Project Report

SuPPL

Supporting Policymakers to negotiate communicative challenges around Pregnancy Loss

Exploring strategies for implementation of an evidence-based approach to policy language

Acceptability in pregnancy loss language

Dr Beth Malory & Dr Louise Nuttall

November 2024

Foreword

The publication of the EStELC report in September 2024 (Malory 2024), following consultation with hundreds of professional and lived experience stakeholders with an interest in pregnancy loss language, was an important moment. It signalled that for the first time, real attention is being paid to the way we communicate about pregnancy loss in clinical settings, and the considerable impacts that communication can have on the lived experience of pregnancy loss. The EStELC report's recommendations acknowledged significant variation in the language needs of different individuals affected by pregnancy loss, as well as the healthcare professionals caring for them. Ultimately, therefore, the EStELC Project showed that a 'one size fits all' approach to pregnancy loss language in clinical settings is not possible: what one person needs might cause trauma to another. Translating these findings into a clinical framework which accommodates individual language needs is clearly a significant challenge, since it poses logistical and practical difficulties. There are other contexts, though, in which accommodating individual language needs is not just challenging but impossible. In mass communication, such as policy, websites, and leaflets- all media commonly used for public health messaging- acknowledging and respecting the individual language needs of any one person is clearly unmanageable. It is therefore vitally important that any work on pregnancy loss language takes a two-pronged approach: on the one hand, facilitating the implementation of a framework which acknowledges and accommodates the significant variation in language needs amongst those going through pregnancy loss, and on the other hand identifying language which is clearly helpful, or clearly unhelpful, in mass communication contexts. Whilst the EStELC report represents progress on the former 'prong' , the evidence and recommendations in this report begin to address the latter.

Beth Malory, November 2024

A Note on Language

The language used in this report reflects its findings. Whilst there will never be a 'one size fits all' approach to language in relation to pregnancy loss, an often life-changing and extremely traumatic event, it is important that we ascertain the kinds of language which are most and least likely to cause harm. Use of language like *baby* and *pregnancy loss* will not align with everyone's language needs, but they are used here because our data suggest them to be the least harmful options at this time. Much of the language considered in this report may be distressing, and its findings should be read with caution.

Introduction

The main aim of the SuPPL project was to identify any language used in relation to pregnancy loss in the UK that is particularly objectionable to people with lived experience of pregnancy loss and, conversely, any language that is acceptable. As noted in the Foreword above, this aim is distinct from that of the EStELC Project, which gathered qualitative data and aimed to amplify the voices of people with lived experience of pregnancy loss who felt that language had played an important role in their experience. That project found significant variation amongst lived experience participants in the language they found helpful and in the language they considered to exacerbate their grief and trauma (Malory 2024). The EStELC project therefore culminated in the recommendation that the individual language needs of people going through pregnancy loss be respected and accommodated in clinical settings wherever possible. Work to implement a clinical framework that can facilitate this accommodation of language needs is therefore ongoing.

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However, work also needs to be done in parallel, to ascertain how language can be optimised in contexts where pregnancy loss language cannot be individualised and cannot respect individual language needs, such as public health information websites or leaflets, and policy language. These so-called 'mass communication' contexts pose a more intractable problem in some ways than individual clinical interactions, since a 'one size fits all' approach has to be taken, regardless of the inevitability, as demonstrated by EStELC, that this will be difficult for some people. This project was designed to tackle this problem head on, taking a quantitative approach to exploring feelings about pregnancy loss language amongst those with recent experience in the UK.

Whilst EStELC findings show considerable variation, therefore, SuPPL Project findings show a consensus emerging about many words and phrases commonly used in the context of pregnancy loss in contemporary British English. In some cases, there is clear consensus that certain words and phrases are unacceptable. In other cases, particular words and phrases emerge as acceptable to a majority of respondents. There is also a category of words which prompt a mixed response. For all these categories, of 'unacceptable', 'acceptable' and 'mixed', the qualitative findings of the EStELC project provide useful contextualisation and complement the quantitative findings presented here. This is especially true where mixed attitudes emerge. Attitudes to the word *miscarriage* (see p.11) provide an example of this; whilst strong criticism of this word emerged during EStELC, SuPPL data shows feelings on it to be split, with no consensus emerging. This indicates, helpfully, that *miscarriage* may be an unhelpful word to many, but that for others it is neutral or even acceptable. In such cases, this report cannot make recommendations, beyond a general suggestion that use of such divisive words be considered carefully in mass communication contexts, unless a term that has similar or equivalent meaning is rated more positively. In the case of *miscarriage*, this is the case, since *pregnancy loss* proved more popular in the SuPPL dataset. Where such clear consensus on either the acceptability or unacceptability of a word emerges from the SuPPL dataset, this allows evidence-based recommendations to be made for use of language in pregnancy loss contexts in mass communication. These recommendations can be found on pages 17, 18, and 19.

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The Project

The aim of the SuPPL project is to evaluate the acceptability of pregnancy loss terminology and to make recommendations for usage in UK mass communication contexts, where clear consensus is reached. Data collection was conducted using a survey design comprising structured questions, hosted in the REDCap platform. Participants were asked about acceptability both in healthcare contexts, and in other settings such as their workplace or home, but the focus of this report is on the kinds of formal language used in healthcare settings. Broad consensus on unacceptability was considered to be reached if 50% of respondents on average rated a word/phrase between 1-3 on a 7-point Likert scale, where 1 was 'Totally unacceptable' and 4 was 'neutral'. Consensus on acceptability was reached if 50% of respondents on average rated a word/phrase between 5-7 on a 7-point Likert scale, where 7 was 'Perfectly acceptable' and 4 was 'neutral'. These 50% thresholds of broad unacceptability/acceptability are used to structure the presentation of the findings below, since they reflect a larger number of respondents rating a word or phrase as either 'unacceptable', or 'acceptable'/'neutral' than have done the opposite.

In order to be eligible to participate in this study, individuals must have experienced pregnancy loss in the past 3 years and have accessed healthcare in the UK as a result of pregnancy loss. The 3-year limit was intended to optimise accuracy of recall and to ensure current language usage would be reflected. The survey was begun by 664 people, but its length and the sensitive nature of the topic led to a high rate of non-completion. It was completed in full by 391 people; slightly exceeding the target sample size of >384 participants calculated to be representative. This figure was reached by extrapolating target population numbers from the estimated incidence of pregnancy loss in the UK in any 3-year period.

Participants were required to answer only questions relating to the language used around loss during the gestational 'bracket(s)' during which they had experienced loss in the past 3 years, or that were specific to a particular type of loss, such as ectopic or anembryonic pregnancy. The gestational brackets used to divide questions were 1-5, 6-9, 9-13, 14-17, 18-23, 24-29, 30-39, and 40+ weeks. Where participants had experienced multiple losses at different stages of pregnancy within the past 3 years, they were invited to consider each experience, and the communication surrounding it, separately. As a result, some participants answered multiple questions and hence rated terms on more than one occasion in the survey. This is why sample sizes for some terms (e.g. *baby* n=485) exceed the number of participants who completed the survey (=391). Consequently, all statistics in this report relate to the number of *respondents* to a given question, as opposed to the number of individual *participants,* where responses relate to individual experiences of pregnancy loss.

Losses in earlier gestational brackets are more common and hence such experiences received larger numbers of respondents. Thus, where gestational brackets are considered on aggregate, data have been weighted to prevent overrepresentation of the views of those in brackets with larger response rates. For example, *fetus* was rated by 137 respondents with lived experience of loss between 6-9 weeks of pregnancy, but only 71 respondents with lived experience of loss between 9-13 weeks. Using weighted averages ensures that none of the additional data points (each representing a participant) in the 6-9 week bracket, by comparison with the 9-13 week bracket, skew the average.

Ethical approval for SuPPL project data gathering was granted in May 2024 by the UCL Research Ethics Committee (Project ID 26991/002).

