

Co-creating a model for the National Dementia Register

Dr Louise Hopper
Engaging Dementia Conference 2019





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PRESENTATION OUTLINE

- ✔ Background on the National Dementia Registry project
- ✔ Dementia Registries the international landscape
- ✔ Project framework how key stakeholders are involved and why their input so important
- ✔ Key benefits of developing a National Dementia Register



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Background to the National Dementia Registry Project

This piece of work has been commissioned by the HSE and National Dementia Office. The purpose is to look at the development of a model for the National Dementia Registry.

It follows on from a feasibility study carried out in 2016.

This project is being led by DCU and is being co-designed with the active and meaningful involvement of a diverse range of stakeholders who will contribute to the model development throughout the project.

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Internationally many countries have a Dementia Register?



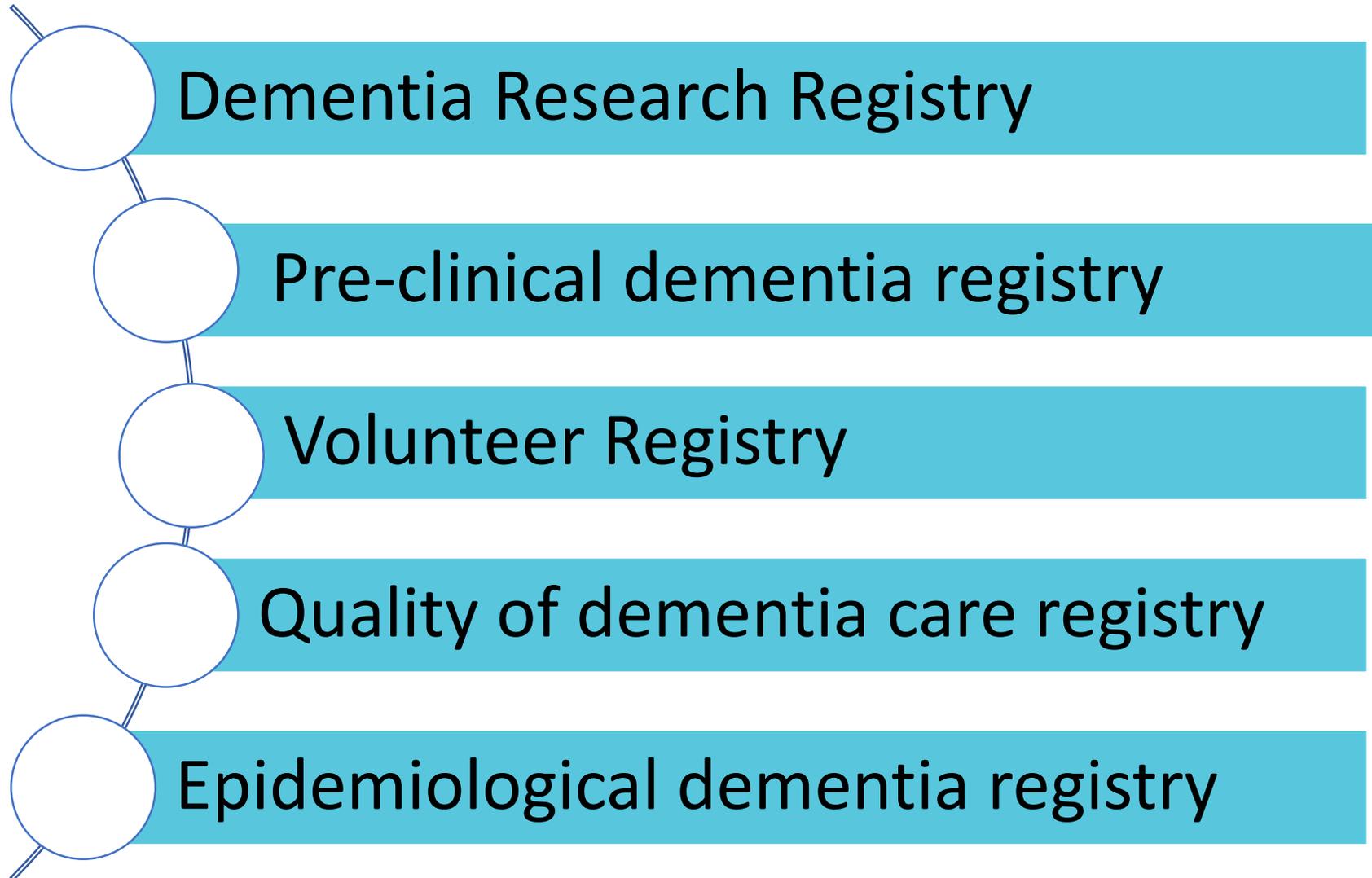
c30 dementia registries have been established internationally – these can be found in Argentina, Austria, Canada, Columbia, Denmark, France, Germany, Italy, Norway, South Korea, Spain, Sweden and numerous registries in UK and across USA
The number of dementia registries continues to grow pilots in Germany Cuba and work commencing in Australia



