

Designing a Public Awareness Campaign on Biobanks with Participatory Research Techniques

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Biobanks and the Belgian Research Ecosystem

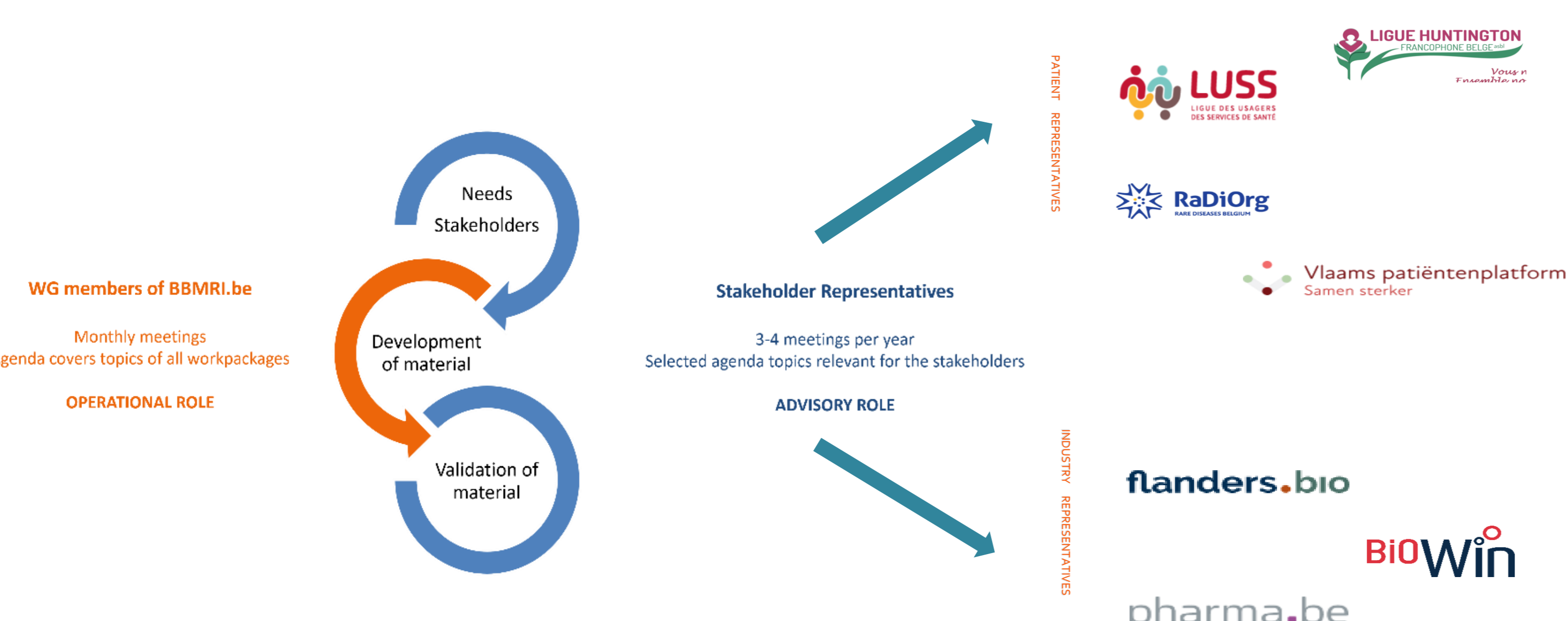
Biobanks are the cornerstone of human research studies. These are resources that store human body materials and associated data for researchers. Biobanks are a strong asset for Belgian university hospitals and academic research centers. However, biobanks do not gather much interest in the media or in general health communications in Belgium.

BBMRI.be, a not-for-profit initiative that connects 20 Belgian public biobanks, is concerned by this lack of information in the public sphere



Stakeholders' Involvement

To propose solutions to enhance public and patients' interest on biobanking - and on research in general - the BBMRI.be Stakeholder Involvement Group (BBMRI-SIG) has been formed. The group's mission is to gather together scientists, patients, members of patient organisations, professionals from pharmaceutical and biotechnology companies, biobankers and hospital representatives, and to foster collaborations between stakeholders.



Participatory Research

To tackle the lack of awareness in the public sphere, the BBMRI.be-SIG and its partners have engaged patients and patients' organisations in public and semi-public participatory activities like workshops, visits in anatomopathological laboratory and focus groups.

Phase 1 : Experiences and perceptions (2)

Do you know which documentation is available from the biobank in your institute?

- Do you use this documentation?
- How often?
- For which purposes?

Phase 2 : What others do ? On What ?

<https://www.biopankki.fi/en/>

Participation in biobank research

Phase 3: Dreaming our own Campaign

- What information on biobanks is needed?
 - Patient brochure
 - Information folder for the broad public?
 - Information for researchers/industry?
 - Educational material for students/schools?
 - ...
- Which information should be in it?
- How should it be made available?
 - Printed folder
 - Website
 - ...

WORKSHOP

BIOBANKS

During this first communication workshop, we discussed the communication on biobanks with different stakeholders in three different phases.

BBMRI.be organized in collaboration with the Jules Bordet Institute and the LUSS (League of health users), a biobank info day to discuss the way biobanks are perceived by patients and citizens.



The results of these encounters allowed to grasp patients' understanding and perspective on biobanking, to seek their local knowledge (i.e. experience of patients with biobanking in their own care pathway), to give more transparency on hospital's activities and to explicit the integration of research into care.

Conclusion

In conclusion, BBMRI.be has the opportunity with its partners to develop a unique engagement methodology and to experience that participatory research techniques have the potential to build strong communities. Hopefully, with the aim of making biobanks more visible, the actions of this community shall result in significantly increasing research literacy of both the public and the patients and in paving the way towards a better engagement of citizens in research.