

The Irish Message Banking Toolkit



Introduction to the Irish Message Banking Toolkit

The *Irish Message Banking Toolkit* is designed to provide information and support for people with communication difficulties who are considering engaging in *message banking* and to guide them through the process. In addition, it is intended as a resource for speech & language therapists (SLTs) and other relevant people who work with them.

- This introduction to the toolkit is written primarily for SLTs who support the person through the process of *message banking*.
- All other documents in the toolkit are written for the person who is considering embarking on the process.

Message Banking is usually undertaken by people with a medical condition that affects communication. It involves the person recording words and phrases that can be used later on electronic communication devices. As these messages are recorded in the person's own voice, they have an important role in:

- Optimising communication.
- Maintaining a 'sense of self' and the individual's identity as a communicator.

The person records messages in their own voice, for later use on an electronic communication device, if required. These messages will sound exactly the same as when they were recorded. Therefore, *message banking* differs from *voice banking*, which refers to the process of using recorded speech to create a *computerised* voice which is based on that of the person but will never sound exactly like them because it is electronic. While this toolkit focuses predominantly on *message banking*, some tools and resources for *voice banking* are addressed briefly as it is frequently discussed and considered at the same time as *message banking*.

Message banking is complex and relies on the knowledge and skills of SLTs who work alongside people with communication difficulties. The process requires the SLT (and/or other relevant people) to support the person by:

- Offering accurate information about *message banking* to enable an early and informed decision about whether or not the process is appropriate for them at that point in time.
- Strategically identifying relevant linguistic and non-linguistic structures to meet their future communication needs.
- Enabling appropriate recording of messages to meet quality requirements for later use.
- Designing, programming and implementing client-specific communication devices.

All of these elements should occur within a therapeutic context that recognises *message banking* is as much about the process as it is about the product. The process may be daunting and emotional but equally it can be empowering when facilitated appropriately.



People who decide to embark on *message banking* have usually been diagnosed with a progressive medical condition such as Motor Neurone Disease (MND). Typically, they are engaged with several services, including a range of SLT and/or Assistive Technology (AT) professionals within the community, hospital and specialist settings. Therefore, the need for services to work within a common framework is important. It is our intention that this toolkit will serve as such a framework and so lessen the potential disruption that can be caused by multiple different interpretations and processes related to *message banking*.

A **streamlined process** allows service users to experience *message banking* as a meaningful, empowering and hopeful journey. However, the toolkit is not designed to be 'one-size-fits-all', but rather it is intended as:

- A framework for a conversation.
- A means to ensure that service users' goals and context shape the process.
- A map of the *message banking* journey within the context of the Irish SLT service.

The intention is not for every person doing *message banking* to use every toolkit document but rather to provide a range of documents from which the person can pick and choose to support the steps that they wish to complete. For this reason, there is a small amount of repetition of key points across some of the documents.

It is hoped the toolkit will enable SLTs in Ireland to consider and integrate *message banking* as a standard option for people with progressive neurological conditions affecting communication. Therefore, it is intended to provide a means for these individuals to navigate their changing identity as communicators and to exert some control over their future communication options.

The Irish Message Banking Toolkit comprises of a number of documents developed for the person who is considering embarking on the process. They include:

1. A **flowchart** so that one can see the process at a glance
To help identify the next steps for the SLT and the person undertaking *message banking*
2. **Overview of information** sheets about what is involved in *message banking*
Timing of information is important. Our research indicated that people who present with speech difficulties at the time of their diagnosis want to be told about banking their speech as soon as possible and, if they choose to record, should be encouraged to start before further speech deterioration occurs. However, those with no present but likely potential speech difficulties would prefer to have time to adjust to their diagnosis and their current symptoms before considering an intervention such as *message banking*. Therefore, some people will opt to take an initial overview leaflet and return to their SLT for further information in the future if/when they feel ready
3. **Procedural information sheets** relating to each step of the process
More detailed information for each part of the process (e.g. phrase generation tips)
4. A number of **'how-to' documents** about the practicalities of doing *message banking*
Support for using technical equipment (e.g. voice recorders, computer files)
5. A **form** to retain important account information
A central place to note storage of recordings/passwords to help retrieve them should the person wish to use them on an electronic communication device in the future



The Irish Message Banking Project

The production of this toolkit represents the work of a *message banking* project made possible by a grant from Research Motor Neurone (RMN). This project has been carried out in two phases.

Phase One: A clinical research collaboration between:

- The Speech & Language Therapy (SLT) Department, Beaumont Hospital, Dublin
- The Department of Clinical Speech & Language Studies, Trinity College, Dublin

This phase involved steps to understand the perspectives of our service users through an initial focus group and a small research study involving group-based delivery of the intervention of *message banking*. Thematic analysis of the participants' views on the experience of *message banking* informed SLT practice.

Phase Two: The group expanded to include:

- The Assistive Technology & Specialised Seating Department, Central Remedial Clinic, Dublin

This phase focused on merging existing *message banking* resources across services. The end products are the pathway and the information documents in this toolkit. In addition to our own clinical experience, much of the feedback from service users in phase 1 has been used to shape these toolkit handouts.

The Irish Message Banking Project has been reported in the following poster/oral presentations with an article in preparation (further information available on request).

Doyle, L. & Jagoe, C. (2014). The Development of Message Banking as a Patient-Driven Clinical Tool. Poster presented at the 25th International Symposium of ALS, 5 - 7 December 2014, Belgium.

Doyle, L. & Jagoe, C. (2016). Message Banking: Impact on Quality of Life of People with ALS/MND. Paper presented at the ALS/MND Allied Professionals Forum, 6th December 2016, Dublin.

Jagoe, C. & Doyle, L. (2016). Experiences of Message Banking: The expectations of people with MND and the impact of engaging in message banking on sense of agency. Paper presented at the conference of the International Association of Logopedics & Phoniatrics, August 2016, Dublin.

Doyle, L. & Jagoe, C. (2017). Patient experiences of Message Banking: Implications for Clinical Practice. Paper presented at the conference of the Irish Association of speech & Language Therapists, April 2017, Dublin.

Doyle, L., Fitzsimons, C. & Jagoe, C. (2019). The Collaborative Development of an Irish Message Banking Pathway. Paper presented at the conference of the Irish Association of speech & Language Therapists, May 2019, Dublin.

Jagoe, C. & Doyle, L. (in preparation). Message banking with people with MND: the impact on quality of life and sense of hope.



All Toolkit documents are available to download from:

- The 'Clinic Related Information' section of www.mnd.ie (transitioning in 2021 to www.rmn.ie)
- The 'IASLT Members' area of www.iaslt.ie



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