Findings

‘Unacceptable’ language

Of all the terms considered by this study, diagnostic phrases including *incompetence* or *incompetent* as modifiers for the anatomical labels *cervix* and *cervical* were the most consistently rated as ‘unacceptable’. The phrases *incompetent cervix* and *cervical incompetence* are used to refer to preterm shortening and dilation of the cervix, in the absence of uterine contractions or labour. Whilst there are both medical and surgical interventions to reduce the risk of pregnancy loss in such circumstances, preterm cervical shortening and dilation is often not detected until it is too late and is therefore thought to be associated with around 50% risk of preterm birth (Brown et al., 2023), including babies born so preterm that their likelihood of survival is very low.

Since this kind of preterm cervical shortening is associated with second and early third trimester births (Menderes et al., 2015) respondents with experience of losing a baby at 14-17; 18-23; 24-29; and/or 30-39 weeks were asked to rate the phrases *incompetent cervix* and *cervical incompetence.* As Figure 1 shows, ‘unacceptable’ ratings were very high, with a mean of 83.5% of respondents who had lost babies at these gestations rating these phrases ‘unacceptable’ for use in healthcare settings.

83.5% of respondents with experience of loss between 14 and 39 weeks rated *incompetent cervix* and/or *cervical incompetence* as ‘unacceptable’ for use in healthcare settings.

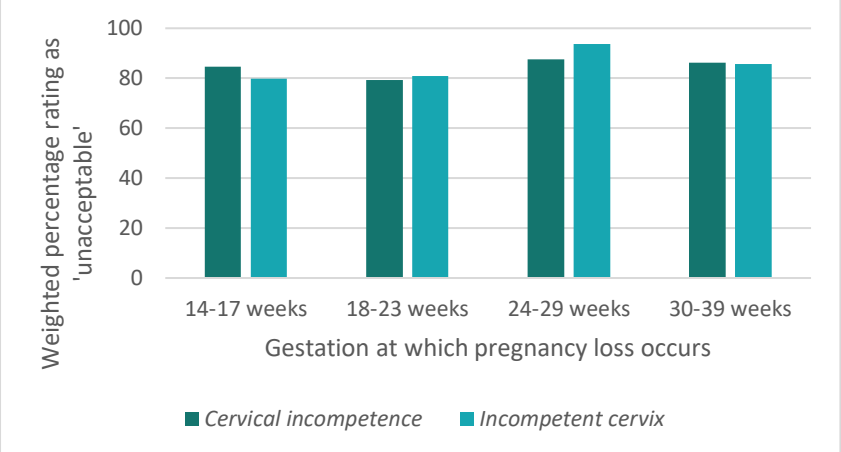

Figure 1. ‘Unacceptable’ ratings for cervical incompetence and incompetent cervix in healthcare settings for losses occurring between 14 and 39 weeks of

Phrases ascribing *incompetence* to the cervix have been acknowledged as offensive and potentially damaging for many years and have given rise to suggestions for substitutes. The most widely-used of these substitutes, *insufficiency* or *insufficient,* has been endorsed by some (e.g., Vimalesvaran et al., 2021), who perceive it as a less damaging way of describing the cervix. Others, however, have argued that there is little difference between being told that your cervix is *insufficient* and that it is *incompetent (*Johnson et al., 2020; Silver et al., 2011). SuPPL survey findings

appear to corroborate this, showing that *cervical insufficiency* had a mean unacceptability rating of 81.1% for use in healthcare settings between 14 and 39 weeks of pregnancy, with only 7.8% of respondents who had experienced loss at these gestations rating this phrase 'acceptable' to some degree, and 11.6% rating it 'neutral' (see Figure 2).

Other terms for types of loss that were overwhelmingly rated as unacceptable included:

- *Spontaneous abortion* was consistently rated unfavourably; 88.9% of respondents who had experienced loss between 6 and 23 weeks of pregnancy considered this phrase 'unacceptable' for use in healthcare settings (see Figure 3). Until the 1980s, *spontaneous abortion* was the technical term for pregnancy loss occurring before 28 weeks in the UK (Malory, 2022), and it is still used in this sense in other English-speaking countries around the world. Findings of the EStELC Project (Malory 2024) indicated that use of *abortion* in contexts of loss occurs mostly in research published outside the UK, and in UK clinical contexts by speakers of English as an additional language. Recollection of *abortion* being used in this sense was relatively rare in SuPPL data, peaking at 14.2% of the respondents, with lived experience of loss between 6-9 weeks of pregnancy recalling this phrase being used in healthcare settings. This may reflect its use, as discussed by EStELC participants (Malory 2024: 39), in documents and health information on surgical management for first trimester losses.
- *Miscarriage* was rated 'unacceptable' by 61.2% of participants who had experienced loss at 18-23 weeks of pregnancy. Despite the medical and legislative definition of *miscarriage* in the UK being pre-24 weeks' gestation, only 22.4% of respondents who had experienced loss between 18 and 23 weeks rated the word *miscarriage* 'acceptable' to label their experience (see Figure 4, as well as Figure 12, below). This corroborates findings of the EStELC project, that *miscarriage* poses particular challenges for people experiencing losses after around 16 weeks' gestation.
- Phrases containing the word *death*, such as *fetal death, intrapartum fetal death*, and *intrauterine death* are all rated 'unacceptable' for use in healthcare settings by a majority of participants 52.6%, 70.1%, and 66.1% respectively, but are less consistently unacceptable than other labels considered. *Fetal loss* was also rated 'unacceptable' by a marginal majority of 50.4%. This may suggest that the clinical jargon such as 'fetal', 'intrapartum' and 'interuterine' may prompt negative reactions; especially since EStELC findings

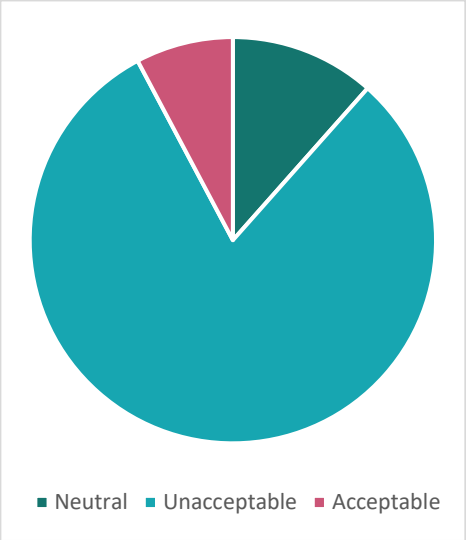

Figure 2. Acceptability ratings for *cervical insufficiency* between 14 and 39 weeks of pregnancy.

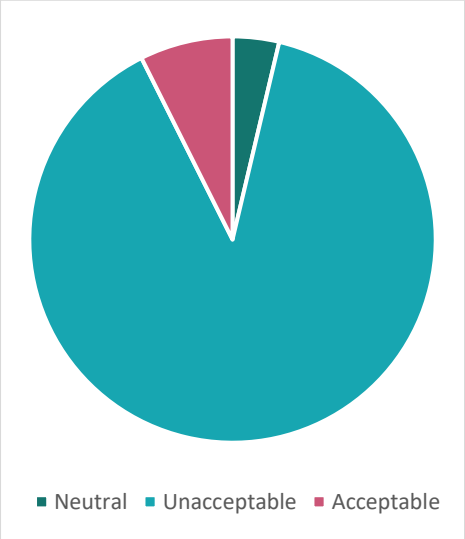

Figure 3. Acceptability ratings for *spontaneous abortion* up to 24 weeks of pregnancy.

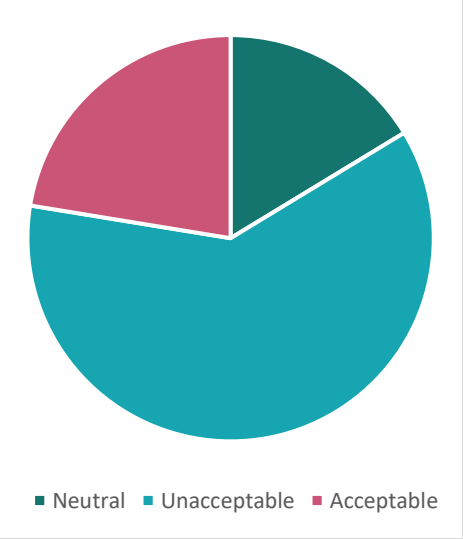

Figure 4. Acceptability ratings for *miscarriage* for loss between 18- and 23-weeks' gestation.

highlighted dissatisfaction with such clinical language, which participants described as “cold” or “cruel” (Malory 2024: 81).

