

# Co-creating a model for the National Dementia Register

Dr Louise Hopper  
*Engaging Dementia Conference 2019*





Ollscoil Chathair  
Bhaile Átha Cliath  
Dublin City University

# 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



Ollscoil Chathair  
Bhaile Átha Cliath  
Dublin City University

# 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.

National  
**Dementia**  
Office Leadership, Integration  
and Innovation



Ollscoil Chathair  
Bhaile Átha Cliath  
Dublin City University

National  
**Dementia**  
Office Leadership, Integration  
and Innovation

# Internationally many countries have a Dementia Register?



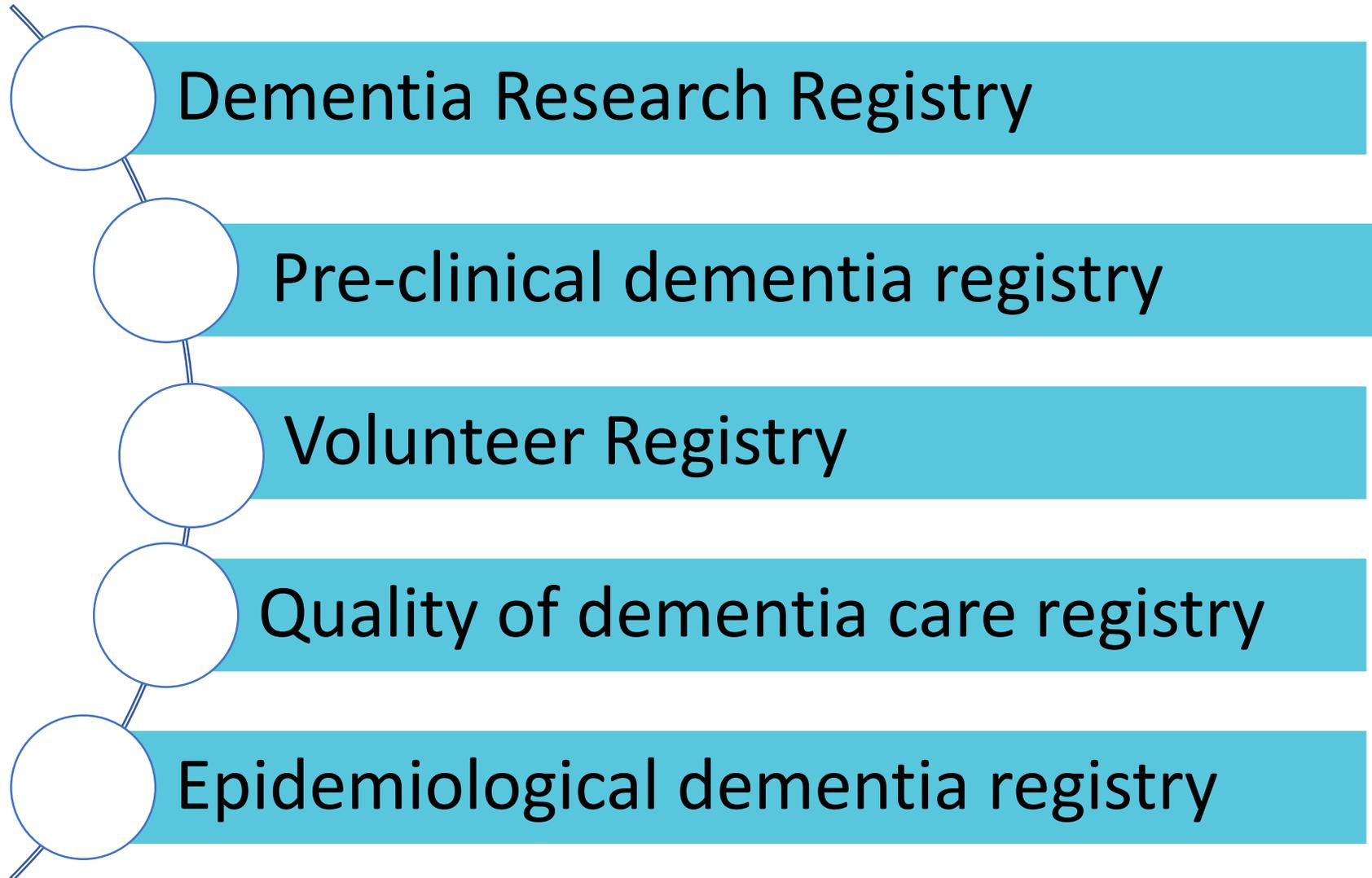
**c30 dementia registries have been established internationally –** these can be found in Argentina, Austria, Canada, Columbia, Denmark, France, Germany, Italy, Norway, South Korea, Spain, Sweden and numerous registries in UK and across USA  
**The number of dementia registries continues to grow pilots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