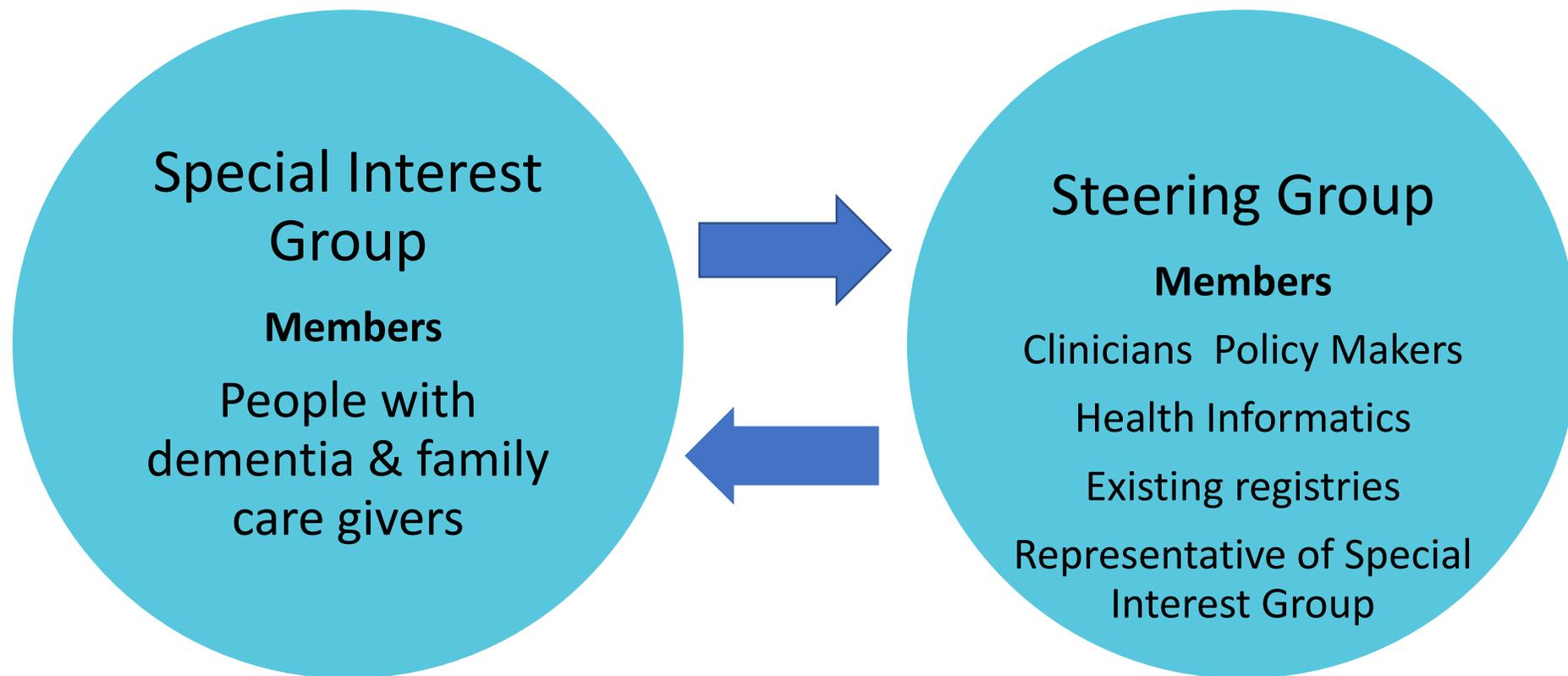
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Different types of Dementia Registries



