right thing to do.'** (Healthcare professional participant H002.3, from a Listening and Discussion Group on pregnancy loss aftercare)

Such emphasis of the importance of individualised care around language in pregnancy loss contexts reflects one of the most significant findings of the EStELC, and the focus of the following section; that high levels of variation exist in terms of which language is experienced as 'difficult'. Accommodating individual variation and preference in order to optimise sensitivity in pregnancy loss care is therefore paramount. Section 4, the conclusion to this report, will explore some of the ways this can be done; both via long-term aspirations and short-term recommendations.

3.3. Individual variation and preference

The importance of using 'reflective listening' techniques, paying careful attention to what someone says and letting them know that they have been heard and understood, in clinical settings (Braillon & Taiebi, 2020) is now recognised across healthcare specialties. Its significance has been highlighted particularly in clinical contexts involving pregnancy loss (Kraus, 2022), and the findings of this project underscore the acute importance of reflective listening in pregnancy loss care.

As we have already seen, the scope for language to impact patient experience of pregnancy loss has been recognised, if not fully explored, for several decades (Malory, 2022). This, in itself, indicates that pregnancy loss is an unusually acute site of linguistic tension within healthcare, and Section 3.2 demonstrated that many so-called 'difficult words' are used in relation to pregnancy loss in the modern UK health sector, and that people with lived experience feel that these words impact them negatively. However, the wide degree of variation reported by EStELC participants in terms of the words they find either appropriate or inappropriate presents a significant challenge in ensuring reflective listening in pregnancy loss care. This variation will be the focus of this section, before potential interventions to ensure individual preferences are respected and accommodated are explored in Section 4.

Of course, many healthcare professionals are already implementing reflective listening in their own practice, and many healthcare professional participants in the EStELC project highlighted their awareness of the importance of reflective listening and of mirroring the language chosen by those experiencing loss during pregnancy:

> '[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' (Written contribution W002, from healthcare professional grouping questionnaire)
>
> '[I want to talk about the] **value of mirroring parents' language** when talking about their loss' (Written contribution W001, from healthcare professional grouping questionnaire)
>
> '[How to present difficult information] **depends on the patient you've got in front of you**' (Healthcare professional participant H001.3, from a Listening and Discussion Group)

Lived experience participants also frequently highlighted the benefits of receiving care from clinicians who listened carefully and respected their conceptualisation of their experience and/or baby, by using their preferred language:

> 'I keep travelling [back to the hospital near my former home] because they know me and because they (…) know that my baby that I gave birth to at 13 weeks was Munchkin[5], they know the one that was a miscarriage is June Bug, and they know this one is Twinkle. **And because they know that I like to talk to them by their name, they will say, "What's this one called [F002.1]?", and I'll tell them, "Right, this is June Bug, or this is Munchkin", and then they will talk about them using that name**. But I don't think I would have had that if I hadn't have kept travelling across the country to go to the same EPU (…) I do think continuity

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[5] As above, this participant wished for her babies to be named in the report.

> of care and building up a relationship particularly with people who have experienced recurrent miscarriage is really important because you'll get to know them and the terms that they like to use' (Lived experience participant F002.1, from a Listening and Discussion Group on First Trimester Loss)

> 'Where I am here at the moment, where I had my last miscarriage, they actually **have a Bereavement Midwife who I have been able to build that relationship [with] and she knows how I talk and that that for me has just been a revelation to be honest. So yeah, just having (…) like even if it's just one person, it feels like one person understands, one person gets this** and especially in a very, very busy hospital when you know they must see so many hundreds of people and these are gynae units and just knowing that one person understands [is so helpful]' (Lived experience participant F002.2, from a Listening and Discussion Group on First Trimester Loss)

This kind of reflective listening was appreciated by one participant especially, when the way that she and her partner referred to their baby changed in the aftermath of his death, and their Bereavement Midwife noticed and asked if they would like her to follow suit:

> 'I think she picked up on how we were talking about him, and **she very much takes our lead** so like when we originally had [name] we wanted to call him [nickname] (…) you know that's what we always wanted to call him when we were pregnant and so on. And we were referring to him as [nickname] and then there was a bit of a shift in that, like actually he wasn't here for long enough to have a nickname, so it sort of reverted back to [name]. **And she (…) watched us sort of go through that process and then very discreetly said, "Would you like me to refer to [nickname] as [nickname] or as [name]? 'Cause I want to make sure that I'm using the correct…", so she's very much tapped into how we've been talking about him'** (Lived experience participant T002.2, from a Listening and Discussion Group on TFMR)

Some participants also highlighted the benefits not just of reflective and responsive listening, but also of healthcare professionals asking them explicitly what their preferred language was, for example:

> 'When people **used more personalised language or asked me what language I preferred (including a counsellor I saw) it helped me to feel seen**, understood and that my losses mattered' (Lived experience participant W251, from a written contribution to the grouping questionnaire)

> '[I]n my sort of booking-in appointment [for a pregnancy after loss] um the midwife there was **fantastic, and she was really aware. And she was asking me the terms that I would like to be used and things. And that was, you know, that was really appreciated**' (Lived experience participant S001.4, from a Listening and Discussion Group on Stillbirth)

> '[S]ome of the people that we got to know that were the best, **some of them asked us what language we preferred. I think that's always a really good way to start something, it's like, "I know that you've had a loss and we're so sorry for the loss of your daughter [name]. How would you prefer that we refer to it? Do you want her to be referred to as [name]?". And you know, that is helpfu**l' (Lived experience participant S001.2, from a Listening and Discussion Group on Stillbirth)

