

# Collaborare: Unleashing the power of patient voices using AI

- **Establishing Patient-Validated Methodology**

Focusing on the use of patient experience data for orphan medicines. This includes the development of a patient-validated methodology to capture and utilize patient-reported outcomes (PROs), patient preferences (PPs), and patient engagement (PE)

- **Overcoming Data Collection Challenges**

Addressing key challenges in patient data collection: lack of standardized methods, cultural gaps in patient organizations, and the absence of a systematic methodology for initiating the process.

- **AI-Driven Approach**

Employing AI to facilitate the initial capture and analysis of patient experience data, particularly in the context of orphan medicines. This involves generating a list of potential patient-reported outcome measures (PROMs) and validating them for major contributions to patient care.

- **Early dialog between EMA and EURORDIS**

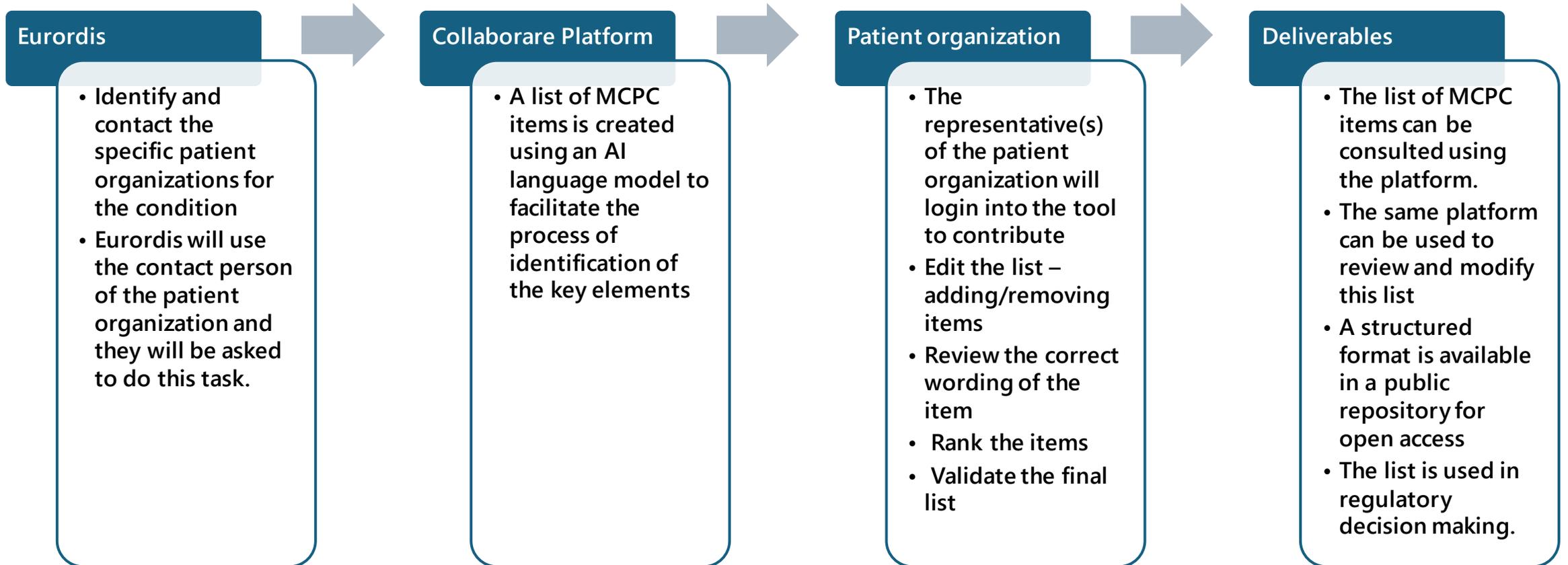
Collaborative effort with the European Medicines Agency (EMA) and EURORDIS. This includes the recognition of the importance of patient data in medicine development and regulatory decision-making, and the joint effort in developing robust methodologies for capturing comprehensive patient information.