Two working groups are providing direction and guidance to this project



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Why it is critical that we involved people with dementia in the co-design of this project

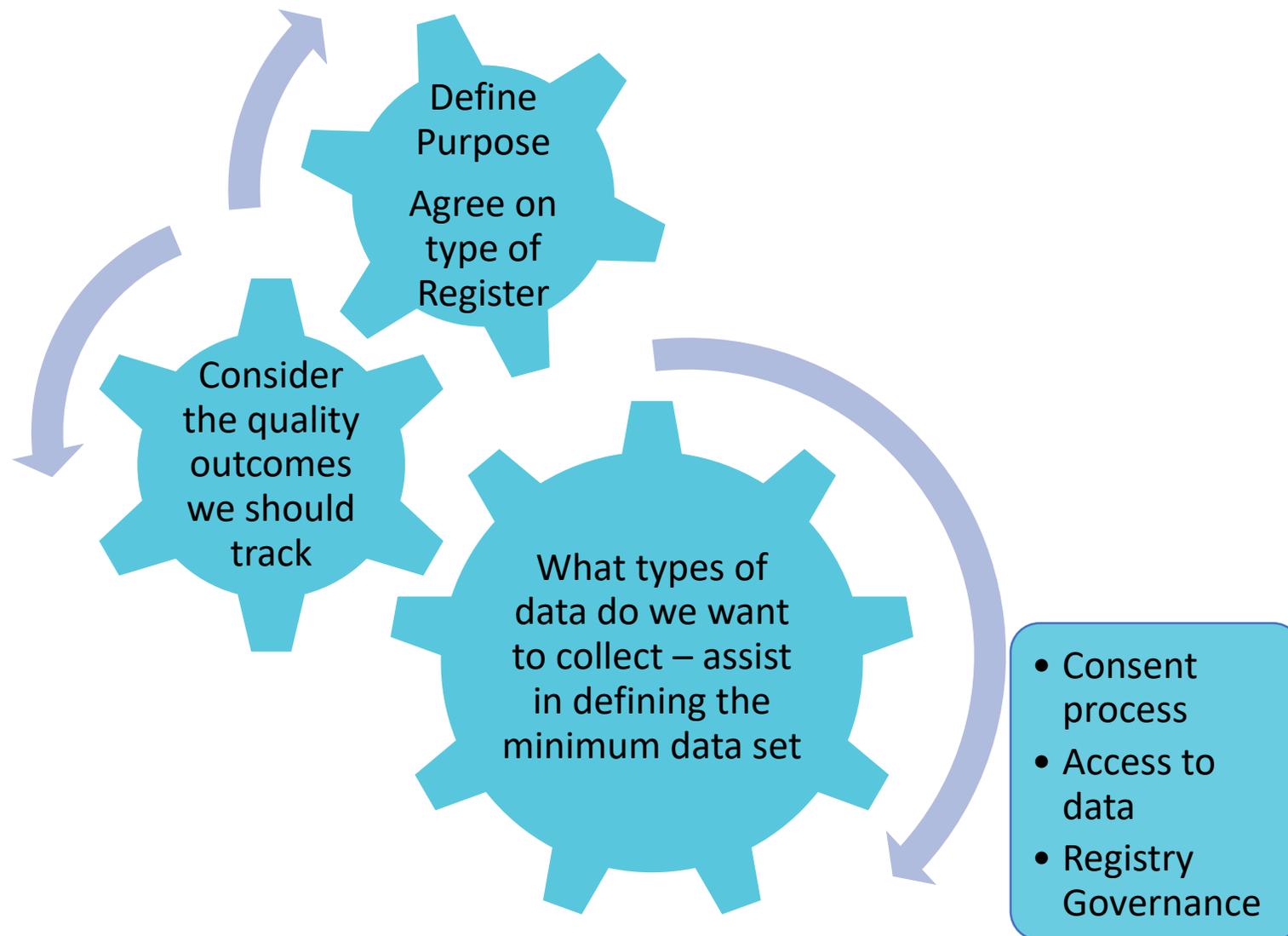
To ensure we get the model right so it is designed for what people with dementia want and need.

