

The Nuts and Bolts of Patient Registries

MRCG workshop on practical elements of developing a patient registry

Irish and International EB Registry DEBRA Ireland

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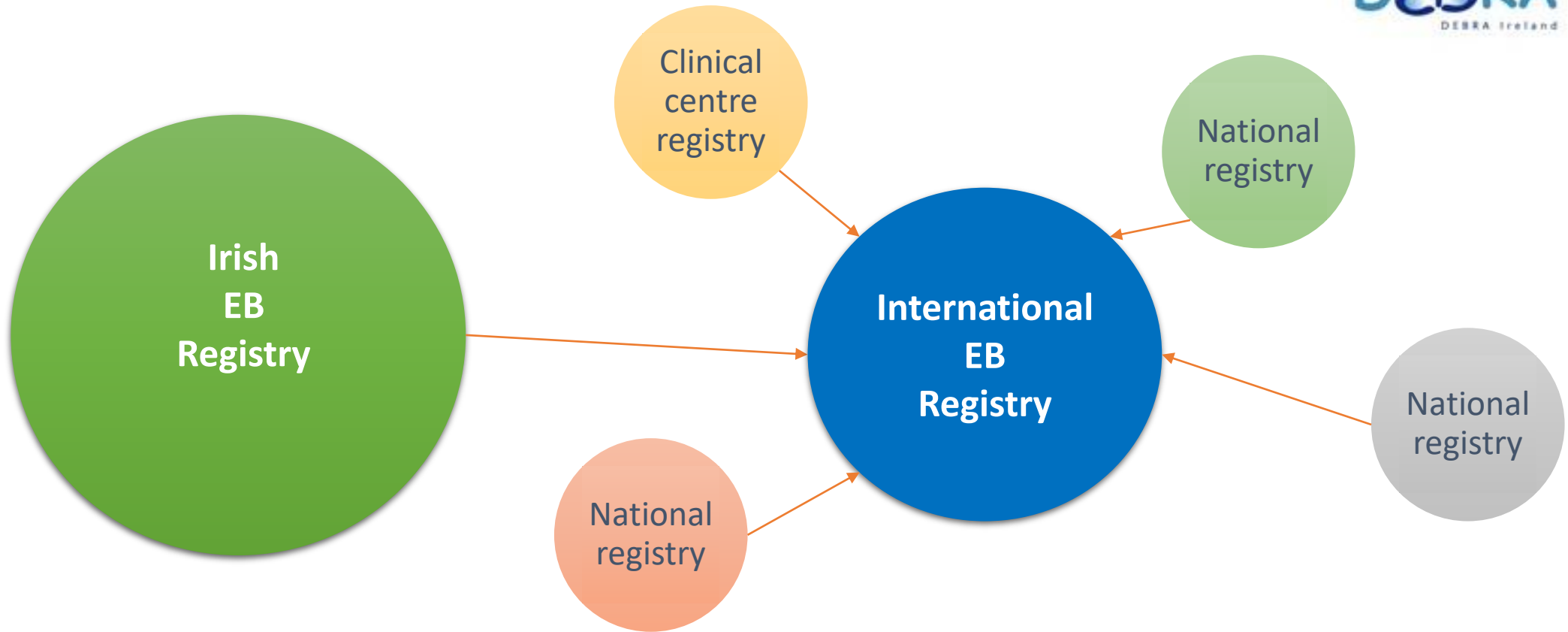


This is Casey. She has EB.

WHAT IS EB?

- ✔ EB = Epidermolysis Bullosa. A severe rare genetic skin blistering condition.
- ✔ EB = Extraordinary Butterflies. EB skin is as fragile as the wings of a butterfly.
- ✔ EB = Endless Blistering. Even gentle skin contact causes devastating wounds.
- ✔ EB = Excruciating Bandaging. When dressings stick, the skin often comes away too.
- ✔ EB = Exhausting Battle. There is no cure and a high risk of developing aggressive skin cancer.

EB = the worst disease you've never heard of.



Governance: at a national level

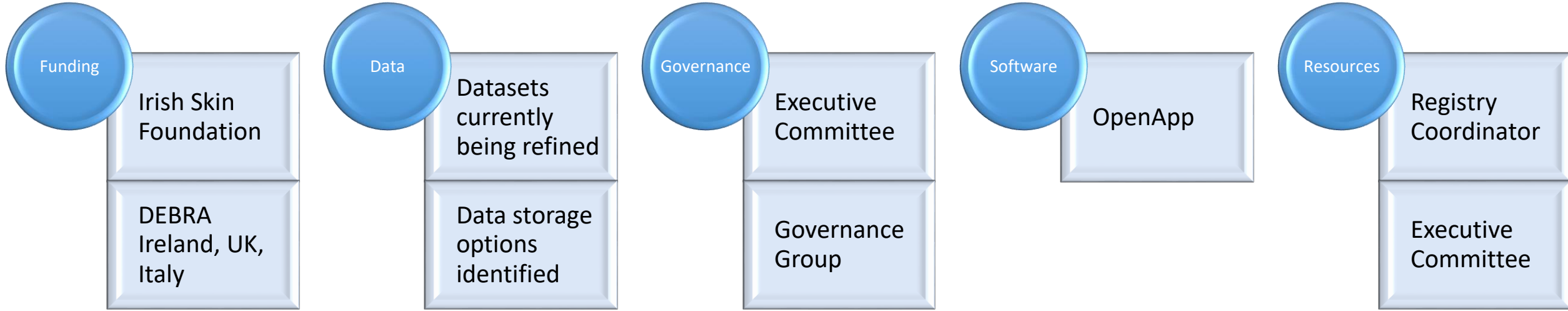
Funding: Irish Skin Foundation
& DEBRA Ireland

Governance: DEBRA International and
representatives from clinical centres

Funding: Irish Skin Foundation will
provide seed funding
DEBRA Ireland, UK, Italy

This platform can be adopted by any
other centres who wish to implement it

Stage of Development



Next Steps
Recruitment of the Registry Coordinator
Refine the consensus dataset
Formalise the Executive Committee and Governance Group





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