# How Collaborare works



An initiative led by EURORDIS to enhance patient experience data through community collaboration with the aim to identify and share Major Contribution to Patient Care (MCPC). EURORDIS is leading a project to improve the way we understand patients' experiences with rare diseases. They are doing this by working together with the community.

# The workflow



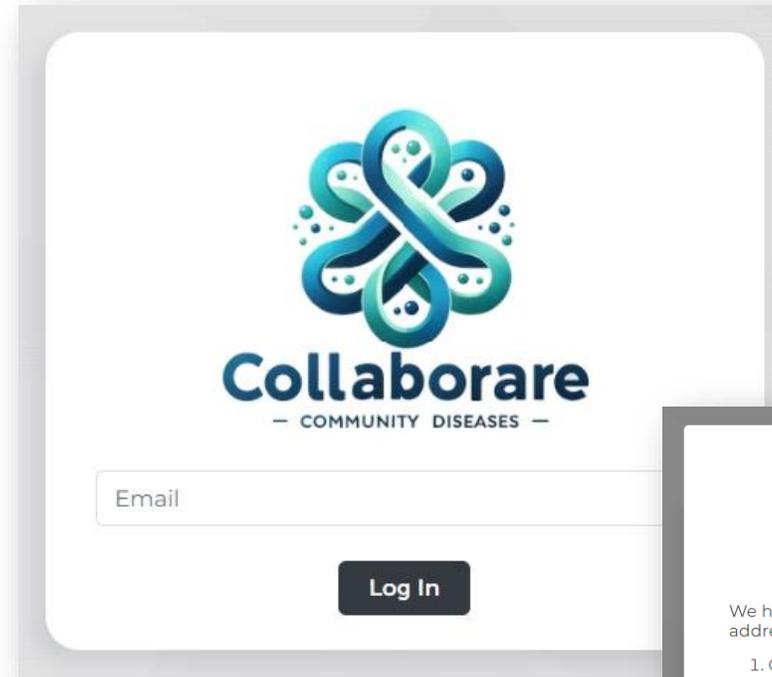
# Eurordis starts the process

- Identify and contact the specific patient organizations for the condition
- Eurordis will use the contact person of the patient organization and they will be asked to do this task.

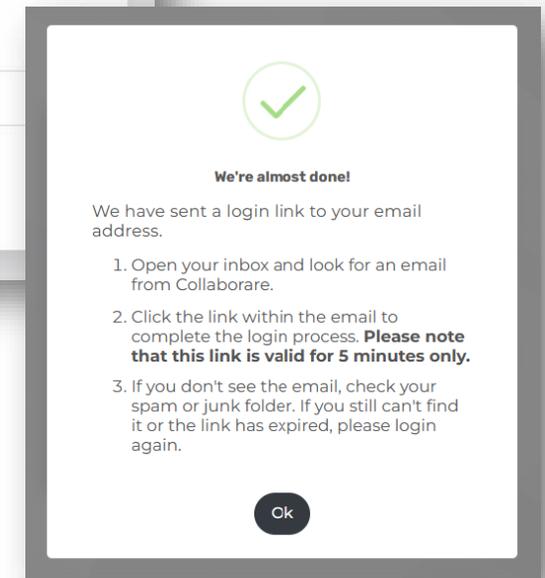


# Patient organization

- The representative(s) of the patient organization will login into the tool to contribute
- Just validated contact will have access to this process to keep data quality



The image shows a login form for Collaborare. At the top center is the Collaborare logo, which consists of a stylized blue and green knot-like shape with small circles around it. Below the logo is the text "Collaborare" in a bold, blue font, followed by "— COMMUNITY DISEASES —" in a smaller, grey font. Below this is a white input field with the placeholder text "Email". At the bottom center is a dark grey button with the text "Log In" in white.