Bring a unique expertise from the lived experience

Opportunity to possibly help next generation who are diagnosed with dementia

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Discuss and provide direction on key registry project decisions

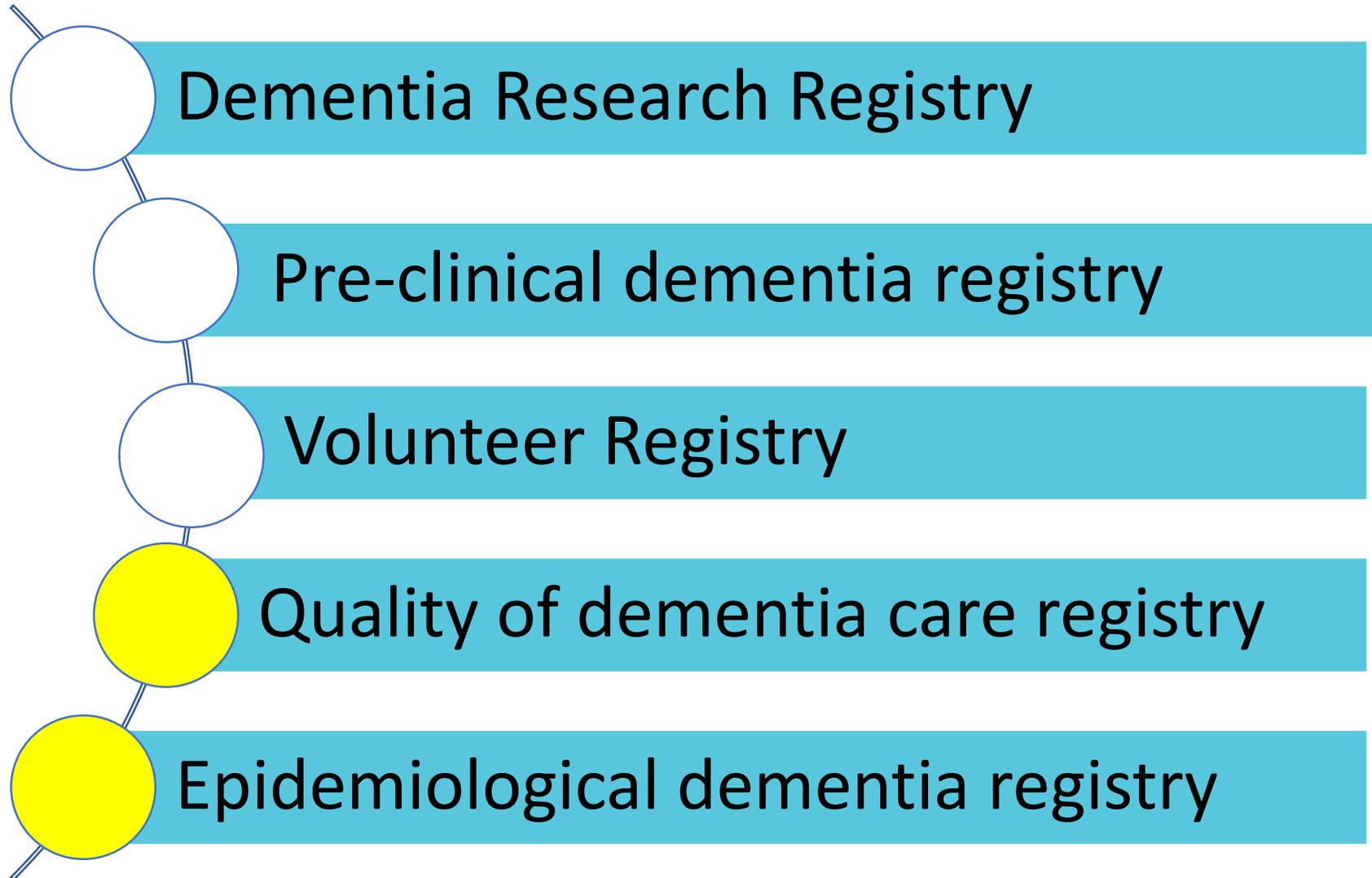