- *Feticide*, the word used for the process of intervening to ensure death as part of some Termination for Medical Reasons (TFMR) procedures was also highlighted as ‘unacceptable’ by several participants. Although not suggested to survey participants, it was added by 3 respondents as a word they had experienced difficulty with, and all 3 rated *feticide* as ‘unacceptable’. This reflects EStELC findings on *feticide* (Malory 2024: 39), but further research is needed to explore this fully.
- *Biochemical/chemical pregnancy* were considered unacceptable by 59.9% of respondents with experience of loss before 5 weeks of pregnancy, reflecting EStELC findings that these phrases invalidate the loss (Malory 2024: 44).
- Similarly, phrases such as *failed implantation, implantation failure* and *late period*, which imply that pregnancy simply did not occur, were considered unacceptable by a majority of respondents. 66.4% of respondents with experience of loss before 5 weeks of pregnancy who rated *failed implantation/implantation failure* considered it ‘unacceptable’, whilst 94.5% of those rating *late period* considered it ‘unacceptable’ (see Figure 5).

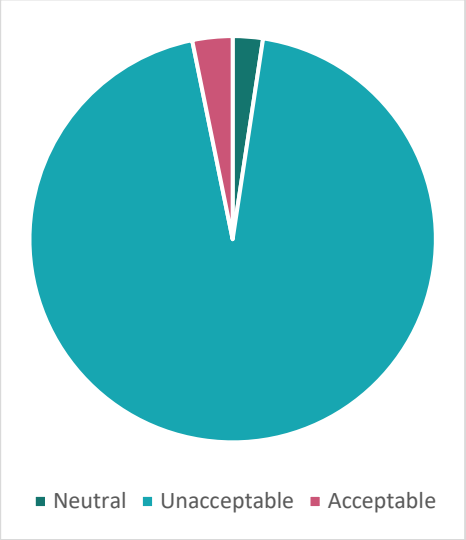

Figure 5. Acceptability ratings for *late period* up to 5 weeks of pregnancy.

Words and phrases including the word *viable*, both to describe ‘fetal viability’, or the ability of a baby to survive outside the uterus if born, and ‘pregnancy viability’, when “an embryo or fetus has a detectable heartbeat” (Pettker et al., 2023: 726) were also generally rated unfavourably. As Pettker et al. point out in their (2023) article entitled ‘The Limits of Viability’, this “distinction between “pregnancy viability” and “fetal viability” indicates the need for care and clarity when using the term “viability” in clinical practice and guidance” (725), since “telling someone being evaluated for early pregnancy that their ultrasonogram shows a viable pregnancy at 8 weeks of gestation can be confusing for someone who has heard the word viability applied in the context of [fetal viability]” (726). The confusing overlap in usage between these two phrases, both often shortened simply to *viability* may be related to the high unacceptability rating words and phrases including *viable/viability* received in this study. Survey participants answering questions about different gestational brackets were asked about words and phrases containing *viable* or *viability* in both senses and as a description of the pregnancy (e.g., *a non-viable pregnancy*), and the baby (e.g. a *pre-viable*, *periviable* or (*non-*)*viable* baby). Overall, in terms of the experience being labelled as *non-viable*, 56.4% of respondents rated this term as ‘unacceptable’. This

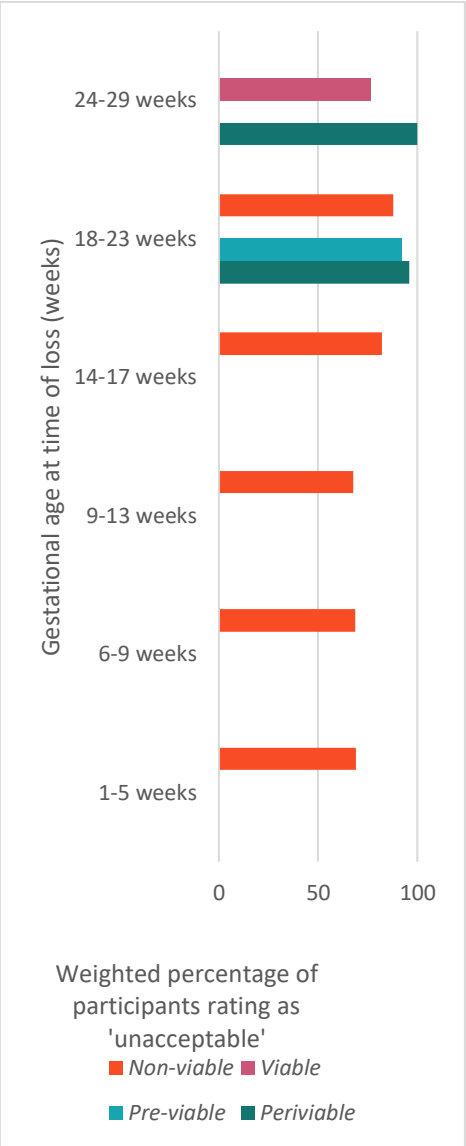

Figure 6. Ratings of words and phrases including *viable* to refer to a lost baby.

figure was higher for description of the lost baby as *non-viable*, with 69.8% of respondents rating this 'unacceptable'. Figure 6 (above) shows the consistently high unacceptability ratings for phrases such as this up to 29 weeks of pregnancy.

Some phrases used to refer to anembryonic pregnancy, when a baby dies before it can be seen on ultrasound but the pregnancy sac continues to grow, often with no outward sign that a loss is occurring, also prompted unfavourable ratings from survey participants. Both *anembryonic pregnancy* and *blighted ovum* have been implicated as challenging medical terms in previous literature on pregnancy loss terminology (Farquharson et al., 2005; Johnson et al., 2020), whilst *empty sac* (along with *missed miscarriage,* as noted above) was criticised strongly by EStELC participants (Malory 2024: 33).

The finding that more respondents rated *blighted ovum* and *empty sac* as 'unacceptable' than either 'acceptable' or 'neutral' is thus consistent with previous considerations of these terms. 58.3% of respondents across the three relevant questions rated *blighted ovum* as 'unacceptable', compared with 14.6% who rated it 'neutral' and 27% who rated it 'acceptable' (see Figure 7). *Empty sac* had a slightly higher mean unacceptability rating, at 60.2%. Still, though, 10.5% of respondents on average considered this phrase 'neutral', and 29.5% rated it 'acceptable' (see Figure 8). In both cases, mean unacceptability ratings do not exceed 60%, and more than a quarter of respondents regard both phrases as 'acceptable'. Whilst these findings indicate broad consensus, therefore, they do not necessarily reflect the strength of feeling about *blighted ovum* and *empty sac* that previous studies have indicated.

In terms of language used to refer not to the process of pregnancy loss but rather the outcome, the overwhelming majority of respondents considered *baby* the most acceptable word to use regardless of the gestation at which the loss occurred. As will be outlined on p.14, across all gestational age brackets, 91% of respondents rated *baby* 'acceptable'. Words and phrases which function to dehumanise what is overwhelmingly considered to be a *baby* were therefore consistently rated negatively. *Contents of the womb, contents of the uterus, tissue, pregnancy tissue, products,* and *products of conception* were all rated 'unacceptable' by a considerable majority of respondents in each gestational bracket up to 24 weeks, as Figure 9 shows.

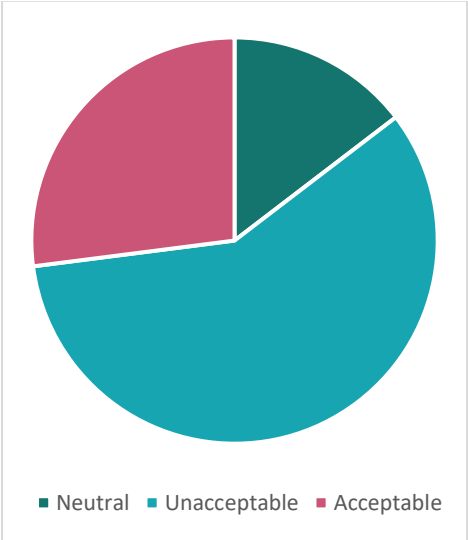

Figure 7. Acceptability ratings for *blighted ovum*.