The image shows a success message dialog box. At the top center is a green checkmark inside a circle. Below this is the text "We're almost done!" in bold. Underneath is the text "We have sent a login link to your email address." followed by a list of three instructions:

1. Open your inbox and look for an email from Collaborare.
2. Click the link within the email to complete the login process. **Please note that this link is valid for 5 minutes only.**
3. If you don't see the email, check your spam or junk folder. If you still can't find it or the link has expired, please login again.

At the bottom center is a dark grey button with the text "OK" in white.

# IA prepopulates the list of items

- A list of MCPC items is created using an AI language model to facilitate the process of identification of the key elements
- The model used is GPT-4 and not fine-tuning is used
- Initial test show big accuracy for items created
- AI is used as a facilitator to the process, to reduce friction

**Refines the list of key elements of Dravet syndrome** Delete condition

Add, reorder, or remove key characteristics for the disease. The higher up the list, the more relevant it is.

Use the drag-and-drop function on the ☰ icon to reorder and customise these lists according to your criteria and experience, contributing to a richer and more diverse knowledge.

Add

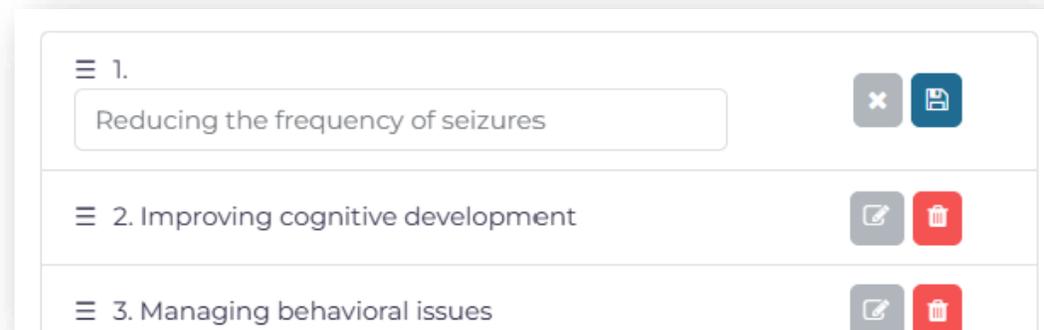
☰ 1. Reducing the frequency of seizures	 
☰ 2. Improving cognitive development	 
☰ 3. Managing behavioral issues	 
☰ 4. Improving motor skills	 
☰ 5. Reducing sleep disturbances	 
☰ 6. Managing feeding difficulties	 
☰ 7. Reducing the risk of sudden unexpected death in epilepsy (SUDEP)	 
☰ 8. Improving quality of life	 
☰ 9. Reducing the side effects of medication	 
☰ 10. Improving communication skills	 

# Patients can edit and add new items

- User must validate the list and rank the list by order of importance from a patient point of view
- Patients can edit the description to improve understanding
- If an item is missing patient representative and add a new item



This screenshot shows a user interface for adding a new item to a list. At the top, there is a text input field containing the text "Feeding problems" and a blue "Add" button to its right. Below this, a list item is displayed: "1. Reducing the frequency of seizures". To the left of the text is a hamburger menu icon. To the right of the text are two icons: a grey edit icon and a red delete icon.



This screenshot shows a patient's list of items. The first item is "1. Reducing the frequency of seizures", which has a text input field containing the same text. To the left of the text is a hamburger menu icon. To the right of the text are two icons: a grey 'x' icon and a blue document icon. Below this, two more items are listed: "2. Improving cognitive development" and "3. Managing behavioral issues". Each of these items has a hamburger menu icon to the left and edit and delete icons to the right.

# Data are published

- When process is done user save the list and data are stored
- The tool has a feature to search for a particular condition and check the MCPC items already identified

Find your condition

dravet

Dravet syndrome

Dravet syndrome

1. Reducing the frequency of seizures
2. Improving cognitive development
3. Managing behavioral issues
4. Improving motor skills
5. Reducing sleep disturbances
6. Managing feeding difficulties
7. Reducing the risk of sudden unexpected death in epilepsy (SUDEP)
8. Improving quality of life
9. Reducing the side effects of medication
10. Improving communication skills