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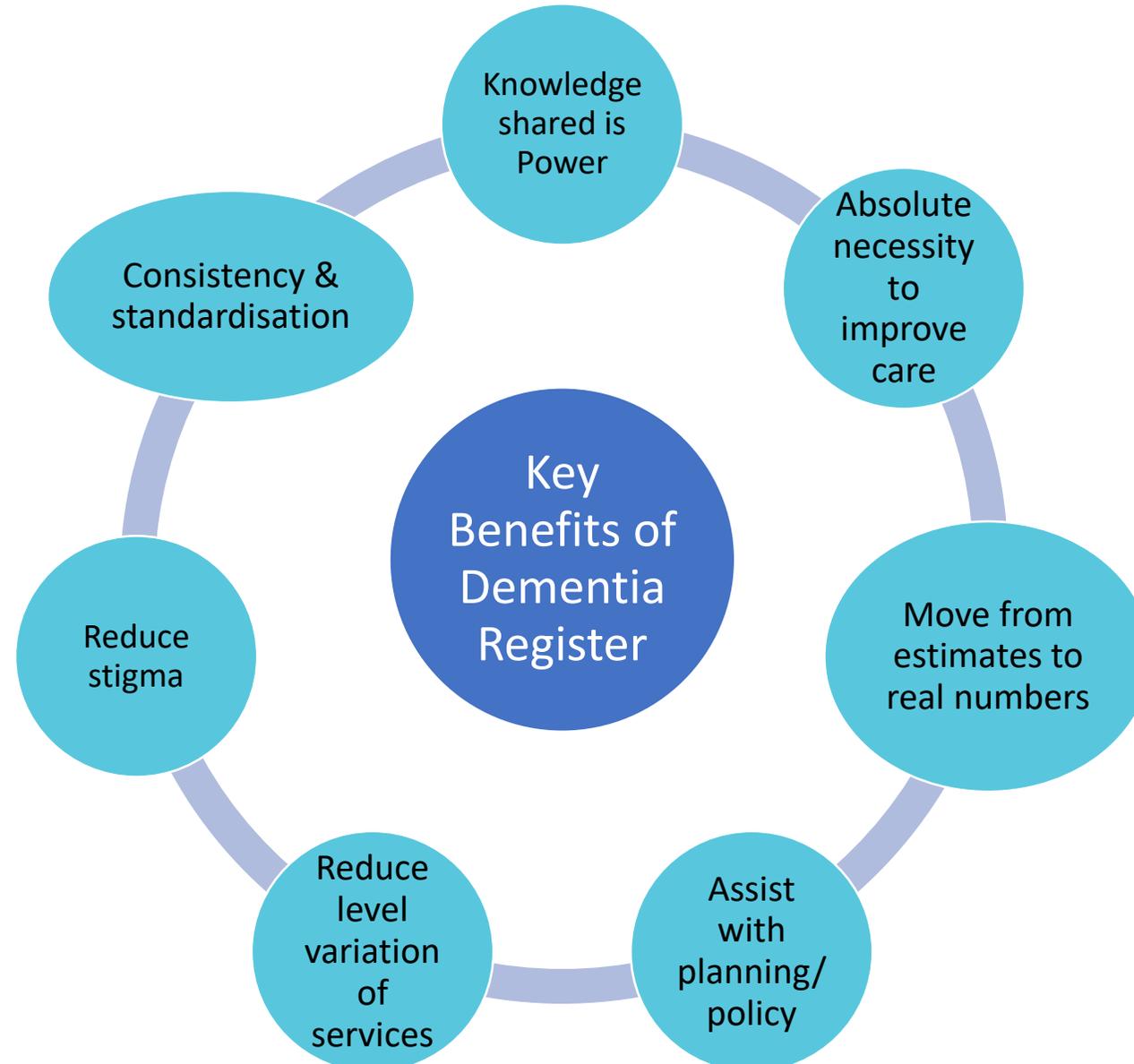
Type Dementia Registry preferred by Special Interest Group



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Key benefits identified by persons with dementia and their family care-givers