87.1% of respondents with experience of loss up to 24 weeks rated *Products of conception* as 'unacceptable'.

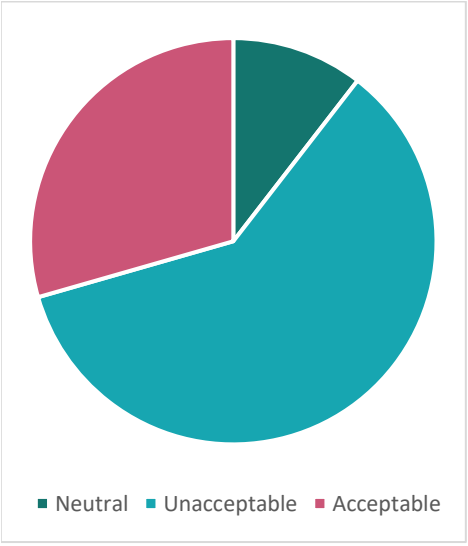

Figure 8. Acceptability ratings for *empty sac*.

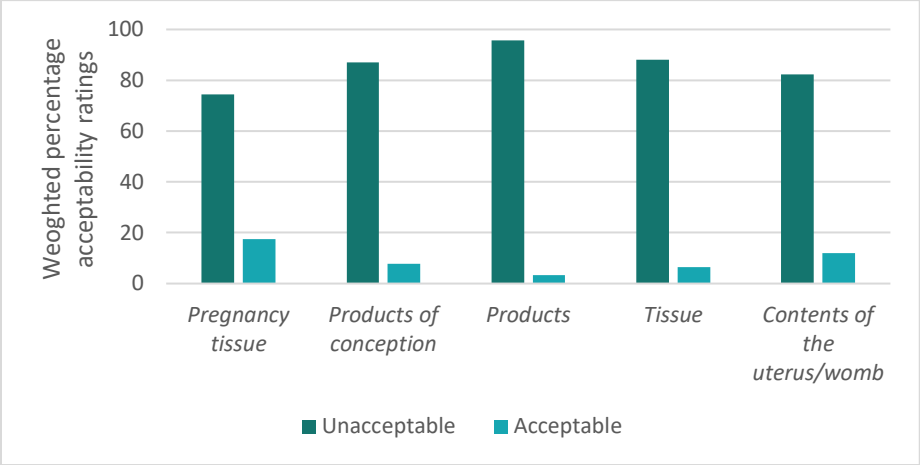

Figure 9. Respondents' ratings of 'dehumanising' labels for babies lost up to 24 weeks.

Cells and *mass,* which tend to be used to refer to the baby in the specific context of ectopic pregnancies, involving implantation outside of the uterus, were rated unfavourably by respondents with lived experience of ectopic pregnancy. Among this group, 73.7% rated *cells* as 'unacceptable', and 89.3% rated *mass* as 'unacceptable'. These responses were in line with respondents with lived experience of other types of first trimester loss. *Fetus* is the exception amongst such 'dehumanising' labels for the lost baby, since unlike *tissue, products,* etc., it evokes mixed responses for losses prior to 14 weeks, with 69% of respondents to questions on losses up to 13 weeks rating it 'acceptable', and only 16.7% 'unacceptable'. These figures will be explored on p.14, below. However, for losses from 14 weeks onwards, as Figure 10 shows, an increasing majority rated *fetus* as 'unacceptable' with each gestational time bracket. On average, 73.7% of respondents with experience of loss after 14 weeks rated this word 'unacceptable' for use in relation to such experiences, with 94.3% rating it 'unacceptable' after 24 weeks.

94.3% of respondents with experience of loss after 24 weeks rated *fetus* as 'unacceptable'.

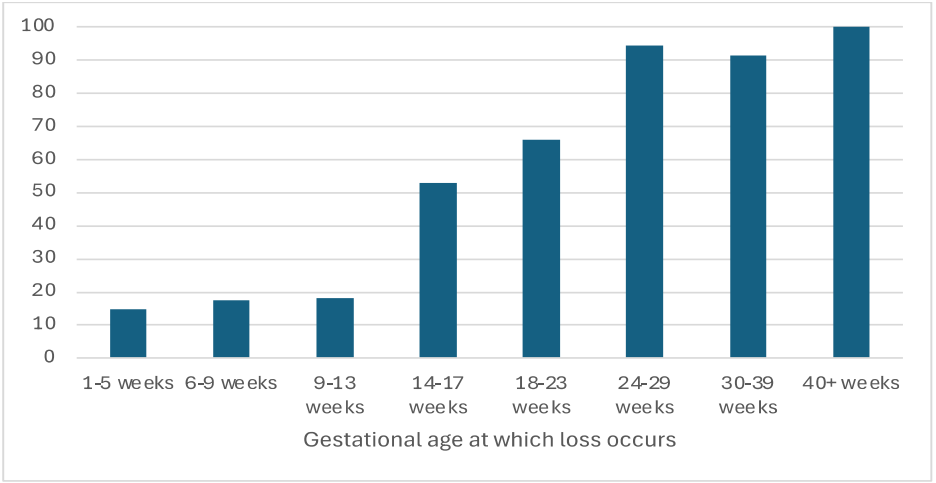

Figure 10. Percentage of respondents rating *fetus* as 'unacceptable' by gestational age bracket.

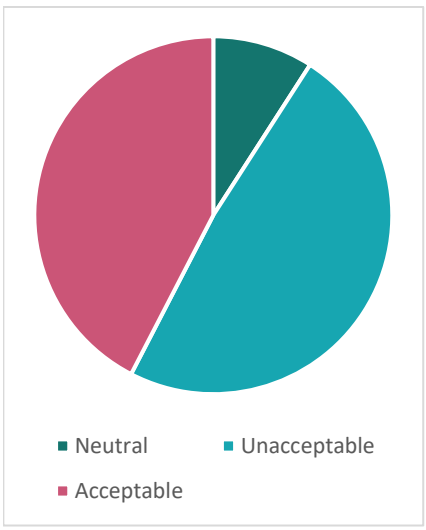

Figure 11. Acceptability ratings for *miscarriage* between 14 and 17 weeks of pregnancy.

Language that prompts mixed responses

As mentioned in the previous section, *miscarriage* was rated as 'unacceptable' by a majority of respondents who had experienced loss between 18- and 23-weeks' gestation. Responses amongst participants who had experienced loss at 14-17 weeks, however, were more mixed, with 48.5% rating *miscarriage* 'unacceptable' and 42.4% rating it 'acceptable' for a loss at this gestation (see Figure 11). This reflects a tendency, shown in Figure 12 below, for respondents to rate *miscarriage* as more acceptable in relation to losses occurring earlier in pregnancy; meaning that on aggregate, 62% of respondents who had experienced loss before 24 weeks' gestation felt that *miscarriage* was 'acceptable' in healthcare settings, and 65.7% rated it 'acceptable' for use in social contexts. As Figure 12 shows, these mixed responses were reflected across all phrases including *miscarriage* which respondents were asked to rate.

