

“MEMOLE”

A PARTICIPATORY ACTION RESEARCH TO MAP QUALITY OF LIFE MATRIX FOR PEOPLE LIVING WITH RARE DISEASES

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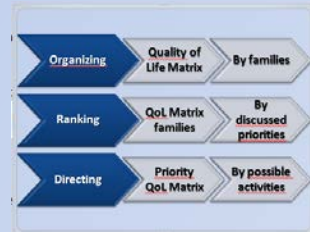
SUMMARY

Telethon, an Italian charity fostering research on rare genetic diseases, was interested in mapping the Italian patients' quality of life (QoL) which improved in the last 25 years thanks also to innovative research generating new possibilities as well as new needs in patients' life. Key factors of the survey were an **experience-based approach** and an overall **deliberative mapping** of people who live with a RD and/or a disability condition as an active partner. The state of the art was defined through **qualitative interviews** and **Socratic dialogues** in order to deliberate QoL matrix. The group deliberated 37 QoL matrix, grouped in 5 families with different priorities and especially possible actions to improve these matrix. The participatory action research underlined, through each matrix, the opportunity for Telethon to steer its mission in order to better fulfill the main patient's needs, particularly: improve access to diagnosis, treatments, information and participation in decision boards on RDs; foster independent living and a better integration with existing services; create social inclusion through a Community made up of patients, volunteers and researchers to create synergies in the society and in the development of a QoL-based research. In order to take actions and create synergies to accomplish the patients' call, Telethon has been creating a new working unit named "Patient Care Unit" that will manage these tasks, asking for patients' advice. The participants of this survey will be involved, indeed, if they are willing, in future meetings to assess the working unit strategy and development plans.

THE METHOD

The survey was initially structured to investigate the needs of people affected by a RD and their caregivers, but, after asking for patients' advice, it was decided not to map what was missing in their life, whereas to acknowledge the conditions that had an impact on their QoL. The survey was based on five steps:

- I. an evaluation of the main reports on RD in Italy. Object: to map the Italian scenario for RD
 - II. 12 interviews with people working or volunteering in PO or health institutions. Object: to determine inclusively the survey and qualitatively configure the Socratic question
 - III. 2 Socratic Dialogues base in Milan and Naples with 17 people representing different targets: patients, families, caregivers and volunteers with different geographical origins, sociocultural levels and types of disabilities. Object: to define together QoL matrix for people living with a rare disease.
 - IV. A debrief with all the participants. Object: to organize the QoL matrix who share common features in few groups; to deliberate priorities for the QoL matrix.
 - V. A final deliberative meeting with all the participants. Object: to take actions for the 2 main QoL matrix, both from the patients' and from the caregivers' point of view.
- The deliberative setting fostered the willingness of each participant to be questioned by each other. Through a step by step collaborative systematization of knowledge and experiences, the action research succeeded in maximizing the inclusion and the sharing of information with patients.



WHAT IS A SOCRATIC DIALOGUE?

- ✓ **Interaction among peers** based on a method that anticipates dissent, considering it as a resource transforms it into a reasonable consensus
- ✓ A small group of people, guided by a facilitator, **finds a precise answer to a universal question** (e.g. "What does create QoL for people living with a rare disease?").
- ✓ **Multiple perspective** are explored: **there is no single right answer.**
- ✓ The method involves group decision-making by a **reasonable consensus**, which is distinctly unlike most other modalities of group function.
- ✓ There are **no winners and losers**: while **the group as a whole** will either succeed or fail to reach the conclusion of the dialogue in the allotted time.
- ✓ Every stage in that process is attained by **collegial argument.**
- ✓ Thus every relevant question, doubt, insight, observation or objection offered by a participant is considered by the group as a whole, until everyone is satisfied by the deliberation.
- ✓ **The participants share the responsibility** with the facilitator to maintain the quality of the debate. They listen actively in order to respond effectively to what others have contributed.
- ✓ This teaches the participants to **think and speak persuasively** using the discussion to support their position.
- ✓ Participants must demonstrate **respect for different ideas, thoughts and values**, and must not interrupt each other.

