



# **FEMS Pilot Service User Literature**

**You said, We did**

**We R Rare Steering Group – September 2024**

**Project Discussion Lead: Eva Clarke**



We  
asked

- What are your initial thoughts on the booklet?
- What are your thoughts on the language used?



You said...

“Breaking it down into a smaller booklet or leaflet could be more reassuring and help take them through the journey.”

Some of the language is “confusing”

“This gives the impression the service is only for children but is also for adults so perhaps it needs re-wording”



We listened...

We agree

We agree.

We agree.



We did...

We replaced some text with a step by step flowchart which helped the readers understand the patient journey.

We used an accessibility tool so that the booklet can be read at a reading age of 9 years old.

We have added ages ranges of 0-100.

We  
asked

- Continued ...What are your thoughts on the language used?



You said...

“This doesn’t feel like a good enough reason to use the word ‘fetal’ when it’s so close to the word ‘fatal’ and is also not the spelling people recognise.

This is going to be read by patients and their families so it’s better to prioritise accessibility over consistency with academic literature”



We listened...

We understand the concerns raised and the complexity that comes with the language used.



We did...

We have shared this view with members of the FVS patient / carer group (a dedicated group focused on shaping FEMS).

Whilst the group understand that perspective, they expressed their desire to keep the spelling of fetal (and not foetal) for consistency with other literature.

**We  
asked**

- Does it include all of the necessary information?
- What can be done to improve the booklet?



**You said...**

“Should highlight what the specific medication is”

There is “too much information”

“I think FAQs should be on a separate sheet”

“Perhaps there should be different versions – one for parents of young child and another for an older person affected?”



**We listened...**

We agree

We agree

We agree

Although the Manchester team were happy to provide separate booklets, the Newcastle Comms team did not agree. As a compromise, both teams agreed to publish a single easy read version instead.



**We did...**

A medications table added at the end of the service booklet.  
We created sections within the booklet and shortened text.

FAQs moved to the end of the booklet as a separate sheet/

We shared the revised easy read version with the FVS patient / carer group and were happier with the new version.