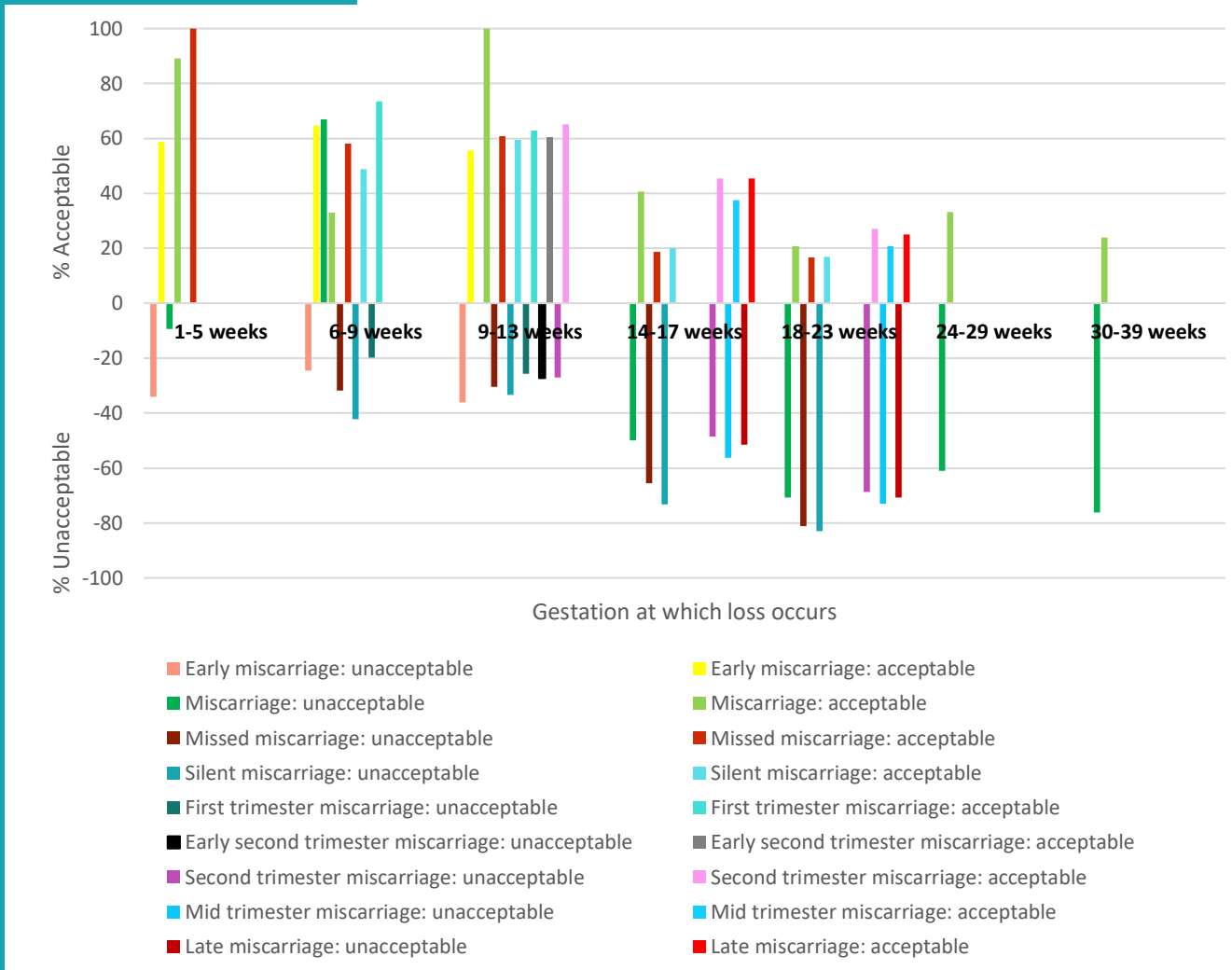

Figure 12. Percentage of respondents rating diagnostic labels involving *miscarriage* as 'acceptable' or 'unacceptable'.

48.5% of respondents with experience of loss between 14-17 weeks' gestation rated *miscarriage* as 'unacceptable, but 42.4% rated it 'acceptable'.

These findings indicate that *miscarriage* is particularly acceptable amongst respondents with experience of loss before 5 weeks of pregnancy. This may reflect the relatively high levels of dissatisfaction with *bio/chemical pregnancy* highlighted above, which make *miscarriage* a more acceptable alternative.

The mixed responses to *miscarriage* are perhaps surprising, in light of EStELC findings that many participants objected strongly to use of the word as a label for losses at all stages of pregnancy, and given that vehement dislike of *missed miscarriage* was highlighted by EStELC. This difference may reflect disparities between the EStELC and SuPPL research cohorts, since involvement in EStELC required significant contributions either in writing or to group discussions, and its self-selecting recruitment model is likely to have favoured individuals with lived experience of pregnancy loss for whom language was perceived to be particularly damaging. By contrast, SuPPL's self-selecting cohort were required to provide less input, in the form of an online survey, and it may therefore have reached more participants with more balanced views on the language used in relation to their experience(s).

Another label which prompted a mixed response from SuPPL participants is *Termination for Medical Reasons* (TFMR), which refers to interventions to end a pregnancy because of a medical condition affecting either the baby or the mother/birthing person. On aggregate, across all gestational brackets, this phrase was rated 'acceptable' by 48.9% of respondents and 'unacceptable' by 41.2% of respondents. Ratings varied significantly across the gestational brackets, however, and showed a marked rise in respondents rating *Termination for Medical Reasons* as 'unacceptable' for losses at 30-49 weeks and after 40 weeks of pregnancy, as Figure 13 shows. This, however, may reflect survey participants' views on appropriateness of terminating a pregnancy for medical reasons at these stages of pregnancy, as opposed to language attitudes.

55% of respondents with experience of loss between 9-29 weeks' gestation rated *Termination for Medical Reasons* as 'acceptable, and 34% rated it 'unacceptable'.

As Figure 13 shows, within the gestational brackets 9-13, 14-17, 18-23, and 24-29 weeks, after which TFMR is uncommon, the phrase *Termination for Medical Reasons* is consistently rated as 'acceptable' by more respondents than rate it as 'unacceptable'. Overall, for losses between 9 and 29 weeks, 55% of respondents who had experienced loss during these weeks rated the phrase 'acceptable', and only 34% rated it 'unacceptable'.

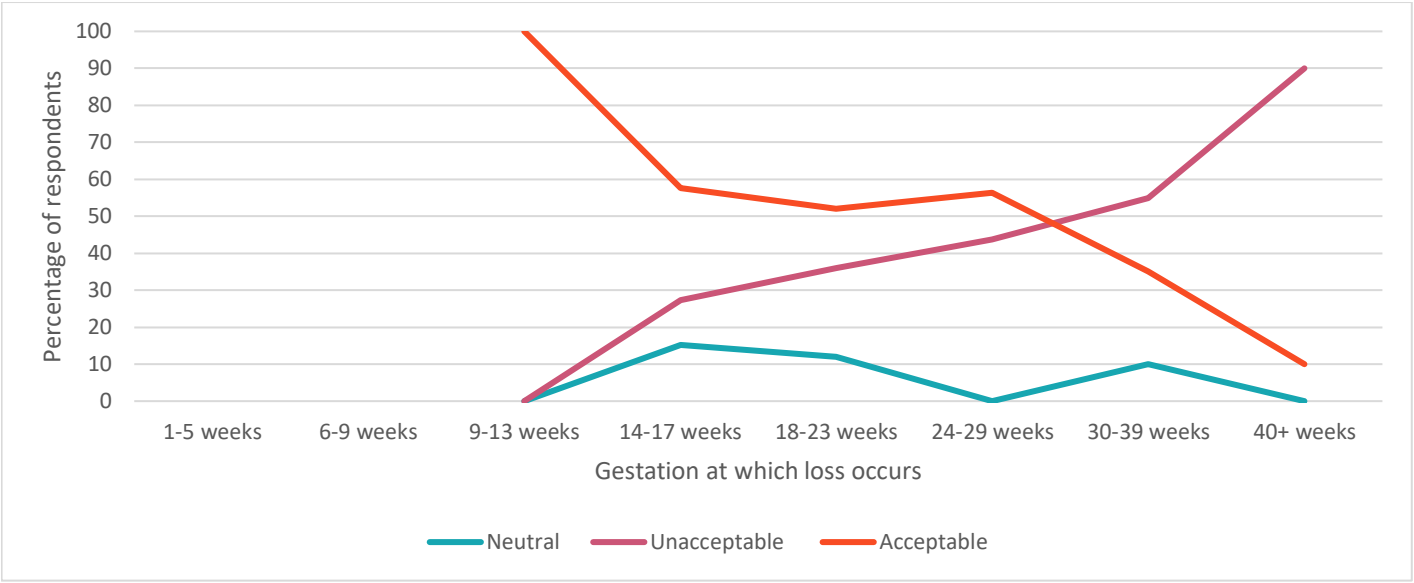

Figure 13. Percentage of respondents rating *Termination for Medical Reasons* as a 'neutral', 'acceptable' or 'unacceptable' phrase.