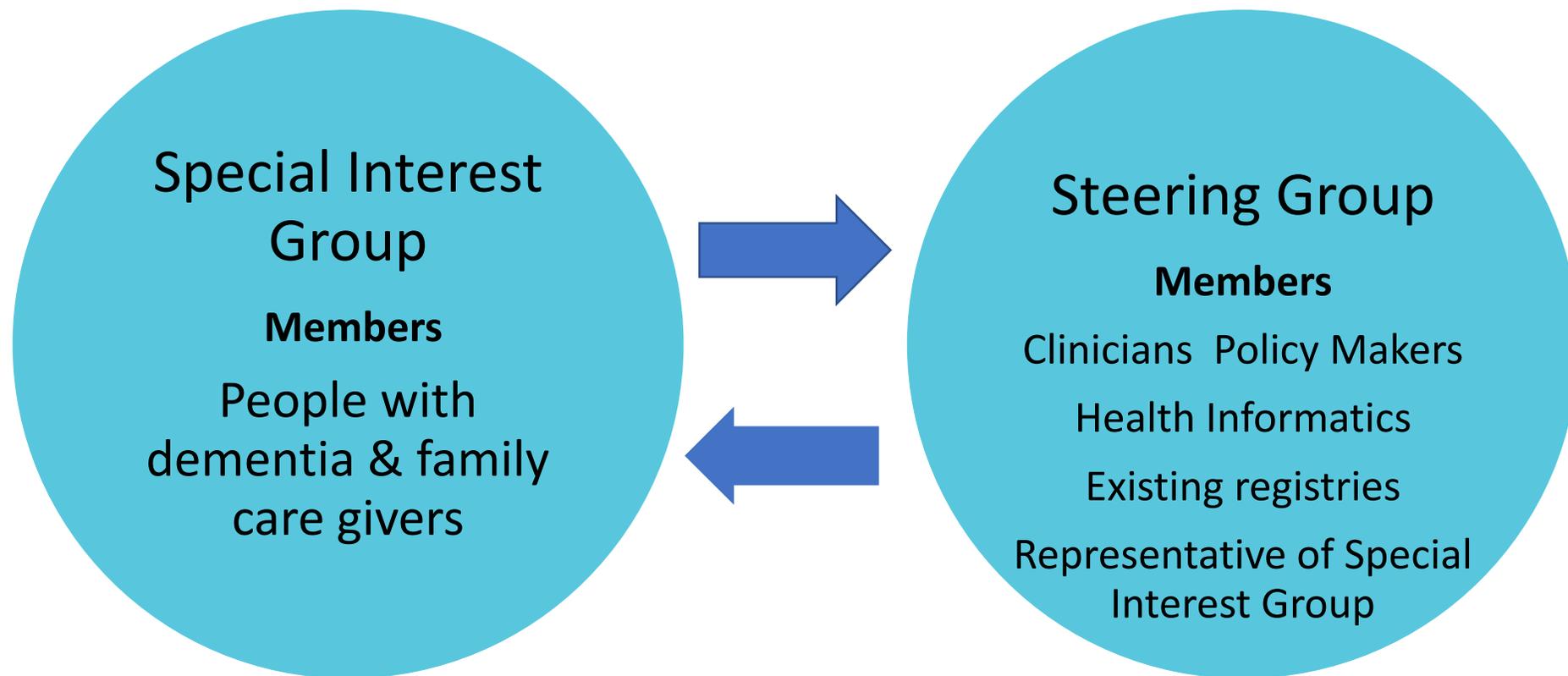
Ollscoil Chathair  
Bhaile Átha Cliath  
Dublin City University