Similarly, several participants noted the importance of reflecting the families' linguistic preferences in written correspondence, citing poor practice by their local hospital and, in one case, good practice by the Tommy's Maternal & Fetal Medicine Centre in Manchester:

> '[Correspondence from our local hospital was] all very clinical and partially worded. And then I have a letter from St Mary's Hospital at Manchester, from their Rainbow Clinic, which is funded by Tommy's charity. **And it's come from their consultant and [name]'s name is all over that letter. Not once as he referred to as *a stillborn* or as *a baby that passed away*. It's just his name**. And if it can be done from one hospital, like why can't it be done from another?' (Lived experience participant S001.1, from a Listening and Discussion Group on Stillbirth)

Other participants noted that they were not given an opportunity to express preference, but would have liked to have been asked how they wished their experiences to be discussed and framed:

> 'I think there's maybe a bit of a, "How would you like us to discuss it with you?", rather than just making the assumption that the right thing is to call it *products of conception* or *tissue* or whatever it might be. Almost having a bit of an open dialogue, because it wouldn't really take that long to gauge for each person what they wanted. It's a…it's a 5-minute conversation out of a…potentially a consultation that lasts (…) we were sat around for hours going through paperwork, all of the consent forms, we were offered things like a memory box and various other things. **It wouldn't have taken long in in that consultation to actually gauge what language was appropriate for myself and my husband in that situation**. And [that] then makes it, it is making it a bit more of a holistic, tailored approach and I appreciate that takes more time and medical professionals are very busy. But it's something that needs to be handled so sensitively that I just think actually for the time that it would take, you could make it a much better experience for someone' (Lived experience participant F001.3, from a Listening and Discussion Group on First Trimester Loss)
>
> '[I]t would be nice for the nurses, or whoever's taking care of us at that point, to offer that to us. **To say, "Right, before anything…before we continue, how would you like us to refer to baby's…the death, everything?". That would help**, maybe' (Lived experience participant M001.2, from a Listening and Discussion Group on Second Trimester Loss)

As noted in the Note on Language (p.4), most lived experience participants in the EStELC project conceptualised their loss(es) as bereavements and their babies as babies. However, this was not universal and is likely to be overrepresented in the self-selecting sample used in this project. One lived experience participant who had been through TFMR felt that use of *baby* and *parents* during her delivery had been hurtful and unnecessary:

> ‘Our midwife I had overnight – 'cause it obviously took a really long time – she kept telling me, “It's time to push the baby, he’s coming!” I’m like, “**Can you stop saying ‘the baby’s coming’? There's no baby coming.** Just say like, ‘It’s happening, you need to push now’, that's fine.” (…) I was so annoyed at her (…) like, I know you've got other people [to look after too] and there's really exciting things happening, **but there is no baby coming for me**’ (Lived experience participant T002.3, from a Listening and Discussion Group on TFMR)

> ‘That was one of my worst experiences and one of my least forgivable actually. Because **I really tried to make it clear, and [she] kept telling me I was a parent. And my husband was like, “We're not. Don’t refer to us as that, we’re already sad enough. I don't need that**.”. We don't (…) feel like we want that label but like I totally get other people totally do, but we don't want it and there was just no asking us how we wanted to be referred to’ (Lived experience participant T002.3, from a Listening and Discussion Group on TFMR)

The same participant also felt that her choice not to refer to a *baby* was not respected by her Bereavement Midwife in the weeks and months after her TFMR, and emphasised the importance of asking families what kind of language they would like, respecting their stated preference, and letting them know that changing their mind subsequently is fine:

> ‘I think asking me first would just [have made] such a big difference. Because I totally get that I might be more on the 25% that don't like this kind of terminology but I…**I think the asking solves a lot of the language questions**. I think if you could ask me what language I like, well (…) I genuinely think if I were just given a few more choices and questions and asked what I like and even given options, “I can refer to this, refer to…use this. Which would you prefer?” […] **Our counsellor does that a lot more…or she sounds you out a bit more, unlike our bereavement midwife. [Our counsellor] was a lot more kind of tuned in she understood quite quickly what we’re like but I just think, “Well just ask me!”**’ (Lived experience participant T002.3, from a Listening and Discussion Group on TFMR)

Whilst several words or phrases attracted something which approaches consensus in terms of its negative evaluation by EStELC lived experience participants (*miscarriage, incompetent cervix*), this project lacks the scope to claim that such consensus is representative. The project dataset also revealed variation, which often related to words such as *baby* and *fetus* which reflect the assignment or denial of personhood. Whilst the majority of lived experience participants rejected dehumanising labels for their babies and strongly preferred the word *baby* and other humanising language to describe losses at all gestations, other participants, like T002.3 above, stressed that it was unhelpful to them to hear *baby*:

> 'My first loss was at almost 10 weeks but the fetus had stopped growing at about 5.5 weeks. It was a missed miscarriage. **The doctor kept referring to it as a *baby*. I didn't find that helpful at all. It wasn't a baby at 5.5 weeks to me, it was a *fetus***. Not even that, it was still an *embryo*.' (Written contribution W307, from lived experience grouping questionnaire)

Since this research is qualitative in design, it is not possible to assess how widespread preference for language which does or does not humanise is at different stages of pregnancy. EStELC's sister project, Supporting Policymakers to Negotiate Communicative Challenges around Pregnancy Loss (SuPPL), which is larger in scale and quantitative in research design, may allow such evaluation to begin. The EStELC project also revealed larger patterns of variation in preference, including one particularly salient pattern relating to use of euphemism, by contrast with direct statements of fact. Such strategies for discussing experiences of pregnancy loss proved divisive, with many participants reporting euphemism to be a helpful way of talking about painful events less directly:

> 'I think, like you say, **it's a bit gentler for me to say *born sleeping* or *lost*. That just helps** me' (Lived experience participant M001.1, from a Listening and Discussion Group on Second Trimester Loss)
>
> 'I think ***born sleeping* and *loss* helps me** as well' (Lived experience participant M001.2, from a Listening and Discussion Group on Second Trimester Loss)

Some participants were explicit that their preference for euphemistic ways of describing their experiences or their babies resulted from a desire to avoid using words related to death:

> **'[I]t's so tricky, isn't it, to say like they like *died* or *dead*?** Those are such hard words that they don't…they don't always feel right either, do they? Well I mean I'm…I'm being presumptuous, but for me they (…) you know, **it took me a long time to say, "He died", because it's just so hard**, and we're talking about a tiny, tiny baby. It just doesn't feel right' (Lived experience participant S001.3, from a Listening and Discussion Group on Stillbirth)

> '**I prefer to say she's not here 'cause I I just can't stand *loss*, *death*, *died*.** I just can't deal with it' (Lived experience participant S002.1, from a Listening and Discussion Group on Stillbirth)

By contrast, others expressed a strong sense that words such as *loss* obscured the difficult truth of their experiences in a way that was not helpful:

> '[P]eople have different preferences but **I was like, 'Don't say that *they're lost* or that *they're born sleeping,* just say *they've died*'** (…) I don't know, that felt really important to me, to like have that kind of a factual…I don't know, I think for me saying they've died carries the implication that they were alive if that makes sense? There's some kind of like strong, yeah, link: "But they died, you know, so of course you have a funeral, and of course you'll, you know, I don't know, want to see them, and of course this…". And they're not just kind of like…lost' (Lived experience participant M001.3, from a Listening and Discussion Group on Second Trimester Loss)

Some participants felt that euphemistic use of language to obfuscate and avoid words such as *death* benefited other people and not the bereaved family:

> 'I strongly disliked the euphemisms that lots of people use - either ones that are overtly medical like 'removal of the evidence of the pregnancy', which was used by staff at the abortion clinic, or 'cutesy' ones used in the baby loss community like

> 'born sleeping'**. I think they are often more for other people's comfort not yours - they don't like to confront the idea of your baby dying**.' (Written contribution W322, from lived experience grouping questionnaire)
>
> 'I think there was sort of two difficult experiences which really stood out for me. One was in discussions I've had with my GP afterwards, and they've used the term pregnancy ended, they just said, "pregnancy ended". And I mean it's technically correct, but (…) **I could just feel they were avoiding saying, "Your baby died". And I…I really wanted them to say, "You lost your baby", rather than, "pregnancy ended", because that sort of acknowledges that she was a person** rather than it was a process that came to an end' (Lived experience participant S002.1, from a Listening and Discussion Group on Stillbirth)

Other participants reported that euphemistic language had led to communicative challenges and even obscured their understanding of what was happening:

> 'I found that the balance was not struck between clear medical language and sensitive human language - when in hospital for surgery on both occasions, overly clinical language felt insensitive to my loss. However, **I also experienced confusion when attempts to be sensitive created ambiguity in terms of what was actually happening** in my body and to my pregnancy.' (Written contribution W307, from lived experience grouping questionnaire)
>
> '[The consultant] said things like, "Just (…) let nature take its course". And I remember at that time looking at my husband, saying, "What is she talking about?". Like, she was right there, and I was literally saying, "What is she talking about? Because she's not…my baby hasn't died. I don't know what's going on! What does nature take its course…? Explain?". Like, and **she was kind of talking in riddles, so that doesn't kind of sit well. I would just prefer someone that was straight-talking, saying, "Look, there's a chance your baby might die", and just using terms which I could understand instead'** (Lived experience participant M001.2, from a Listening and Discussion Group on Second Trimester Loss)

As will be discussed in Section 4, few lived experience participants reported feeling able to ask that their language preferences be respected by those involved in their care. Disappointingly, of those that did feel confident enough to make their preferences known, some participants reported that their stated preferences had not been respected, especially in the context of formal procedures and correspondence, where templates are used:

> 'It's in the investigation afterwards, the PMRT [Perinatal Mortality Review Tool] process afterwards, the sort of letters you get from the hospital afterwards. That's when it becomes more clinical instead of less, like, empathetic and compassionate and understanding. We went through the Health and Safety Investigation Board process, and one of the first things I said to them when I went to the doctors, when they came to see us within a week of her the passing, the loss…they were talking to me about "my birth". And I told them I didn't like them using *birth* for [name], because that created trauma for me. Because I found, like I…you know [older child], he was fine, he was born, we got a birth certificate for him. We only ever got a death certificate for [name], so I just didn't like the use of *birth* in the context. So H&S were quite careful when I was interviewed to try and change the terminology throughout. **But the paperwork comes through and it's just standard, "[W]e will just refer to *birth* in terms of discussing her…delivery" and I'm like, "Can't you change the standard template if you know that that's a word that's triggering to me?".** It's just like, where's the flexibility, you know? How do you deal…with a system that's not willing…? Like, "This is the template, this is what we use". **I think everyone's different. There might be a triggering word that's different for everyone,** and when I sort of went through my reasoning and explained to people why, they went, "We've never thought about that in the context of talking to someone about their loss before, perhaps not using the word *birth,* and using the word *delivering.*" Like, "Maybe we should think about that". But it's just…yeah, I think it's that, that clinical side where they have standard templates, when they're filling in standard things, that maybe the templates need changing' (Lived experience participant S001.2, from a Listening and Discussion Group on Stillbirth)

As this participant notes, and as this section has demonstrated, there is of course considerable variation in the language individuals find acceptable and unacceptable for use in the context of pregnancy loss, and what is helpful for one person may very well be triggering for another. This was acknowledged by other participants, one of whom suggested that the lack of public discourse about individual preference outside healthcare settings contributes to social uncertainty around pregnancy loss.

