

# PLAYING CARDS WITH BIOBANKS:

# A TOOL FOR PROMOTING PUBLIC ENGAGEMENT

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## The context

The assurance of public support is vital to the future sustainability of the biobanks. Therefore the **involvement of citizens** in the biobanking is crucial for building and maintaining public trust.

Recognising the importance of engaging a liaison with public, **three Ligurian Biobanks**, two of which are RD-biobank members of the Telethon Network of Genetic Biobanks (Figure 1), participated in a local initiative organised in collaboration with A.Li.Sa. (Regional Health Authority) and BBMRI.it within the European Biotech Week 2017.

Focus of the event, held in Genoa (Italy) in September 2017, was the dissemination of the biobanks' services and the increase of the public awareness.

## The idea: a card game



The objective was pursued by developing an interactive **ad hoc game card** which consisted of (i) a dice; (ii) a deck of cards, each containing multi-choice questions on six biobanking topics (Figure 2); and (iii) six descriptive fiches (Figure 3).

**Six topics** were identified and each one was matched up with **six different colours**, as follows:

### RECURRENT WORDS

Definition of the main "words" of biobanking, such as biobank, types of biobanks, biological samples and associated data, user, participant and informed consent

### VALUE

Explanation of the biobank's value and its key role in research

### MAIN ACTIVITIES

Detailed description of the biobank's activities (i.e. sample collection, processing, storage and distribution)

### ACTORS

Introduction of the different actors revolving around the biobanking field, their roles and competence needed

### GOVERNANCE & ELSI

Description of the fundamental organisational and logistical aspects, including ELSI ones

### ALLIANCE

Explanation of the importance of building alliance with both other networks/infrastructures and lay members

To stimulate the discussion between the player and the game facilitator (i.e. biobanker) on the various biobanking aspects, **six descriptive fiches** (Figure 3) explaining the relevant topics were designed and gathered in a booklet that eventually was given to the players to foster the spread of biobanking.

Getting in the game, the cards, gathered by the six topics represented by diverse colours, were chosen by the player(s) by rolling the dice. Each card included a question on the relevant topic with three alternative answers of which only one was the correct answer.

## The results

Thanks to the positive interaction created by the game, the facilitators had the opportunity to discuss with the players the importance of biobanking and networking in the field of rare diseases via presentations and videos concerning some projects such as **Telethon Network of Genetic Biobanks** and **RD-Connect**. The event was well-attended by approximately 50 people including citizens, students, health professionals and journalists. A news conference was also held by the regional councillor of healthcare, social policy and security giving visibility to the event also on local television.

