# 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.

## 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

## TO WHOM?

- All academic 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.

- Starting from a user’s need
- Co-design workshop
- Roadmap and usage scenario
- Pilot and Prototype phase

## 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.

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