> 'People were afraid to speak to me most the time about it. They would acknowledge it, but I don't think they knew the correct…**even my friends didn't really know the correct language to use and what I wanted to hear.** I think it's kinda just…I think it's never, **you're never going to find something that suits everybody**' (Lived experience participant S002.3, from a Listening and Discussion Group on Stillbirth)

As this section has shown, the truth of this participant's observation that "you're never going to find something that suits everybody" is borne out strikingly in the EStELC project data. The variation demonstrated here adds weight to participants' calls for some kind of formal mechanism which would allow them to state their language preferences explicitly, for example:

> **'I think that would be really helpful some kind of [language] guidelines (…) We could sit with it for 10 minutes, as me and my husband, and just go, "What do we want to be called?"** (…) I think it would have also given me and my husband a good chance to sit and discuss it ourselves before it happened, 'cause I also think like it's all so hectic like maybe we needed the opportunity to have those 10 minutes on how are we going to approach this?' (Lived experience participant T002.3, from a Listening and Discussion Group on TFMR)

Several other participants also noted that they would have liked the space and opportunity to reflect on the language that they wanted to be used, as a means of deciding upon and beginning to process their own conceptualisation of the events occurring:

> 'I wish **I'd had that time to, like, process those sort of things** because there was so many different words being thrown around in that bereavement delivery suite that

> my head was just spinning' (Lived experience participant M001.1, from a Listening and Discussion Group on Second Trimester Loss)

The kind of form an intervention introducing such a mechanism could take will be discussed in Section 4, as will the overall conclusions that can be drawn from the EStELC project, future directions for this topic of research, and the strengths and limitations of the research presented here.

4. Conclusions

To some, it may seem a stretch to say that the language we use to talk and write about the often-traumatic experience of a baby dying during pregnancy can play a significant role in determining just how traumatic that experience is. Yet the EStELC project findings outlined here have shown that for many going through such experiences, it is indeed the case that language made their experience harder or, in a minority of instances, easier to cope with. Via the participant contributions highlighted in Section 3, above, the project has begun to answer the first 3 of the 4 questions it set out to ask:

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.

Participant contributions make clear that language truly matters and 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. This seems to be because language is a proxy by which we can understand the potentially very different ways of conceptualising the experience of losing a baby during pregnancy, and the baby themselves. Any language which contravenes, contradicts, or rejects an individual’s conceptualisation of their experience and baby can therefore, as highlighted in Section 3.2.4, be distressing and invalidating. With this in mind, the purpose of this section is to answer question 4 from Figure 1, and consider how the findings presented above can be translated into impactful strategies for improving experiences of pregnancy loss in future. As noted in Section 3.3., the cornerstone of any such strategies must be respect for, and accommodation of, individual preference.

4.1. Accommodating and respecting preference

As discussed at length in Sections 3.1 and 3.3, the past decade has seen growing emphasis placed on the importance of ‘reflective listening’ across all healthcare specialties, with its particular importance in pregnancy loss contexts also noted (Braillon & Taiebi, 2020; Brann & Bute, 2017; Meluch, 2022; Royal College of Midwives, 2022). However, the significant degree of variation in individual preference demonstrated in the participant data presented in Section 3.3, as well as the role language plays as a proxy for conceptualisation of pregnancy loss experiences, can make reflective listening in these contexts particularly challenging. These factors also make reflective listening around pregnancy loss a particularly high-stakes endeavour, in the sense of the damage that can be inflicted where misalignment occurs between the language an individual is exposed to, and their own conceptualisation of their experience or baby. Several healthcare professional participants acknowledged this, and made clear the challenges of listening reflectively about pregnancy loss:

> 'If parents aren't speaking first, it can be hard to know quite how to approach language because no two parents are the same in how they would refer to their loss. And what's right for one person might not be right for another. And I think we as professionals, counsellors, midwives are **often the ones perhaps starting the conversation and that can be quite a…you need to navigate quite carefully sort of using language that you hope [won't cause distress]…'cause I have had an experience that I use the word *baby* and someone was upset that I'd used the word *baby'*** (Healthcare professional participant H002.3, from a Listening and Discussion Group on pregnancy loss aftercare)

With this in mind, the principal recommendation arising from the EStELC Project is that healthcare professionals prioritise not just reflective listening but also eliciting from people their preferences, by asking people experiencing pregnancy loss how they conceptualise what is happening, or what has happened, and being guided by their responses. The examples of good practice highlighted in Section 3.3 demonstrate that this is already being done in some settings, for example:

> '[I]n my sort of booking-in appointment [for a pregnancy after loss] um the midwife there was **fantastic, and she was really aware. And she was asking me the terms that I would like to be used and things. And that was, you know, that was really appreciated**' (Lived experience participant S001.4, from a Listening and Discussion Group on Stillbirth)

> '[S]ome of the people that we got to know that were the best, **some of them asked us what language we preferred. I think that's always a really good way to start something, it's like, "I know that you've had a loss and we're so sorry for the loss of your daughter [name]. How would you prefer that we refer to it? Do you want her to be referred to as [name]?". And you know, that is helpfu**l' (Lived experience participant S001.2, from a Listening and Discussion Group on Stillbirth)

