



# Global Access to Voice Preservation in ALS/MND Populations

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## BACKGROUND

Dysarthria is among the most common symptoms of people living with Amyotrophic Lateral Sclerosis (ALS) (PALS) and is characterized by difficulty in articulation and intelligibility of speech. Voice preservation (VP) technologies involve recording samples of a person's speech to preserve their natural voice and acoustic identity. From these recordings, a synthetic voice can be created with the aim of enhancing quality of life.

Message and voice banking are two of the main ways a person may wish to preserve their voice. However, this process has high costs and is available in relatively few languages, resulting in limited access, often to richer and English-speaking countries.

The International Alliance of ALS/MND Associations is currently leading a pilot project in Colombia, working with PALS and caregivers of people living with ALS/MND (CALs), to help deliver a communication solution that is cost-effective and reflects the significance of voice to a person's self-identity while being sensitive to the cultural aspects of language such as accents, idioms, and dialect.

In Colombia, 80% of PALS are in urban areas, and it takes an average of two years to go from symptoms to diagnosis due to a lack of awareness and access to experts. However, the use of remote telehealth increased significantly during the pandemic. In addition, the level of knowledge and skill in using technology varies greatly.

## METHOD

Through a collaboration between the National University Hospital (HUN), the Colombian Association of Amyotrophic Lateral Sclerosis (ACELA), and the Alliance, this field project seeks to establish a broader understanding of the current state of service and availability of these systems and deliver a pilot centred around the needs of 12-15 PALS. Figure 3 below conveys the emotional and practical aspects that each person, and their family and friends, go through. We aim to align that with a view of the technology landscape that can be used to support the desired outcomes, ensuring the solution will be fit for purpose and aligned to the socio-cultural and economic environment in Colombia.

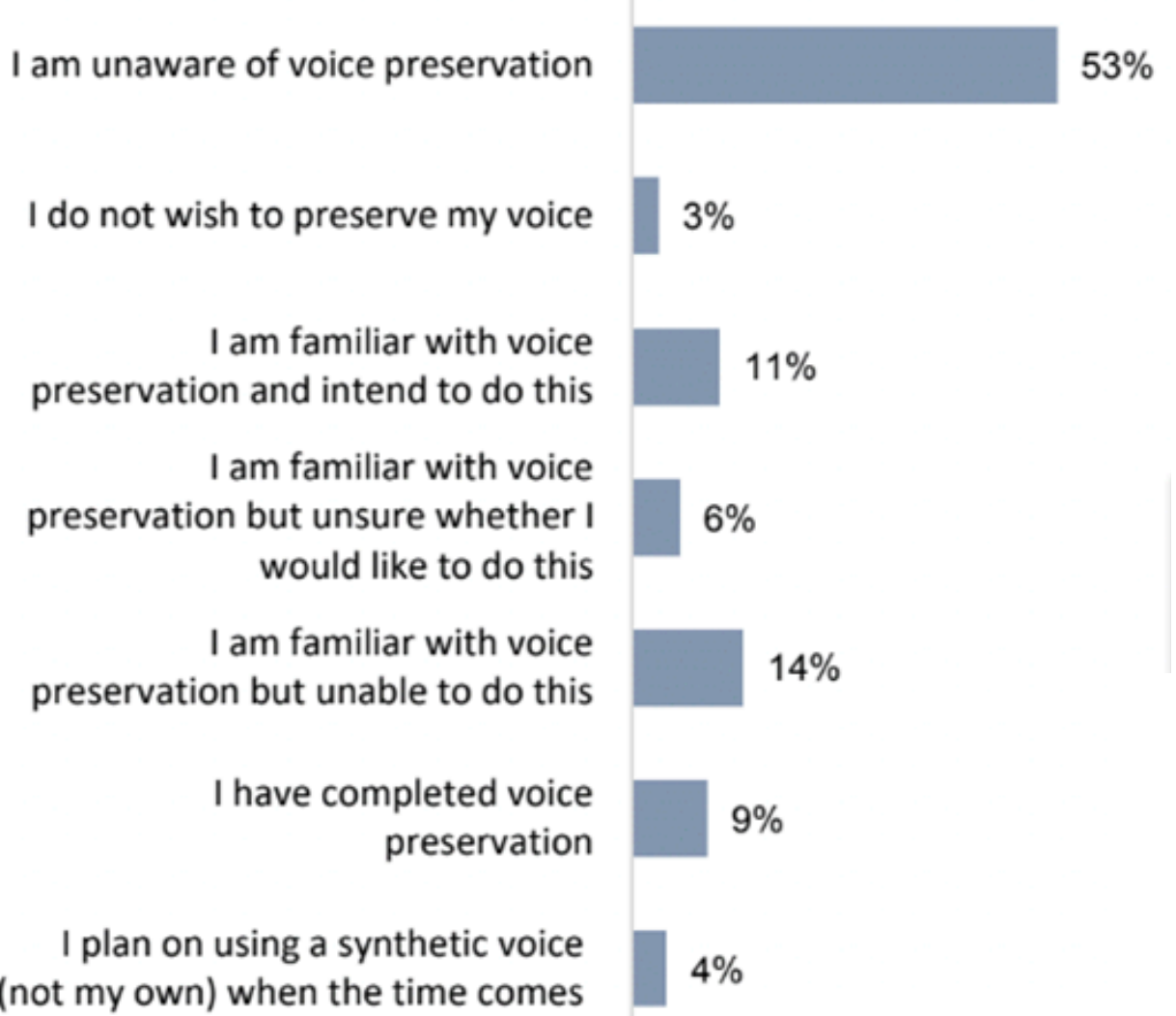
ACELA sourced the PALS participants in the project and HUN have ensured ethics compliance and developed a research protocol and clinical assessment process specifically for the pilot. Access to the VP technology has been provided by Acapela's 'My-own-voice' app (using International Spanish.)