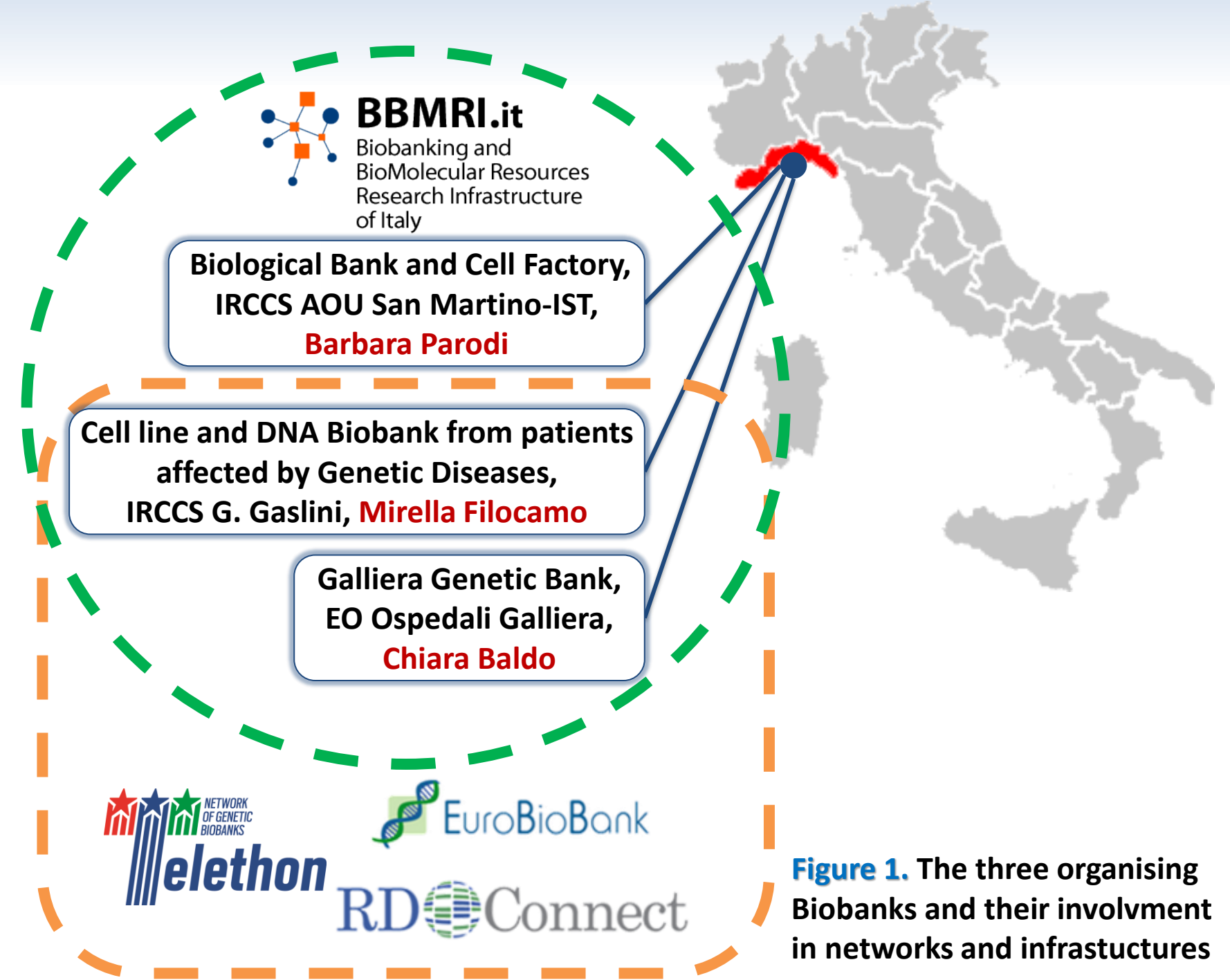


Figure 1. The three organising Biobanks and their involvement in networks and infrastructures



Figure 2. Dice and cards

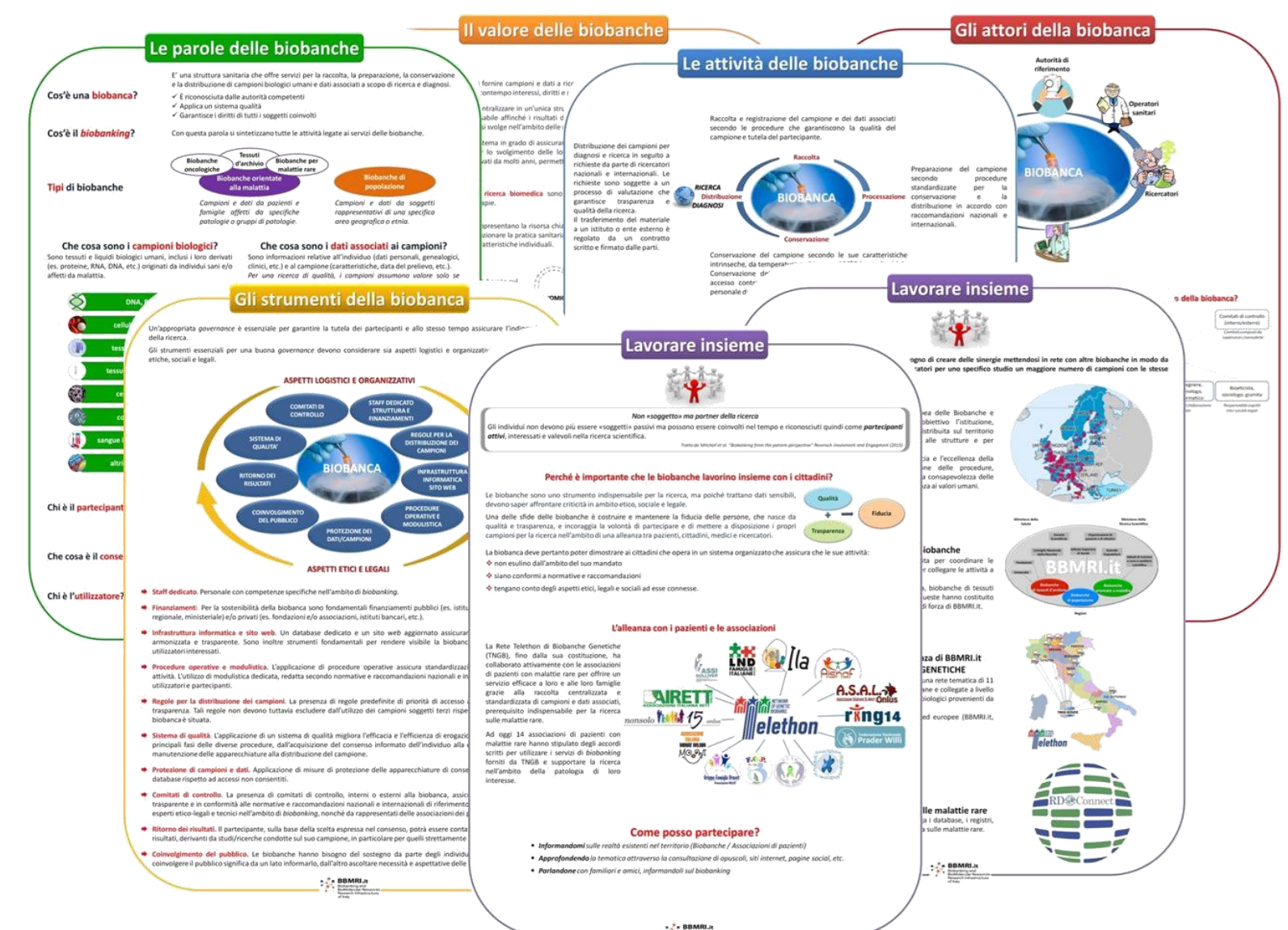


Figure 3. Descriptive fiches on biobanking topics. To be noted that the topic "Alliance" was split in two sub-topics: "Alliance among biobanks/networks" and "Alliance with patient associations and lay members"