However, contributions from lived experience participants presented in Section 3.3 also showed that this kind of elicitation of preference is not the norm in healthcare settings at present. This is especially problematic in instances where someone's language preferences and conceptualisation of what is happening is not what a healthcare professional assumes:

> 'Our midwife I had overnight – 'cause it obviously took a really long time – she kept telling me, "It's time to push the baby, he's coming!" I'm like, "**Can you stop saying 'the baby's coming'? There's no baby coming.**"' (Lived experience participant T002.3, from a Listening and Discussion Group on TFMR)

The assumption that someone going through TFMR will conceptualise their delivery as the birth of a *baby* may reveal a phenomenon of 'cultural reflective listening', whereby what is considered the 'norm' for conceptualising a TFMR experience (whether correctly or not) is unthinkingly imposed by a healthcare professional. This can be damaging in cases such as the one described above, and underscores the vital importance of eliciting the language preferences of an individual or couple, and not making assumptions.

For some lived experience participants, the risk that language might be used in a way that was unacceptable to them, or which might be at odds with their conceptualisation of what was happening or had happened, led them to make their own preferences explicit and to insist on particular words and phrases. As noted in Section 3.3, this did not always result in the desired outcome, as for participant S001.2, whose request for *birth* not to be used was ignored:

> **But the paperwork comes through and it's just standard, "[W]e will just refer to *birth* in terms of discussing her…delivery" and I'm like, "Can't you change the standard template if you know that that's a word that's triggering to me?".** It's just like where's the flexibility, you know? How do you deal…with a system that's not willing…? Like, "This is the template, this is what we use". (…) I think it's that, that clinical side where they have standard templates, when they're filling in standard things, that maybe the templates need changing' (Lived experience participant S001.2, from a Listening and Discussion Group on Stillbirth)

Without any kind of formal infrastructure in place, and where those experiencing pregnancy loss do not feel able to assert their language preferences, the onus for preference elicitation is currently on individual healthcare professionals. As such, several participants in different Listening and Discussion Groups suggested that formal infrastructure to support preference elicitation would be helpful.

> ‘**[W]here's the bit where somebody gives you a choice of language and uses that?** (…) It would be different if it's a midwife in later pregnancy, [who] could be very individualised to you. But like I've been, before and after giving birth to the twins (…) in and out hospital with various things, for scans and stuff and you always have a different person every time, apart from there’s a few nurses that I know very well but (…) it's not practical to have a long conversation with each healthcare person…[so] **why don't they just give you (…) like a little form and say, “This is completely optional but would you like to write down…? This is, like, a birth plan form, a second trimester birth plan form,” or whatever. And you could just say, or you could tick it, or whatever like how you want to refer to these things. Like, that could be standard and that could then kind of clear up all the languagey bits**’ (Lived experience participant M001.3, from a Listening and Discussion Group on Second Trimester Loss)

> ‘Me and my husband have been discussing this. It's like, you know how on the bottom of emails now lots of people have put their pronouns? **Like, 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’** (Lived experience participant T002.1, from a Listening and Discussion Group on TFMR)

> ‘When it’s at the end of your pregnancy they give you options, like a birth plan (…) but you know I kinda think **it would be great if you can have that from the beginning, you can have a plan just to say how you can call your baby’** (Lived experience participant F002.4, from a Listening and Discussion Group on First Trimester Loss)

> 'I feel like we should be given an option (…) "What language would you like?" 'Cause some mothers might not like the word *baby*, [that] might be too triggering for them**…"Before we start having a conversation around your loss," you know, "How would you like to reference your pregnancy?" That's it.** Yeah, 'cause what you might want might be entirely different to what I want, so maybe give us the choice' (Lived experience participant F003.5, from a Listening and Discussion Group on First Trimester Loss)

Such calls, from lived experience participants who had experienced pregnancy loss at a range of different gestational ages, reveal an apparent appetite for opportunities to state language preferences via some kind of official mechanism. Encouragingly, one healthcare participant reported a local initiative to provide this sort of official mechanism, which is in place at the Royal Berkshire NHS Foundation Trust:

> '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**. So, we still have to use certain language to communicate across teams, but we also have a version of a family's story in the mix as well, which they have felt at the beginning of their journey. They can tell us, you know, "This would help," and, you know, (…) that does help … [It's] a trust initiative, it came from working with families and feedback that communication wasn't good, that communication within the pregnancy after loss [team] was really good because we're a pregnancy after loss team, but if you get someone in for a scan [you can't always be there in person] and we were like (…) "We need to ensure that [continuity of communication]", so we introduced it on digital records, so we invite all families to, if they want to, and most do, to complete it and um then it pops up on their…when people open their record' (Healthcare professional participant H002.3, from a Listening and Discussion Group on pregnancy loss aftercare)

Whilst rolling out this kind of preference elicitation initiative nationally would be challenging, given that different NHS Trusts use different medical records software and have different administrative systems, this healthcare professional's testimony as to the value of this system makes a compelling case for attempting to implement a similar procedure nationally. This case is, moreover, strengthened by the desire expressed by lived experience participants for this kind of framework, which would allow them to make clear how they conceptualise their experiences and their language preferences, and to feel more confident that these preferences would be accommodated and respected. Whilst the EStELC project data strongly suggests that such an initiative at a national level should be a long-term strategy for mitigating the impact of language on experiences of pregnancy loss, there are also some short-term recommendations that can be made on the basis of the gathered data. These will be outlined in Section 4.3. Firstly, however, the importance of the EStELC project's role as a simple consciousness-raising exercise will be discussed in Section 4.2.