## DISCUSSION

To fulfil the objective of making VP technology available everywhere, the project will develop a range of artefacts that will be shared with the global community. The purpose of these resources is to provide a means for sharing the different approaches, processes, and steps relating to voice preservation. They will focus on training, support, and knowledge transfer among Speech and Language Therapists (SLTs), health professionals, and care providers around the world.

## RESULTS

Which of the following statements best describe your situation as it relates to voice preservation.



	2023											
	%	TUR	BRA	ESP	USA	AUS	CAN	COL	JPN	NLD	DNK	KOR
<b>TOTAL RESPONDENTS</b>	<b>883</b>	<b>172</b>	<b>132</b>	<b>82</b>	<b>79</b>	<b>59</b>	<b>48</b>	<b>44</b>	<b>42</b>	<b>35</b>	<b>28</b>	<b>27</b>
Unaware of voice preservation	53%	76%	70%	65%	9%	29%	31%	70%	12%	31%	64%	70%
Do not wish to preserve voice	3%	4%	2%	4%	3%	2%	4%	0%	5%	11%	0%	0%
Intend to do this	11%	3%	9%	10%	23%	12%	19%	2%	7%	23%	7%	7%
Familiar with voice preservation but unsure whether to do this	6%	1%	3%	2%	14%	12%	17%	2%	17%	14%	7%	4%
Familiar with voice preservation but unable to do this	14%	13%	9%	12%	10%	14%	13%	25%	19%	9%	21%	11%
Have completed voice preservation (voice banking and/or message banking)	9%	1%	1%	6%	37%	25%	8%	0%	33%	6%	0%	0%
Plan on using a synthetic voice when the time comes	4%	1%	7%	1%	5%	7%	8%	0%	7%	6%	0%	7%

Figures 1 & 2. The majority of PALS respondents are unaware of VP, and Colombia is among the six countries with the highest unawareness of voice preservation. Based on data from the International Alliance 2023 Fundamental Rights Survey.