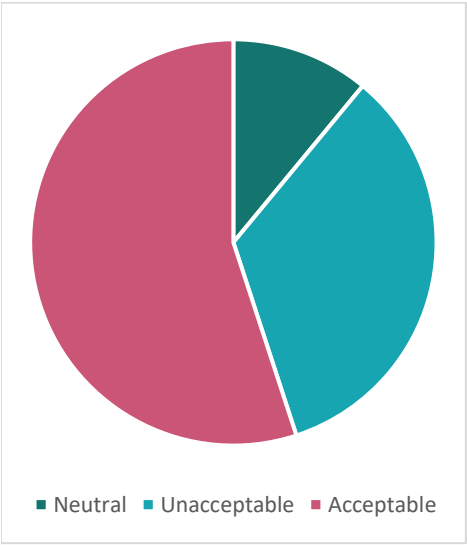

Figure 14. Acceptability ratings for *Termination for Medical Reasons* for losses between 9-29-weeks.

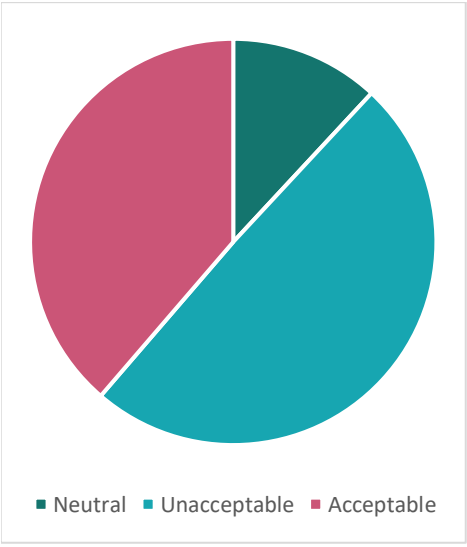

Figure 15. Acceptability ratings for *anembryonic pregnancy*.

SuPPL findings therefore indicate that *Termination for Medical Reasons* does not provoke widespread dissatisfaction. Qualitative findings arising from the EStELC study do however highlight the importance for people going through TFMR of the full phrase, including *for medical reasons*, being used (Malory, 2024), since *termination* is increasingly used to refer to unwanted pregnancies/those which are ended voluntarily (Malory, 2023).

As was discussed on p.9 above, the phrases *blighted ovum* and *empty sac* to refer to anembryonic pregnancy were rated unfavourably by a small majority of respondents to the 3 questions relating to losses between 6-9 weeks, 9-13 weeks, and those where only a sac was visible on ultrasound. These marginal findings would pose a challenge to formulation of a recommendation in relation to this experience were it not for a finding that *anembryonic pregnancy* is 'acceptable' or 'neutral' to most respondents in these groups. The mean percentage rating *anembryonic pregnancy* as 'unacceptable' across the 3 questions relating to such losses was 48.9% (see Figure 15). On average, therefore, marginally more respondents to these three questions (50.1%) considered *anembryonic pregnancy* to be either 'neutral' or 'acceptable' than 'unacceptable'. As is reflected in the recommendations on pp.17-19, this indicates that at this time, *anembryonic pregnancy* should be preferred to *blighted ovum* or *empty sac* in this context.

In the next section, language considered acceptable by a majority of participants with relevant experience will be considered.

‘Acceptable’ language

As was noted on p.10, above, one of the words most consistently rated as ‘acceptable’ by SuPPL participants was *baby*, with most respondents with experience of loss in every gestational bracket rating this as ‘acceptable’. Across all brackets, as Figure 16 shows, on average 91% of respondents rated *baby* as ‘acceptable’, and only 4.1% rated it ‘unacceptable’.

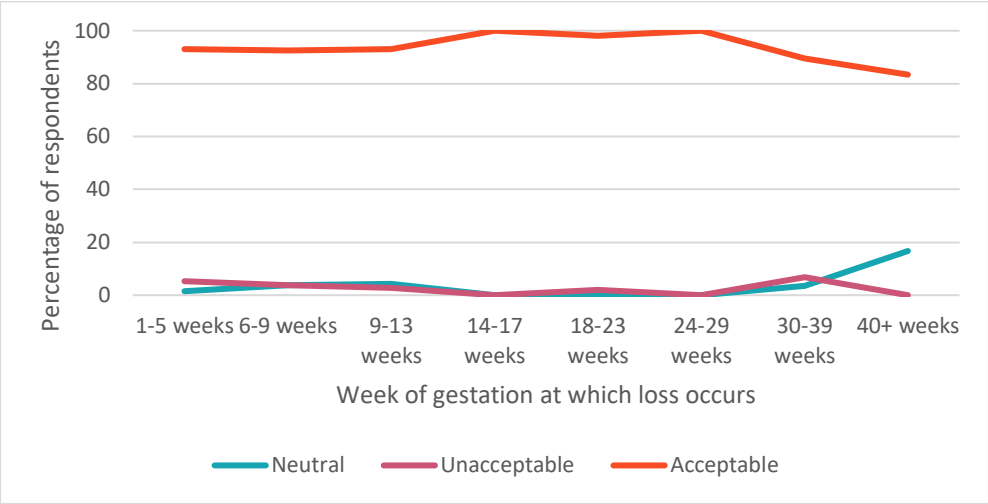

Figure 16. Percentage of respondents rating *baby* as a ‘neutral’, ‘acceptable’ or ‘unacceptable’ word when experiencing a loss in the same gestational bracket as them.

91% of respondents with experience of loss at any gestation rated *baby* as ‘acceptable, and 4.1% rated it ‘unacceptable’.

The lowest acceptability ratings for *baby* occur in the 30-39 week (89.6%) and 40+ week (83.4%) brackets. This is likely to reflect preference for more specific labels, such as ‘Their given name’, as the way to refer to a baby lost, since in all gestational brackets after 24 weeks, this is rated ‘acceptable’ by 100% of respondents. A relatively low sample size for the 40+ weeks bracket may also influence this trend. Slightly lower acceptability ratings for *baby* in gestational brackets up to 12 weeks may reflect a greater tendency during the first trimester for a minority to conceptualise the loss as that of something other than a baby (for example, *embryo* or *fetus*).

Overall, ‘humanising’ labels such as *baby* and ‘Their given name’ were rated as highly acceptable, no matter what stage of pregnancy a loss occurred.

However, *baby* was considered ‘acceptable’ on average by 92.9% of respondents who had experienced loss before 14 weeks’ gestation, by comparison with 69% of respondents who considered *fetus* acceptable at the same gestations (see Figure 10, above). Overall, therefore, humanising labels such as *baby* and ‘Their given name’ were rated very positively. These findings provide robust evidence that *baby* should be preferred in mass communication contexts involving the loss of a wanted pregnancy at any gestation, and that dehumanising language such as *products of conception* and *pregnancy tissue*, as discussed on p.9, should be avoided wherever possible. However, contextualisation provided by the qualitative EStELC findings shows that such ‘humanising’ labels can be harmful for some, and this compounds the recommendation that individual language needs such as this should be accommodated in clinical settings wherever possible.

Turning to diagnostic labels for types of loss which were rated as ‘acceptable’; as Figure 17 shows, *pregnancy loss* was consistently rated by a majority of respondents as ‘acceptable’ in every gestational bracket for which participants

were asked to rate this term[1], apart from 40+ weeks. Indeed, in the pre-24 week gestation brackets for which data are available, *pregnancy loss* is rated as acceptable for use in healthcare settings by 86.9% of respondents. This is a greater proportion of respondents than the 62% who, as noted above, felt that *miscarriage* was acceptable in the same contexts. *Recurrent loss* and *recurrent pregnancy loss* were also rated 'acceptable' by 75.7% and 81.3% of respondents with experience of recurrent loss before 24 weeks, respectively.