4.2. Raising awareness

Until now, we have lacked any cohesive dataset which demonstrates what has long been suspected, and what many have experienced: language around pregnancy loss can and does play a decisive role in determining how people feel about their experience and their baby. Thanks to the generosity of lived experience and healthcare professional participants, the EStELC project has developed such a dataset. It is now hoped that the recommendations for clinical interactions this dataset yields, which can be found in the following section, will begin to ensure that language does not inflict further harm during and after what is very often an extremely traumatic time of people's lives. Of course, these concrete recommendations will not immediately be enacted in all, or even most, clinical settings dealing with pregnancy loss in the UK. It is hoped, however, that the testimonies and analysis presented in this report will play a much-needed role in highlighting language as a potentially significant determinant of psychological wellbeing for any individual experiencing pregnancy loss.

4.3. Recommendations

The findings outlined above show very clearly that language can be harmful when someone experiencing pregnancy loss is exposed to language which does not reflect their conceptualisation of the experience and/or their baby. Echoing research in this domain (Braillon & Taiebi, 2020; Brann et al., 2020), the most rudimentary recommendation arising from the EStELC project relates to awareness:

Recommendation 1: Be aware that language matters

Be aware that how language is used plays a key role in experiences of pregnancy loss, and take linguistic cues from the person you are caring for

Language can compound feelings of guilt and self-blame, as explored in Section 3.2.1, or a sense of stigma, as explored in Section 3.2.2. It can disenfranchise grief, and fail to convey the gravity of an experience in a way that seems adequate to the person who has experienced it, as we saw in Section 3.2.5, and it can seem "cold and cruel" when biomedical terminology is used where personal language is expected, as explored in Section 3.2.6. As such, the language used in the context of pregnancy loss emerged from the EStELC project as much more than just a medium for conveying and receiving information. Instead, it often became the mechanism through which someone's fraught and fragile conceptualisation of their experience and their baby was either endorsed by the outside world, or, more often, by which it was undermined or dismantled. As outlined in the previous sections, therefore, the second, and principal, recommendation for healthcare professionals arising from the data gathered during this project is therefore to go beyond 'reflective listening', where necessary, and to practice active preference elicitation:

Recommendation 2: If in doubt, ask

Ask how someone wants you to talk or write about their experience and their baby. This gives you a 'key' to how they conceptualise the experience and the baby, and allows you to choose language which aligns with their conceptualisation.

You might say:

> "Can you tell me in your own words what has happened so far?"
> "Did you give your baby a name?"
> "I can see that you experienced a loss previously. How would you like me to refer to that experience?"

As outlined above, exposure to the language of official documents which contain 'difficult words' such as *products of conception, abortion, termination,* or *feticide,* is sometimes unavoidable. Substitution of such language, which often plays important clinical or legislative roles, would be a challenging and lengthy process. However, the EStELC dataset highlights the value of framing which mitigates the impact of such 'difficult language', as well as the fact that this kind of framing device is more often used where a loss has occurred at a later gestational age. A third recommendation arising from the project is therefore to use such framing to diminish the impact of language that might cause distress wherever possible:

Recommendation 3: Use framing to mitigate difficult language

Once you know how someone conceptualises their loss and their baby, consider using framing to mitigate the impacts of exposure to 'difficult language'.

You might say:

> "The technical name for this procedure is *Termination for Medical Reasons*, but what that means is…"
>
> "This procedure is to remove what we call the *products of conception*, which means your baby and any other pregnancy tissue that is still in your uterus"
>
> "You are having what we call a *missed miscarriage*, which means that there were no signs that your baby had died. It doesn't mean that you missed anything, or that you could have done anything differently"

On the other hand, the project data also showed clearly that clinicians' and others' attempts to reframe experiences which challenged or undermined stated preferences could be very damaging and hurtful. A fourth recommendation therefore relates to the need to avoid using framing devices to contravene someone's stated conceptualisation of their experience or baby:

Recommendation 4: Avoid challenging or undermining stated preference

Do not use framing to contravene someone's clearly-stated conceptualisation of their experience or baby. This includes using dehumanising language where you know that a baby has a name:

Do not say:

> "You might find it easier if you don't think of it as a baby who has died, but a pregnancy that has ended", if someone has said that their baby died
>
> "You experienced a stillbirth at 40 weeks", if someone has told you their baby's name
>
> "We have sent it off for analysis", where 'it' is someone's baby
>
> (Examples adapted from participant testimonies)

These recommendations may begin to help ease the challenges reported by both lived experience and healthcare professional participants in the EStELC Project. However, the significant challenges reported by participants highlight an urgent need for further research in this area, as will be outlined in the following section.

4.4. Future work

There is a clear need for further research on use of language around pregnancy loss, both in the UK context and beyond. As noted in Section 1, above, there is in particular a clear need for a strategy which distinguishes between contexts where language can be individualised, as in clinical settings, and contexts where mass communication is necessary, as in public health information and policy documents, where a standardised lexicon that minimises harm is needed. The recommendations arising from the EStELC project (see Section 4.3) are aimed at developing a trauma-informed framework for supporting individual language preference in clinical interactions during and following pregnancy loss. At present, these recommendations are aimed at individual clinicians who may consider implementing active preference elicitation and using language as a key to an individual's conceptualisation of their experience, where this is not already their habit. Future translational work to develop a national framework to support this approach, such as the existing Trust-level 'Know our Story' initiative described in 4.1 above (p.100) may be key to ensuring that this evidence-based recommendation can be implemented as widely as possible.