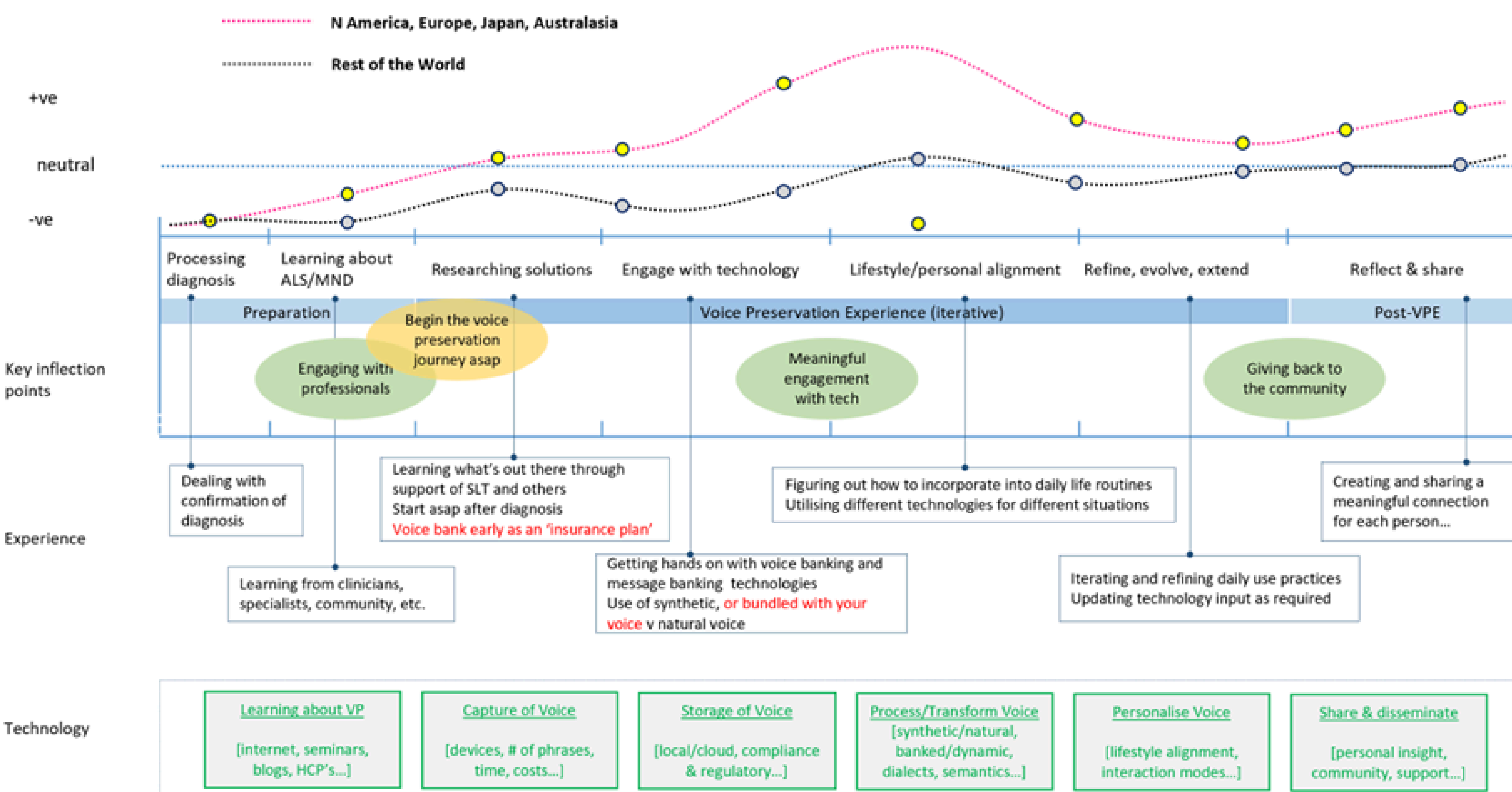


Figure 3. End-to-end experience map depicting the voice preservation journey.