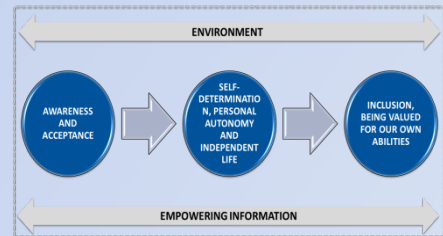
THE OUTCOMES

The main fields with impact on QoL emerged from qualitative interviews and Socratic Dialogues were: access to diagnosis, healthcare services, social services, individual & systemic empowerment, involvement, inclusive environment (social, school, work), independent housing and information networks. The deliberative mapping underlined 37 matrix.

During the prospective debrief the participants have grouped the matrix who have common features in five small families, three main QoL matrix crossed by other two:

1. awareness and acceptance
2. self-determination, personal autonomy and independent life
3. inclusion, being valued for our own abilities
4. crossing matrix: empowering information
5. crossing matrix: environment

The third matrix (inclusion) was recommended as the main priority by caregivers, whereas patients defined information, the crossing matrix, as the most important. In particular, patients indicated the need to improve information across all the fields, especially in scientific results and in the communication between patients and clinicians. Only after empowering everyone's personal capacity building, people living with a RD can create assumptions for social inclusion and appreciation of everyone abilities. The environment can then become a key factor to allow access to education, employment, relationships and the possibility to escape a condition of invisibility.



In the last meeting the participants deliberated for the two priority matrix some possible actions that can be taken into account by all the actors of the Rd scenario: Telethon, the Patient Organizations, the Government, the clinicians, etc.

Target	Activities
Patients	Training for patients on Rd, research;
and families	A better integration of the different Help lines; PO are the first point of information on the disease, orphan drugs, rehabilitations (peer to peer information, validated by the clinicians); Sharing our own experiences in Rd with the others families and patients, in order to empower them
Clinicians	High quality Training, also provided by patients ; Training in communication (how to communicate a diagnosis); Develop the diagnostic doubt.
Media	PO should contribute to give very high quality contents to media; Information should create inclusion for fragile people; Raise awareness on RD.

Inclusion comes after giving a proper value to everyone abilities, according to everyone potential, removing the barriers to mobility, creating new possibilities at school, work, but even at home. It's mandatory to:

- ✓ make projects for everyone, according to human differences
- ✓ adopt a comprehensive language
- ✓ be proactive
- ✓ educate children to human differences

PARTICIPANTS

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| <ul style="list-style-type: none"> Tonino Aceti, interviewed Anna Ambrosini, observer Renza Barbon Galluppi, interviewed Daniela Baldessari, observer Simona Bellagambi, observer Emanuela Bertini, interviewed Monica Bertolotti, Socratic dialogue Marina Bianchi, Socratic dialogue Ives Brizzi, Socratic dialogue Giulietta Cafiero, Socratic dialogue Anna Maria Cazzato, observer and co-author Sara Casati, scientific responsible Antonella Cimaglia, interviewed Wanda Danzi, interviewed | <ul style="list-style-type: none"> Alessia Daturi, observer and co-author Alberto Fontana, interviewed Marina Garcea, Socratic dialogue Patrizia Gentile, Socratic dialogue Tommasina Iorno, interviewed Renato La Cara, Socratic dialogue Rina Licusato, Socratic dialogue Maurizio Nicosia, Socratic dialogue Anita Pallara, Socratic dialogue Barbara Pisano, Socratic dialogue Renato Pocaterra, interviewed Susanna Pozzi, observer Marco Rasconi, interviewed | <ul style="list-style-type: none"> Cristina Rebagliati, Socratic dialogue Rodolfo Schiavo, observer Alessandra Scoglio, Socratic dialogue Angela Serrentino, Socratic dialogue Marco Solci, Socratic dialogue Simona Spinoglio, interviewed Roberta Speciale, observer Roberto Speciale, interviewed Domenico Tripodi, Socratic dialogue Manuela Vaccarotto, interviewed Daniela Vettosi, Socratic dialogue |
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