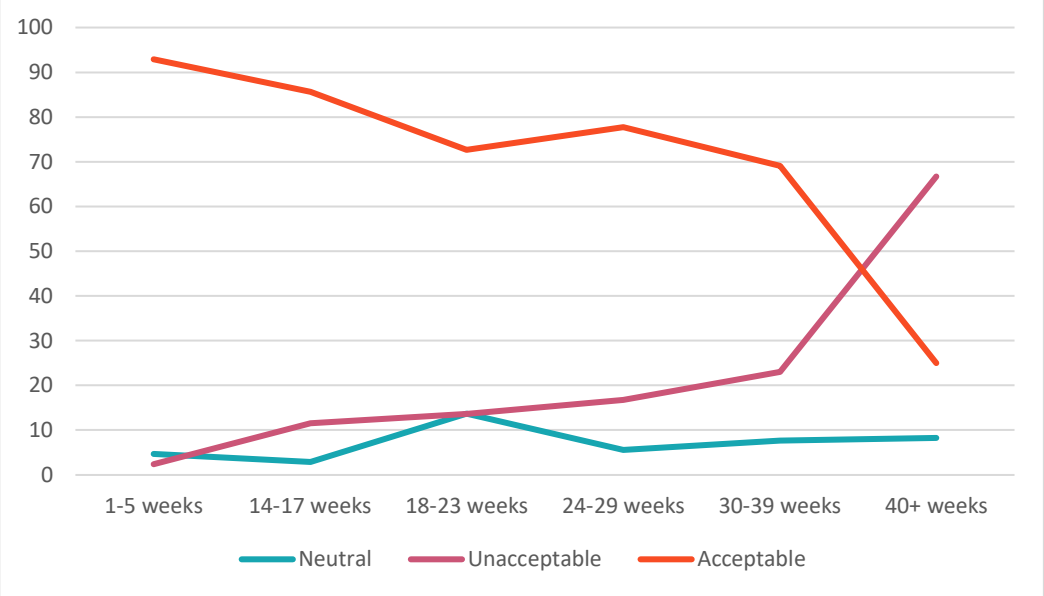

Figure 17. Percentage of respondents rating *pregnancy loss* as 'neutral', 'acceptable' or 'unacceptable' in each gestational bracket.

The decline in acceptability of *pregnancy loss* after 40 weeks' gestation may reflect a perception, voiced during the EStELC Project (Malory, 2024: 49), that the phrase implies loss *of* rather than *during* pregnancy. However, the number of respondents rating this phrase for use at 40+ weeks was small, and the result may merely reflect personal preference in this small sample. Smaller sample sizes for losses in later pregnancy, which are much rarer than those in early pregnancy, also make it difficult to draw robust conclusions as to the acceptability of words to refer to losses after 24 weeks' gestation. In the UK, such loss is categorised as *stillbirth* for medical and legislative purposes, and the EStELC Project found only idiosyncratic dissatisfaction with this term (Malory 2024: 93). Whilst such dissatisfaction should always be accommodated in clinical interactions, there was no evidence that *stillbirth* was widely unacceptable, and this finding is borne out in SuPPL data. Here, as Figure 20 shows, 83.4% of respondents on loss after 24 weeks rated *stillbirth* as 'acceptable'. The survey also reflected the EStELC project's finding that respondents who had experienced second trimester loss rated *stillbirth* as more acceptable than *miscarriage*. 76.3% of respondents in the gestational brackets 14-17 and 18-23 weeks rated *stillbirth* as acceptable, by comparison with a 32.5% acceptability rating for *miscarriage* during this period (see p.11, above).

Like *stillbirth*, *born asleep/born sleeping* was consistently rated 'acceptable' by a significant majority of participants who experienced loss after 14 weeks, both

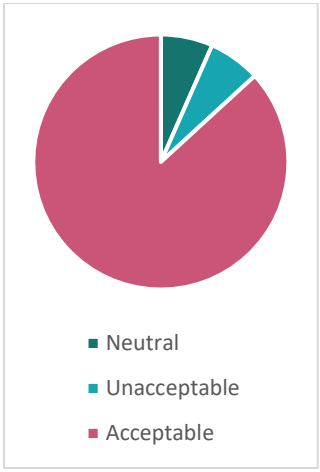

Figure 18. Acceptability ratings for *pregnancy loss* before 24 weeks of pregnancy.

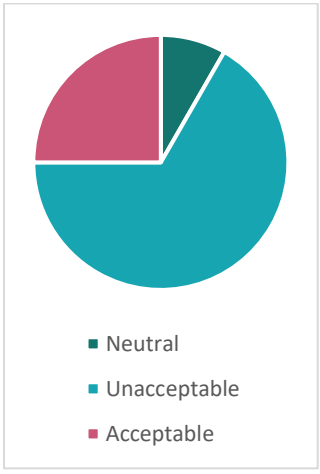

Figure 19. Acceptability ratings for *pregnancy loss* after 40 weeks of pregnancy.

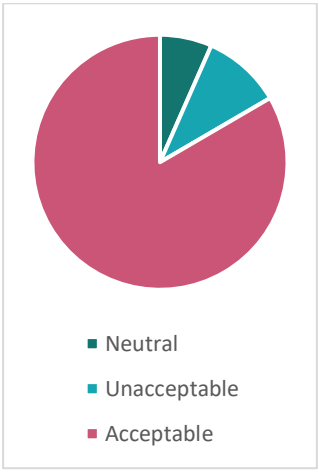

Figure 20. Acceptability ratings for *stillbirth* after 24 weeks of pregnancy.

[1] This figure includes ratings by participants responding to questions about experiences of implantation outside the uterus.

inside and outside of healthcare settings, with little variation according to the stage of pregnancy during which the loss occurred. Though prompting a slightly larger proportion of 'unacceptable' responses among our small sample (for losses at 40+ weeks (33.3%), in general, 81.8% of responses rated this phrase 'acceptable' in healthcare settings across all stages of pregnancy after 14 weeks.

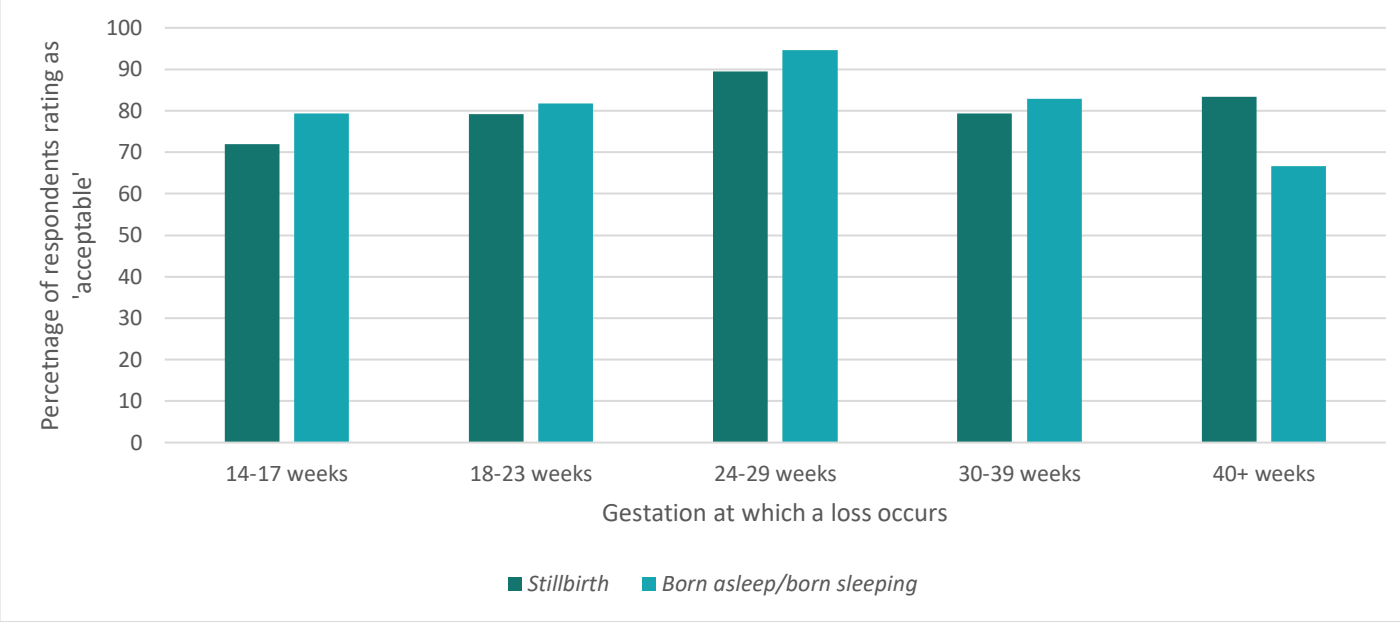

Figure 21. Acceptability ratings for *stillbirth* and *born asleep/born sleeping*.