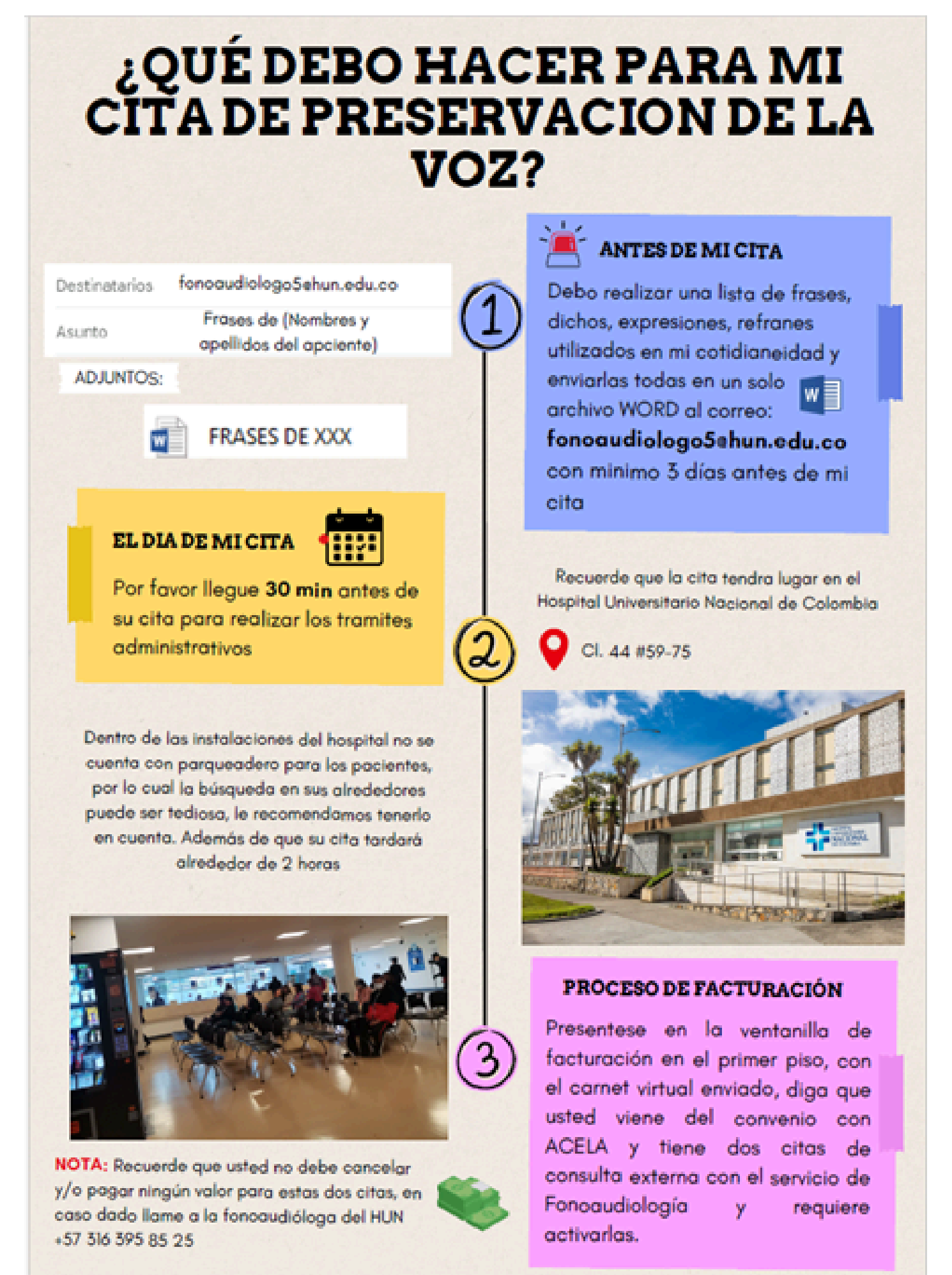


Figure 4. Infographic depicting pre-appointment information for PALS. Developed by an SLT from HUN.

### APPENDIX: LIST OF CUSTOM MESSAGES

Capturing custom phrases which can be used as a shared resource and is developed from input from people around the world to provide greater cultural diversity and range in VP systems.

Custom Phrases are 'spoken' in exactly the voice you recorded the custom message with, and therefore can convey emotion or be said in exactly the way you want them to be heard by others.

The content Custom Phrases are entirely your choice and people record words and phrases that are meaningful in their lives. Having worked with literally hundreds of people to record custom phrases there is only one phrase that most people record and that is 'I love you'.

Beyond that, here are common categories that people may record:

- Names of people (family names, pet names, friends) places where they live or visit, things they have of do (hobbies, objects)
- Transactional phrases (for example 'coffee with sugar', 'shall we go out later?', 'how was your day?' 'can I have some help')
- Calls to pets
- Custom phrases have no limit and some people use them to sing songs, to record laughter, to make sounds they are known for.
- Others record extended custom phrases for special events like a wedding speech, or recite poetry, or important phrases for a regular appointment
- Some people record the same message in multiple different ways to convey emotion or context. One person recorded "I'm OK" five different ways to express different meanings.

In summary – custom phrases are available for you to record in your natural voice anything you want in your own life.

There are no wrong or incorrect custom phrases – just record as many or as few that suit you!

However, it can be hard to think of things to record straight away and we recommend you make a note of anything as it comes to you and record them over time. Acapela allow you to record custom phrases even after your voice bank has been created – just keep adding!

Figure 5. Content sample from shared resource on VP.

## CONCLUSION

The project is currently underway with the aim of completion by the end of 2024. We will be applying the learnings and insights from the pilot to other low- and middle-income countries where there are territorial challenges, relatively scarce technology access, and complex language structures. Additionally, on completion, we will develop marketing and communication materials for the broader community to raise awareness of VP and the value and impact it can have on quality of life for PALS and CALs globally. Fundamentally, we believe this work will help set the stage to make voice preservation accessible worldwide on a sustainable foundation.

## ACKNOWLEDGEMENTS

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