

E-HEALTH & RARE DISEASES CO-DESIGN WORKSHOP

FROM IDEA TO INNOVATIVE PROJECT REALIZATION : BRINGING THE CO-CONSTRUCTION PROCESS TO LIFE



Yribarren AS ⁽¹⁾ , Espinoza P ⁽²⁾

(1) French Foundation for Rare Diseases (2) French Society for Digital health
Contact : anne-sophie.yribarren@fondation-maladiesrares.com

Supporting by  IRCEM
Fondation d'entreprise

OBJECTIVES

Help to initiate e-health projects, targeting the major challenges for rare diseases.

In particular: reduction of diagnostic wandering and inequalities in care and life courses ⁽¹⁾.

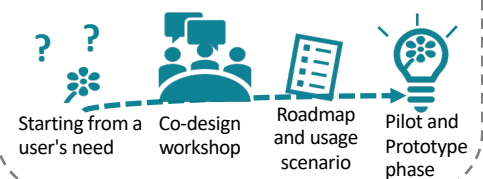
Create synergies and stimulate inter-professional dialogue between specialists of e-health and rare diseases, from the first stages of project design.

TO WHOM ?

All academical and associative actors of the rare disease ecosystem, having an idea of a concrete digital innovation: health professionals, medico-social workers, project managers, patient and family organisations, researchers, ...

METHODOLOGY of CO-CONSTRUCTION

By relying on the multidisciplinary expertise of players involved in major structuring e-health projects in France.



1ST PILOT WORKSHOP

27 JUNE 2019

in « Paris Biotech Santé » incubator

Selection of 5 emerging and innovative projects at key stages of the care process

- 1 project leading by a patient organisation
- 4 projects from rare disease reference centers

1 dedicated working day, 3 to 5 thematic experts per project team

1 roadmap as deliverable

The 5 supported projects :

- # AI-based diagnostic support tool
- # Rare Diseases Digital Health Record
- # Quality of life/natural history metadata collection tool
- # Telemedicine project for palliative care coordination
- # Educational content aggregation portal

TOPICS WORKED ON :

- Legal and regulatory framework
- Multimodal data
- Interoperable systems
- Usability, modeling of new uses
- User experience feedback, quality of life with technology
- Humanities and Social Sciences
- Financing and business models

FINDINGS AND PERSPECTIVES

THE WORKSHOP APPROACH

The concept of « co-design », adopted by project leaders and thematic experts as a means of accelerating the ideation and implementation process

The plurality of points of view (technical, medical, humanities and social sciences): considering as essential for the modelling of new uses.

THE DIGITAL REVOLUTION:

A TREMENDOUS OPPORTUNITY FOR RARE DISEASES

Multitude of rare disease applications arising from digital medicine

Organisational innovation in the rare disease ecosystem (sectors, medical networks and associations, with dedicated project teams) : a key asset for the deployment and sustainability of projects.

E-HEALTH & RARE DISEASES CO-DESIGN WORKSHOPS

Discover in 2min some testimonials to understand the approach of the workshop and its objectives.



<https://bit.ly/2VAAZ2A>

Acknowledgements : the IRCEM Corporate Foundation for its trust and financial support, Paris Biotech Santé for making its premises available free of charge

Collaborations for the 2019 edition :



(1) Plan National Maladies Rares –PNMR3 2018-2022. Partager l'innovation, un diagnostic et un traitement pour chacun.

Fondation Maladies Rares

Plateforme Maladies Rares - 96 rue Didot, 75014 Paris
www.fondation-maladiesrares.org