

From an idea to the real world

How to develop and adapt a co-design model to design interventions for communicating genetic diagnoses.

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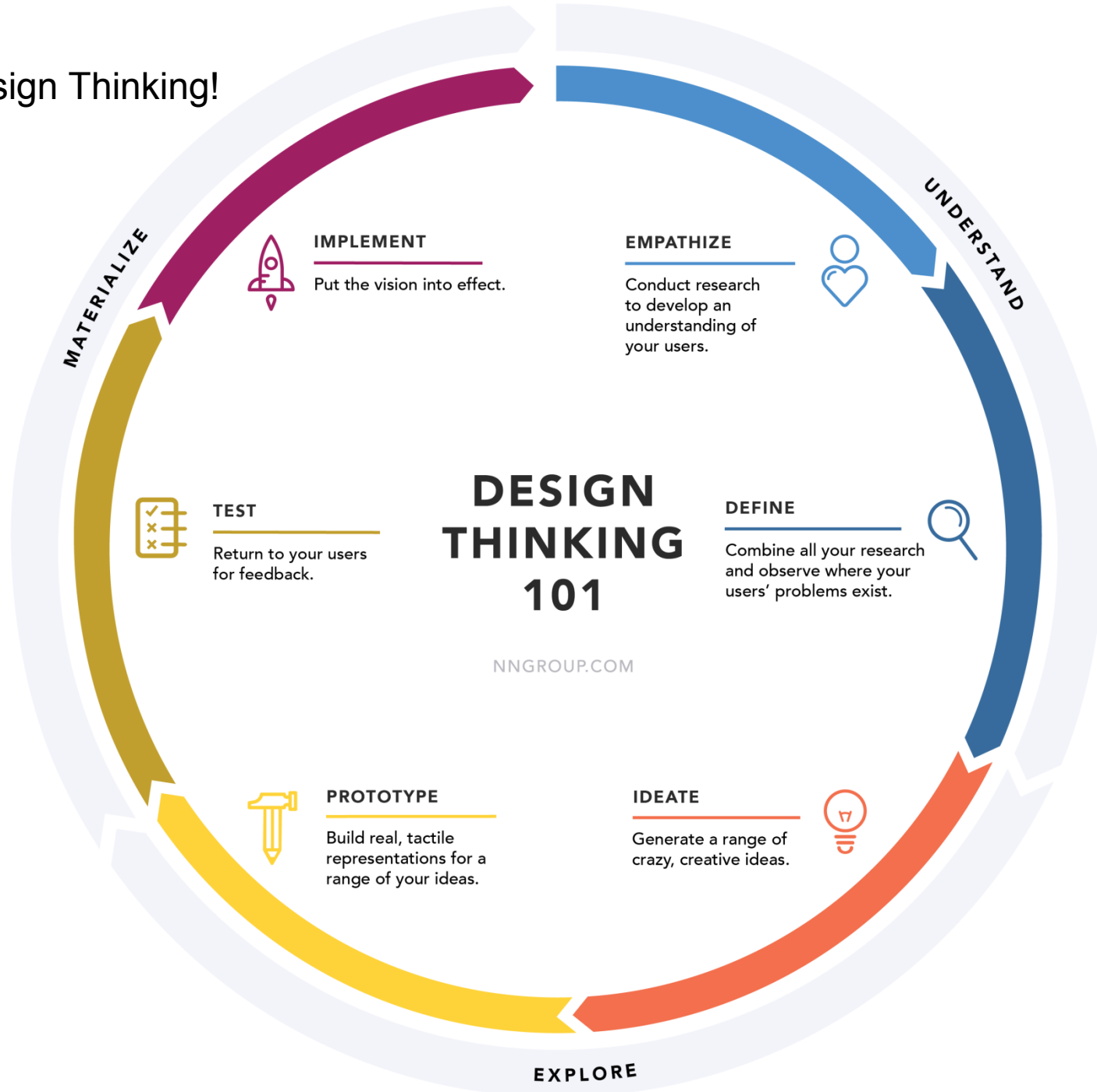
Background

- Previously worked with patients and families to co-design interventions to facilitate the sharing of genetic risk information within families.
- Joined the Solve-RD research team, to discuss sharing diagnoses / non-diagnoses between health professional and patients.

Our aim

- To collaborate with patients (and their families) and health professionals to design an intervention or service that most effectively and satisfactorily shares the outcome of a genetic / Solve-RD results for rare disease from a patient's perspective.
- Under development in two centers that have distinct cultural differences
- Part of EU Funded - Solve-RD

Use Design Thinking!



DESIGN THINKING 101

NNGROUP.COM

MATERIALIZE

UNDERSTAND

EXPLORE



IMPLEMENT

Put the vision into effect.

EMPATHIZE

Conduct research to develop an understanding of your users.



TEST

Return to your users for feedback.

DEFINE

Combine all your research and observe where your users' problems exist.



PROTOTYPE

Build real, tactile representations for a range of your ideas.

IDEATE

Generate a range of crazy, creative ideas.



Experience Based Co-Design (EBCD)

- Uses principles of design thinking
- Participatory - patients and health professionals involved in collaboration.
- Equality and equity in the approach all views and experience is valid.
- Democratic
- Results in co-design on an intervention or service

EBCD is following a six stage process using design thinking

UNDERSTANDING

EMPATHISE AND DEFINE (EBCD stage i - iii)

- i. Setting up the project.
- ii. Gathering staff experiences of providing the sequencing of results through non-participant observation and in-depth interviews.
- iii. Gathering patient and carer experiences of receiving the sequencing results through 12-15 filmed narrative based interviews.

EXPLORE (EBCD stage iv - v)

IDEATE (stage iv)

iv. Bringing staff, patients, and carers together to share their experiences and identify their shared priorities for improving the sharing of results, prompted by an edited 30 minute “trigger” film of patient narratives.

PROTOTYPE AND TEST (stage v)

v. Small groups of patients and staff work on the identified priorities (typically 4-6) over three or four months and try them in practice.

MATERIALISE

TEST and **IMPLEMENT** (EBCD stage v-vi)

vi. *A celebration and review event*

Expected outcomes

- Implement the intervention / service in a European Reference Network (ERN) - (probably ITHECA) and undertake a process evaluation to ascertain whether it is effective and what mechanisms or context of delivery make it work for patients, families and health professionals.
- Produce a manual to describe the process for other European Reference Networks (ERNs) to follow / learn from if the wish.

Examples of where experience based co-design has worked:

- Reforming health care services in more than 8 countries.
- Design of interventions to support carers
- Design of new dressings and garments for rare skin diseases.

Overview publication

Robert et al., (2015) Patients and staff as codesigners of healthcare services BMJ 2015; 350 doi:<https://doi.org/10.1136/bmj.g7714> (Published 10 February 2015) Cite this as: BMJ 2015;350:g7714

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- Previous work referenced and collaborators (SPRinG colleagues listed in the following publications:
Socio-Psychological Research in Genomics (SPRinG) Collaborative. (2016) Training Genetic Counsellors to Deliver an Innovative Therapeutic Intervention: Their views and experiences of Facilitating Multi-Family Discussion Groups. *Journal of Genetic Counselling* doi:10.1007/s10897-016-0008-0.
Socio-Psychological Research in Genomics (SPRinG) Collaborative. (2015) Developing an intervention to facilitate family communication about inherited genetic conditions and training genetic counsellors in its delivery *European Journal of Human Genetics* advance online publication, 7 October 2015; doi:10.1038/ejhg.2015.215

Thank you for listening

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