Finally, *ectopic pregnancy* was rated as 'acceptable' by 91.2% of respondents with lived experience of a pregnancy involving implantation outside the uterus, showing that whilst this group object to *cells* and *mass* (see p.10) to refer to their baby, the overwhelming majority do not have an issue with diagnostic use of *ectopic*. The acceptability of ectopic pregnancy is reflected in Figure 22. 80% of participants with lived experience of this type of pregnancy also rated *pregnancy loss* as 'acceptable' in this context.

Other ways of referring to this specific type of loss that were rated as 'acceptable' include *tubal pregnancy*, which was rated 'acceptable' by 62.3% of respondents, and *extrauterine pregnancy*, which was rated 'acceptable' by 51%. However, given that *ectopic pregnancy*, as the predominant phrase used to refer to this experience, has high approval ratings, this phrase should be preferred over these alternatives.

The findings presented here allow evidence based recommendations to be made in the following section.

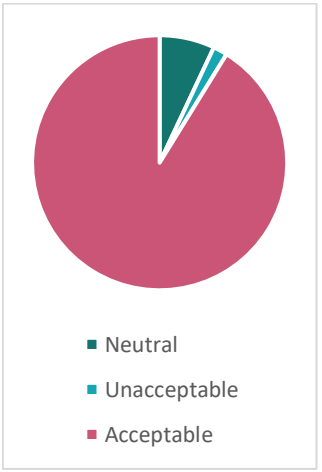

Figure 22. Acceptability ratings for *ectopic pregnancy* amongst participants with experience of a pregnancy involving implantation outside the uterus.

Recommendations

The empirical findings presented above allow evidence-based recommendations for pregnancy loss language to be made. These recommendations are in no way intended to undermine the strong recommendation of the EStELC Project report (Malory 2024) that a clinical framework for accommodating language needs around pregnancy loss be implemented in the UK as soon as is practicable. Rather, they are intended to limit harms associated with use of language around pregnancy loss in mass communication contexts, such as policy and public health information.

Table 1 summarises the words and phrases for which the SuPPL Project data indicate a consensus on unacceptability. The table reflects a graded approach, whereby clear consensus constitutes a rating of 'unacceptable' by 80-100% of participants with relevant lived experience, whereas apparent consensus reflects a rating of 'unacceptable' by 65-80% of respondents, and marginal consensus constitutes a rating of 'unacceptable' by 50-65% of participants with relevant lived experience.

% rating	Unacceptable words/phrases	
80-100% (clear consensus)	**For the experience**	**For the baby**
	Incompetent cervix/cervical incompetence	*Products of conception*
	Cervical insufficiency	*Contents of the womb/uterus*
	Abortion	*Tissue*
	Late period	*Products*
65-80% (apparent consensus)	*Miscarriage* (when used for loss between 18-23 weeks' gestation)	*Non-viable*
	Intrapartum fetal death	*Pregnancy tissue*
	Intrauterine death	*Fetus* (from 14 weeks' gestation)
	Failed implantation/implantation failure	
50-65% (marginal consensus)	*Biochemical/chemical pregnancy*	
	Fetal death	
	Fetal loss	
	Non-viable	
	Blighted ovum	
	Empty sac	

Table 1. Words and phrases found to be rated 'unacceptable' in SuPPL dataset.

Though in some cases, consensus was much clearer than in others, all words and phrases with an apparent or marginal consensus have an alternative with a higher acceptability rating in the SuPPL dataset. This allows clear, evidence-based recommendations to be made for alternatives to most of the language in Table 1, as laid out in Table 2.

Unacceptable language	Recommended alternative
Abortion	Pregnancy loss/Surgical management for pregnancy loss
Failed implantation/implantation failure	*Early pregnancy loss*
Late period	
Biochemical/chemical pregnancy	
Miscarriage	*Pregnancy loss*
Intrapartum fetal death	
Intrauterine death	
Fetal death	
Fetal death	
Blighted ovum	*Anembryonic pregnancy*
Empty sac	
Fetus	*Baby*

Table 2. Recommended alternatives to words/phrases found to be 'unacceptable'.

The recommendations in Table 2 reflect the SuPPL Project's primary goal of ascertaining the feelings of those with recent lived experience of pregnancy loss on the language currently used in the UK to describe experiences like theirs, and not to canvass opinion on possible alternatives. Whilst in many cases, such alternatives are already in use and therefore manifest in the SuPPL data, it does mean that for some of the words and phrases listed in Table 1, further research is needed to find an optimal alternative. Unfortunately, the words and phrases lacking an obvious alternative are some of those which attracted the highest unacceptability ratings in the SuPPL dataset. For this reason, suggestions extrapolated from the findings of the EStELC and SuPPL projects are made in Table 3, but it is important to note that these are empirically-derived extrapolations and not evidence-based recommendations like those in Table 2, above.

Unacceptable language	Suggested alternative
Incompetent cervix/cervical incompetence	*Preterm cervical shortening*
Cervical insufficiency	
Products of conception	Where necessary, for example when discussing removal of placental tissue or uterine lining following an incomplete loss, or in addition to the baby, consider using this language in an additive way, i.e. *the baby and other pregnancy tissue*
Contents of the womb/uterus	
Tissue	
Products	
***Non-viable* (of both baby and pregnancy)**	
Pregnancy tissue	

Table 3. Suggested alternatives to words/phrases found to be 'unacceptable' for which no clear alternative exists.

In addition to providing the evidence base for the recommendations above, on language which should be avoided in pregnancy loss contexts, the SuPPL dataset also showed consensus on the *acceptability* of some words. This language is listed in Table 4 and is graded in terms of degree of consensus on acceptability, just as Table 1 was graded on degree of consensus on *un*acceptability.

% rating	Acceptable words/phrases	Notes
80-100% (clear consensus)	*Pregnancy loss*	
	Recurrent pregnancy loss (before 24 weeks)	
	Stillbirth (after 24 weeks)	
	Ectopic pregnancy	
	Baby	
	Their given name	
65-80% (apparent consensus)	*Termination for Medical Reasons* (TFMR)	
	Recurrent loss (before 24 weeks)	Less acceptable overall than *recurrent **pregnancy** loss*. *Recurrent **pregnancy** loss*. should be used instead
	Stillbirth (14-23 weeks)	Care should be taken to be clear that the medico-legal threshold for classifying stillbirth in the UK is 24 weeks
	Born asleep/born sleeping (after 14 weeks)	Less acceptable overall than *stillbirth*. *Stillbirth*. should be used instead
	**Fetus* (up to 13 weeks)	Less acceptable overall than *baby*. *Baby* should be used instead
50-65% (marginal consensus)	*Anembryonic pregnancy*	
	Miscarriage (before 24 weeks)	
	Tubal pregnancy	Less acceptable overall than *ectopic pregnancy*. *Ectopic pregnancy* should be used instead
	Extrauterine pregnancy	

Table 4. Words and phrases found to be rated 'unacceptable' in SuPPL dataset.

As in Table 1, Table 4 shows that consensus was much clearer in some cases than in others. Overall, however, the language listed here can be considered broadly acceptable for use in pregnancy loss contexts at this time. Where two or more words or phrases in Table 4 mean the same thing, such as *ectopic pregnancy* and *tubal pregnancy*, or *baby* and *fetus*, the option with higher acceptability ratings in SuPPL data (in these cases, *ectopic pregnancy* and *baby*) can be privileged. The notes in Table 4 reflect this.

The SuPPL Project has thus made significant strides in ascertaining how language can be optimised in contexts where pregnancy loss language cannot be individualised, such as public health information websites or leaflets, and policy language. Its quantitative approach to exploring attitudes to pregnancy loss language in the UK has yielded the first evidence-based recommendations on pregnancy loss language, which can be used to guide language use in mass communication contexts.

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Get in touch

If you would like to discuss any of the findings in this report, please email b.malory@ucl.ac.uk