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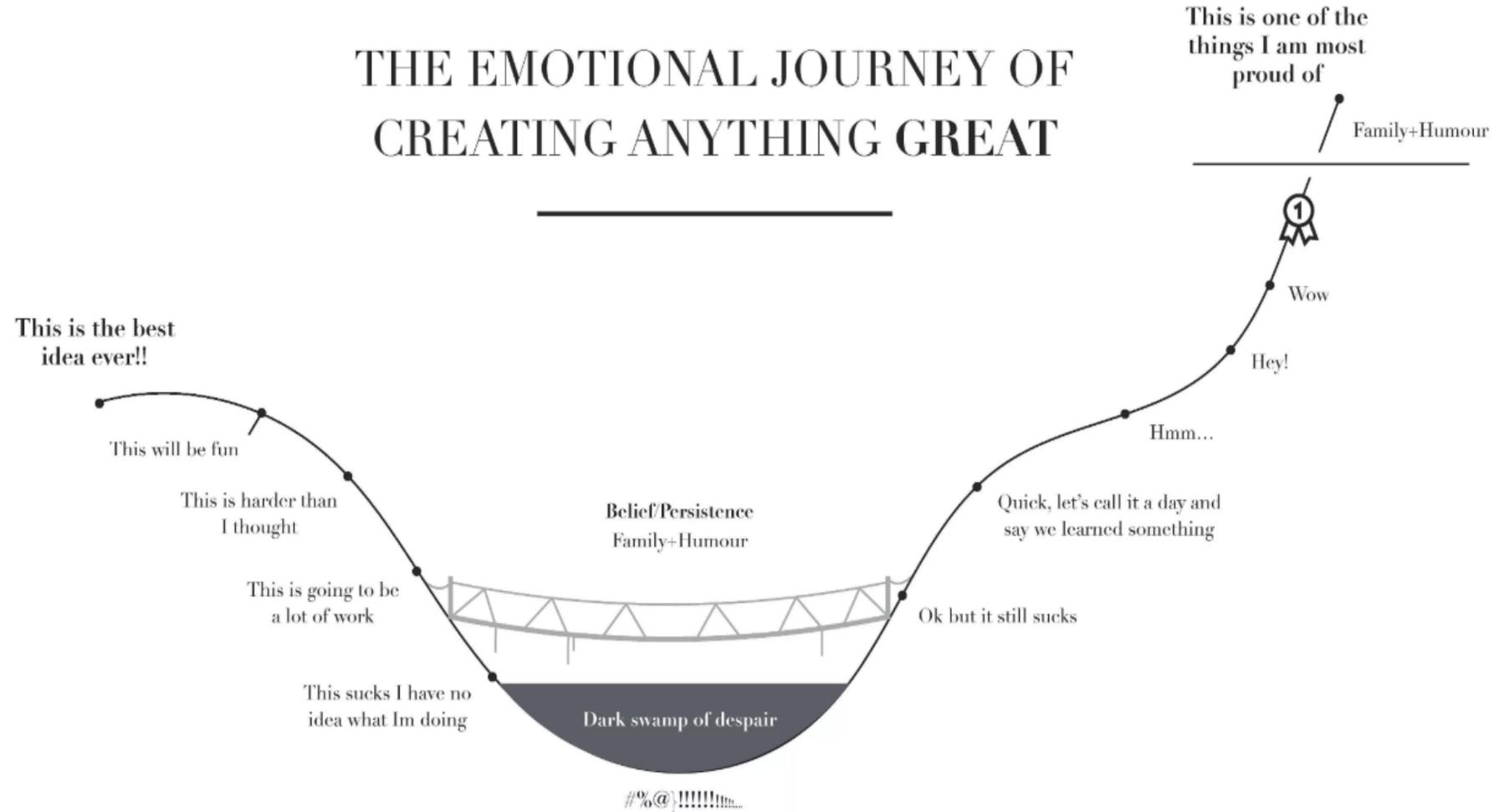
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"The Emotional Journey of Creating Anything Great" by John Saddington



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THE EMOTIONAL JOURNEY OF CREATING ANYTHING GREAT



THE EMOTIONAL JOURNEY IS INEVITABLE AND PERHAPS NECESSARY

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Closing comment

The inclusion and involvement of stakeholders is critical in developing a model that is fit for purpose, offers interoperability and long-term viability.

Engagement of people living with dementia within this framework is essential if the full potential of the registry is to be reached.

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