



## Questions to ask before starting a co-design project

- ❑ How will I go about ensuring the rare disease community is involved in my work from the very beginning, including identifying needs and goals?
- ❑ How will I go about seeking expertise and input from the rare disease community? What questions will I ask?
- ❑ Who will I engage with from the rare disease community? How do I plan to engage with them?
- ❑ What steps do I need to take to achieve the goal or vision in partnership with the rare disease community?
- ❑ Is our process iterative and does it bring along the rare disease community with every iteration?
- ❑ How can I establish a safe space for storytelling? What measures do I need to take and what are the key considerations?
- ❑ What are the risks for my storytellers in sharing their lived experience? How will I support storytellers sharing their lived experience and set up mechanisms for follow-up?
- ❑ Which other key stakeholders from the sector do I need to align with?
- ❑ How can we frame and strengthen our message as a collective, and ensure the rare disease community are part of crafting that message?