The EStELC project was never intended to gauge usage and preference at a representative level, using an empirical research model, and to extrapolate these findings in the hope of finding a clear, cohesive, standardised set of terminology for pregnancy loss. Research which does aim to do this is, however, ongoing within EStELC's sister project SuPPL (Supporting Policymakers to Negotiate Communicative Challenges around Pregnancy Loss). The findings of this project, to be published in late 2024, will be used to inform recommendations on language which can function optimally in mass communication contexts across the necessary domains of public health and policy in the UK, maximising clarity and comprehensibility whilst minimising harms.

The EStELC project dataset also highlighted other work around pregnancy loss communication that is sorely needed. Firstly, it highlighted a need for joined-up communication systems within the health service. This is an issue that could be explored in any translational research following on from EStELC, which considers how language and conceptualisation preferences are shared between healthcare settings. However, the lack of joined-up communication systems, exacerbated by differences between administrative systems in different NHS Trusts and variation in use of different medical records software packages, presents a very significant challenge. EStELC participants particularly highlighted ineffectual communication between hospital and primary care settings:

> ‘I went for a smear [test] and the nurse at the time was just making conversation, she was like **“Oh so you have children?” So I said, “Yes, I have a son that passed away.” And she said, “Oh no…when was that?” And I was like, “Last year, he was stillborn,” and just saying the words out loud, I just burst into tears in the middle of having the smear** (…) She could not stop apologising and (…) she ended up crying herself, which didn't help me, but (…) she should have read the notes before going into that really and she didn't’ (Lived experience participant S001.1, from a Listening and Discussion Group on Stillbirth)

> “When I had to ring to book in my six-week check after [name was born], [Bereavement Midwife] said it will be on the screen, it’ll pop up. So I like psyched myself up to ring and I've booked it in and the lady said, **“Oh do you need to bring your baby with you?” And I just (…) literally crumbled’** (Lived experience participant S001.4, from a Listening and Discussion Group on Stillbirth)

Such experiences speak to the need for systems which clearly flag the experience of pregnancy loss, in order to provide a healthcare space that feels safe for people traumatised by their experience. This was also a need voiced explicitly by lived experience participants:

> ‘One of the most important things I [fed back to my Trust] is that you need to read notes (…) If you're dealing with people that are coming in that have suffered a trauma, just by being prepared, you can just make their experience so much better by being prepared (…) **I said so if you have a patient that you've booked in for appointment that you know has suffered a loss, put that right in the front of the notes.** Put it in the appointment notes, put it somewhere that the doctor who's looking at it. I mean my husband [a medical doctor] says when he's doing clinics, he's like, “I don't always get a look at everything, but I generally look at like the last clinical letter that was down or something like that, or summary.” That's where things like that should be’ (Lived experience participant S001.2, from a Listening and Discussion Group on Stillbirth)

Other participants raised concerns about digitisation and the risk that paper-based systems with mechanisms developed to flag previous experiences are being replaced with digital equivalents, without consideration of how previous experiences can be flagged:

> 'With this pregnancy, because [in our Trust] you don't have your blue book [pregnancy notes] anymore, and before they put a big sticker on the front so that people were aware. And now it's all apps and stuff, so **I asked if there was a way that would flag up easily, that even if it just said you know like, "You need to read the notes," or something that was quite obvious. And they said it's something they were looking into, but it kind of blew my mind that they transitioned to a new way and not thought about that aspect of things!** It's scary' (Lived experience participant S001.4, from a Listening and Discussion Group on Stillbirth)

Lived experience participants also highlighted that increasing reliance on digital systems also presents additional risks of exposure to clinical language not intended for patient consumption, which can be distressing:

> 'I found on my pregnancy notes (…) even after I'd given birth, they were being updated and stuff [with] exchanges between my bereavement midwives and different consultants and things and like updates on when she come to see me in the house and when she checked in and stuff. **And everything that was updated [was] all in like code, and I get that's between them so maybe I shouldn't have seen some of the stuff that they've written. I was like, "I don't really need to see that, it's quite harshly worded" (…) it's clinical**, all the codes that you understand and I don't understand what you said' (Lived experience participant S001.1, from a Listening and Discussion Group on Stillbirth)

Although beyond the scope of the EStELC project, therefore, the project dataset did flag issues relating to communication after pregnancy loss that warrant urgent consideration. Likewise, though also beyond the project's scope, its dataset raised questions as to the communication of risk around pregnancy loss, and the ways in which such communication can exacerbate, externalise, and legitimise feelings of guilt and self-blame. As Jennie Agg has noted, "[i]t feels confusing, to put it mildly, when you are so often told 'it's nothing you did' after a miscarriage, only to be presented with a list of things that relate to what you might have done, or what you can't control, like your age" (2023: 145). Future research should explore the ramifications of communicating risk of pregnancy loss, and the impact such communication has on wellbeing after pregnancy loss and in any subsequent pregnancies.

