

Designing a Made-in-Alberta Rare Disease Framework

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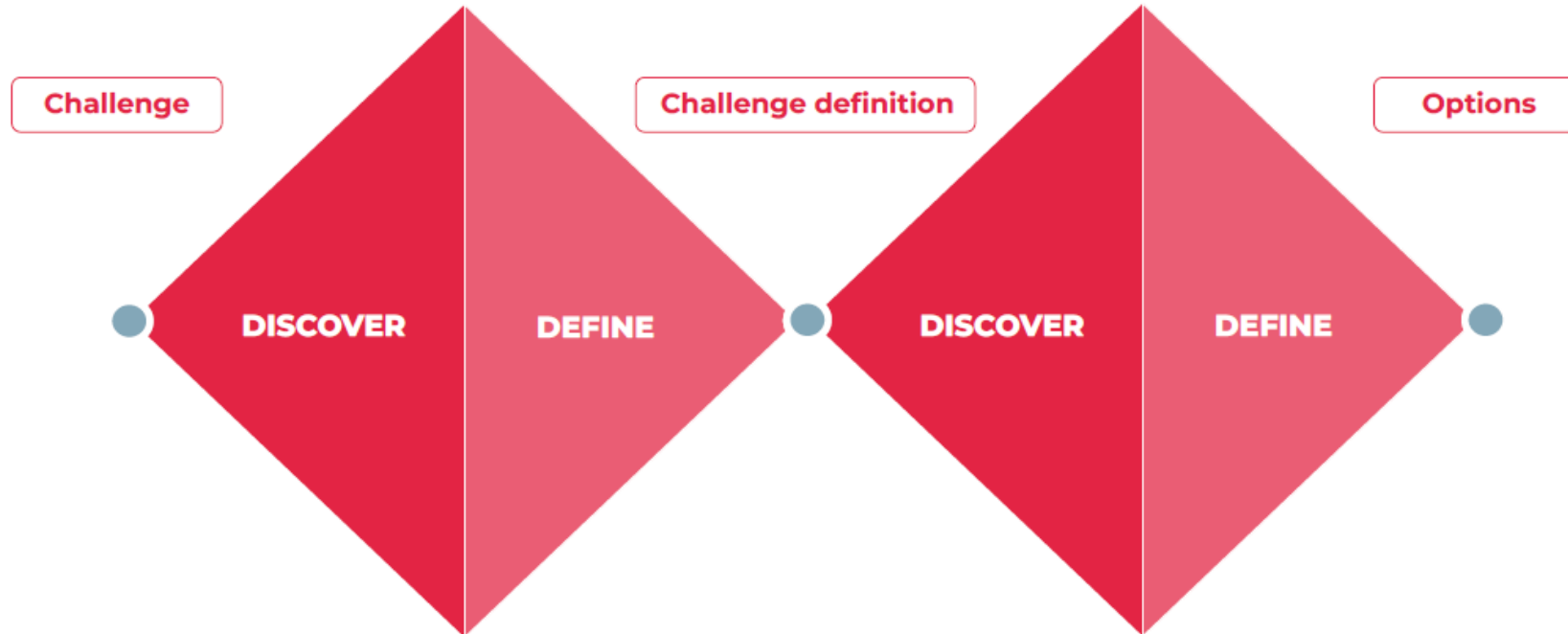
1. Generate insights through data and user experiences on the provision of care for rare disease patients and their families and caregivers in the province.
2. Understand the evidence around the current strengths and challenges in the system from different perspectives and generate potential solutions.
3. Generate guidance which enables Alberta to take a leadership role in developing a best-in-class system of care for rare disease patients and their families and caregivers.

Partners



How we did it

THE DESIGN PROCESS



Planning

Who needs to be engaged, how are we engaging them, current state of rare disease.

Discovery

Engage with experts and multiple stakeholders to gain a deep understanding of the current experience of patients and families.

Define

Share the thematic analysis with those interviewed, and identify key leverage points for change and innovation.

Develop

Finalize the patient pathway and identify policy recommendations for future implementation..

Deliver

Create a finalized report that includes pathway and policy recommendations.

- **31 interviews conducted** (11 patients, 11 clinicians, 3 from government, 4 from industry, and 2 from stakeholder/partners)
- **27 participants in the 2-day session**
 - Provincial: Patient partners and caregivers, clinicians, Bio Alberta, Health Coalition of Alberta, Institute of Health Economics, Saventic Health
 - National: CORD, CRDN, Centre iRARE, IMC & Industry partners

Preliminary Recommendations for Alberta

1. Sign the DRD bilateral agreement and claim Alberta's share of the funds
2. Prioritize efforts to increase care coordination across the rare disease pathway
3. Reduce the administrative burden on clinicians and patients; increasing time for clinical visits
4. Ensure high quality evidence generation and analytics to support rare disease research and treatment
5. Use Alberta's leadership position to advocate for improvements in the drug approval and reimbursement process

Next steps

- A draft recommendations document has been developed for the government of Alberta and shared with one of the MLAs for feedback
- Based on his insights a revised version will be presented to the Alberta Minister of Health
- A larger strategy document is also being developed with contains some more of the longer-term objectives and goals and which we hope will serve as a blueprint for work with other provincial jurisdictions