Looking beyond scope for future research, the project also highlighted a clear appetite amongst both lived experience and healthcare professional participants for training and guidance for clinicians in using language around pregnancy after loss:

> 'Midwives and **hospital staff need to know how to support and the right language to use in pregnancy after loss** (…) Hospital staff from receptionists, midwives, sonographers, consultants should receive some kind is training in support.' (Written contribution W144, from lived experience eligibility questionnaire)
>
> '[Even as a specialist,] I can find it quite challenging sometimes, to give that clear explanation to a woman about exactly what's going on. And (…) **perhaps sonographers need to have more training in how they break that and how they explain that**. Because they're potentially the first people to let these women know. I think often it's that first terminology or experience that sticks with women, you know that moment when they found out. And also midwives probably need more training in it as well to support' (Healthcare professional participant H001.2, from a Listening and Discussion Group on providing care during pregnancy loss)

Another healthcare professional participant highlighted the discrepancies between different types of healthcare setting and the language used within each:

> 'If you've fought enough and got, in your area, a pregnancy unit that is open all of the time (…) a dedicated path (…) the terminology used can be more empathic and compassionate. **If you come through a department where the pregnancy wards aren't open or emergency units (…) often, depending on who's on shift they**

> **won't know themselves what phrases or terms or terminology to use.** And it can be really…you know, you might be working with an individual in the future who can't touch the loss [in counselling] because of the words they've used and the anger over the terminology distracts from the fact that they've lost their baby, their world's fell apart' (Lived experience participant H002.4, from a Listening and Discussion Group on pregnancy loss aftercare)

As these contributions highlight, evidence-based consciousness raising and tailored communication training around pregnancy loss is needed. Working toward such training infrastructure is beyond the scope of the project, but it would be remiss not to highlight that its importance was voiced repeatedly throughout the project.

4.5. Strengths and limitations

This project is the first of its kind to consult people with bodily lived experience of pregnancy and those who care for them about how language impacts experiences of pregnancy loss.

The project was limited in terms of the time and resources available to it, and this resulted in pragmatic decisions being made during data collection. Only 10 Listening and Discussion Groups were feasible, and where some people did not attend as planned, we had to continue with those in attendance, resulting in a slight shortfall in the number of oral lived experience participants. Likewise, though we aimed for 4 Listening and Discussion Group sessions to be held with healthcare professionals, recruitment proved challenging and ultimately, we held only 2.

A further limitation relates to the project's narrow focus on British English. The use of 'difficult language' in pregnancy loss contexts is by no means restricted to the English language, and consideration of the impact of language in other linguistic contexts would be an extremely worthwhile undertaking. Whilst we were able to consider the impact of British English usage on some speakers of English as an additional language during the project and during this report, we were not able to draw any meaningful conclusions on this subject.

The project's core values of listening, inclusivity, open-mindedness, and empiricism guided the choices made throughout. The project was designed to balance rigour with open-mindedness, and to be as inclusive and expansive as possible, within its limited scope. The project has been characterised by complexity, nuance, disagreeing well, debate and reflexivity, and the Expert Advisory Group have played a key role in guiding, supporting and challenging the core project team throughout. Ultimately, the achievement of the EStELC project is a significant one; we have shown the impact language can have in experiences of pregnancy loss, supported those calling for change, and, we hope, amplified those calls.

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Appendix I: Expert Advisory Group Members

Member name	Member role and organisation	Symposia attended	
		Symp. 1	Symp. 2
Ali Brett	Bereavement Midwife, East Suffolk, North Essex Foundation Trust	Yes	Yes
Professor Alexander Heazell	Director of Tommy's Maternal and Fetal Health Research Centre, St Mary's Hospital, Manchester; University of Manchester	Yes	No
Dr Emily Cornish	Clinical Research Fellow, UCL EGA Institute for Women's Health	Yes	Yes
Jane Fisher	Chief Executive, Antenatal Results and Choices	Yes	Yes
Eloise Parr	Project Research Assistant, University College London	Yes	Yes
Karen Burgess	Chief Executive, Petals	No	No
Dr Katharine Williams	Project Co-lead representative; Research Editor at Tommy's	Yes	Yes
Professor Siobhan Quenby	Professor of Obstetrics, University of Warwick; Consultant Obstetrician at University Hospital Coventry and Warwick	Yes	No
Dr Beth Malory	Project Lead, University College London	Yes	Yes
Mehali Patel	Project Co-lead representative; Research Manager at Sands	Yes	Yes
Munira Oza	Chief Executive, The Ectopic Pregnancy Trust	Yes	Yes
Nina Parker	Clinical Research Fellow, Imperial College Healthcare NHS Trust	Yes	Yes
Oonagh Pickering	Lead Research Nurse at the Tommy's National Centre for Miscarriage Research, University of Birmingham	Yes	Yes
Rachel Roberts	Project Co-lead representative, Senior Research Manager at Tommy's	Yes	No

Rachel Small	Clinical Matron, University Hospital Birmingham; Chair of the Association of Early Pregnancy Units	Yes	No
Vicki Robinson	Chief Executive Officer, The Miscarriage Association	No	No

Table 1. EAG members and symposium attendance information.

Appendix II: Data sources

Data source	Number of participants contributing
Lived experience eligibility questionnaire, long form statements in response to the prompt, 'Why would you like to take part in this study?'	237
Lived experience grouping questionnaire, long form statements in response to the prompt, 'Are there any issues or events related to language and pregnancy loss that you would particularly like to share during this project?'	98
Healthcare professional grouping questionnaire, long form statements in response to the prompt, 'Are there any issues, topics, or events related to language and pregnancy loss that you would particularly like to discuss during this project?'	10
Lived experience participants in Listening and Discussion Groups	32
Healthcare professional participants in Listening and Discussion Groups	10

Table 2. Sources of EStELC Project data.

Accessing support

Sands provides trauma-informed support to anyone affected by the death of a baby before, during or shortly after birth.

Sands
Saving babies' lives. Supporting bereaved families.

Get support or find out more
[Support for you | Sands - Saving babies' lives. Supporting bereaved families.]

At Tommy's, we're here for everyone, no matter where you are on your pregnancy journey.

Tommy's
The pregnancy and baby charity

Tommy's midwives are available to support you via email or the phone, during and after pregnancy and loss, and our pregnancy and baby loss information and support resources are available whenever you need them at www.tommys.org.