National  
**Dementia**  
Office Leadership, Integration  
and Innovation

# Different types of Dementia Registries



# Two working groups are providing direction and guidance to this project





Ollscoil Chathair  
Bhaile Átha Cliath  
Dublin City University

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

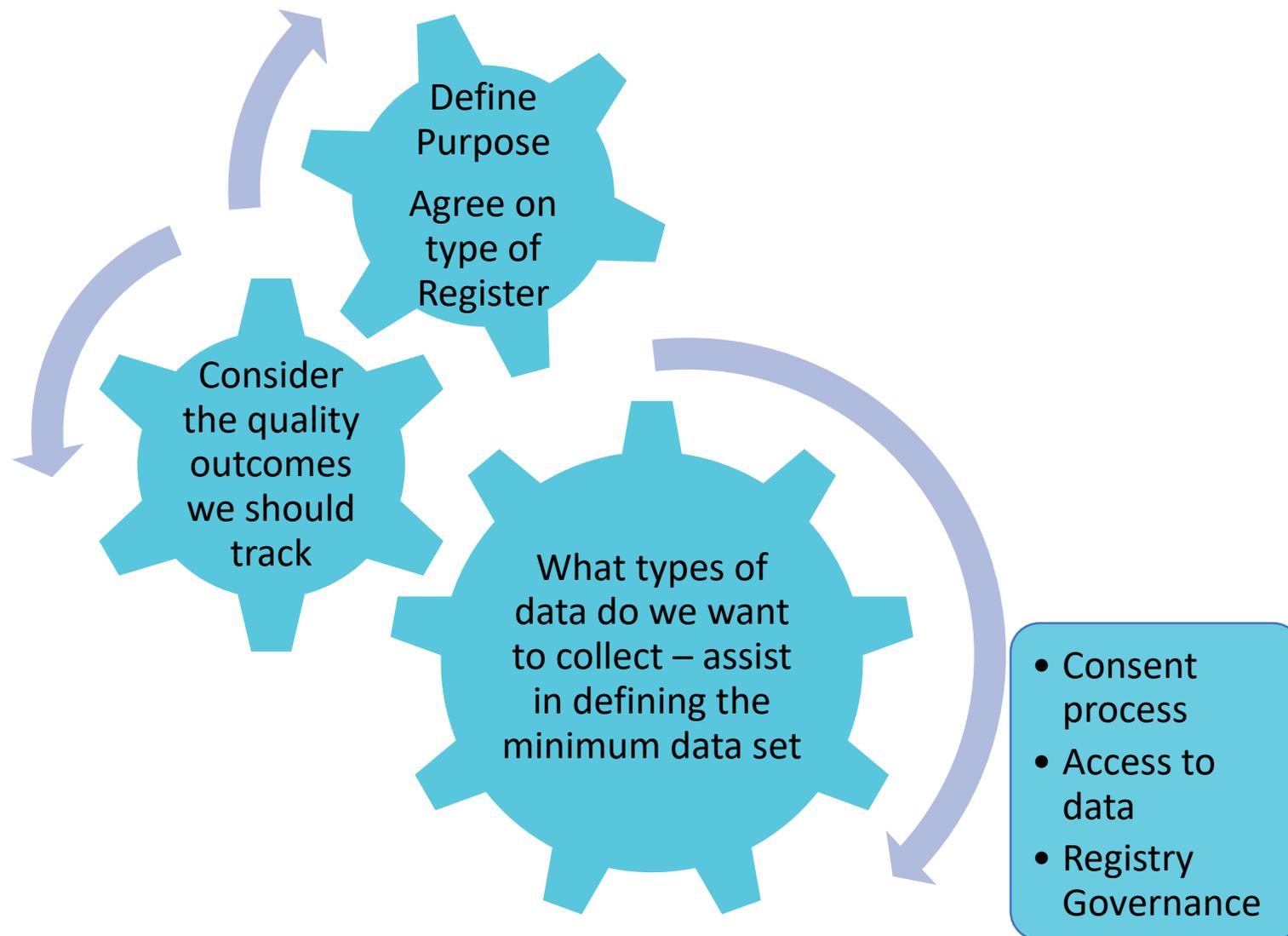
To ensure we get the model right so it is designed for what people with dementia want and need.

Bring a unique expertise from the lived experience

Opportunity to possibly help next generation who are diagnosed with dementia

National  
**Dementia**  
Office Leadership, Integration  
and Innovation

# Discuss and provide direction on key registry project decisions

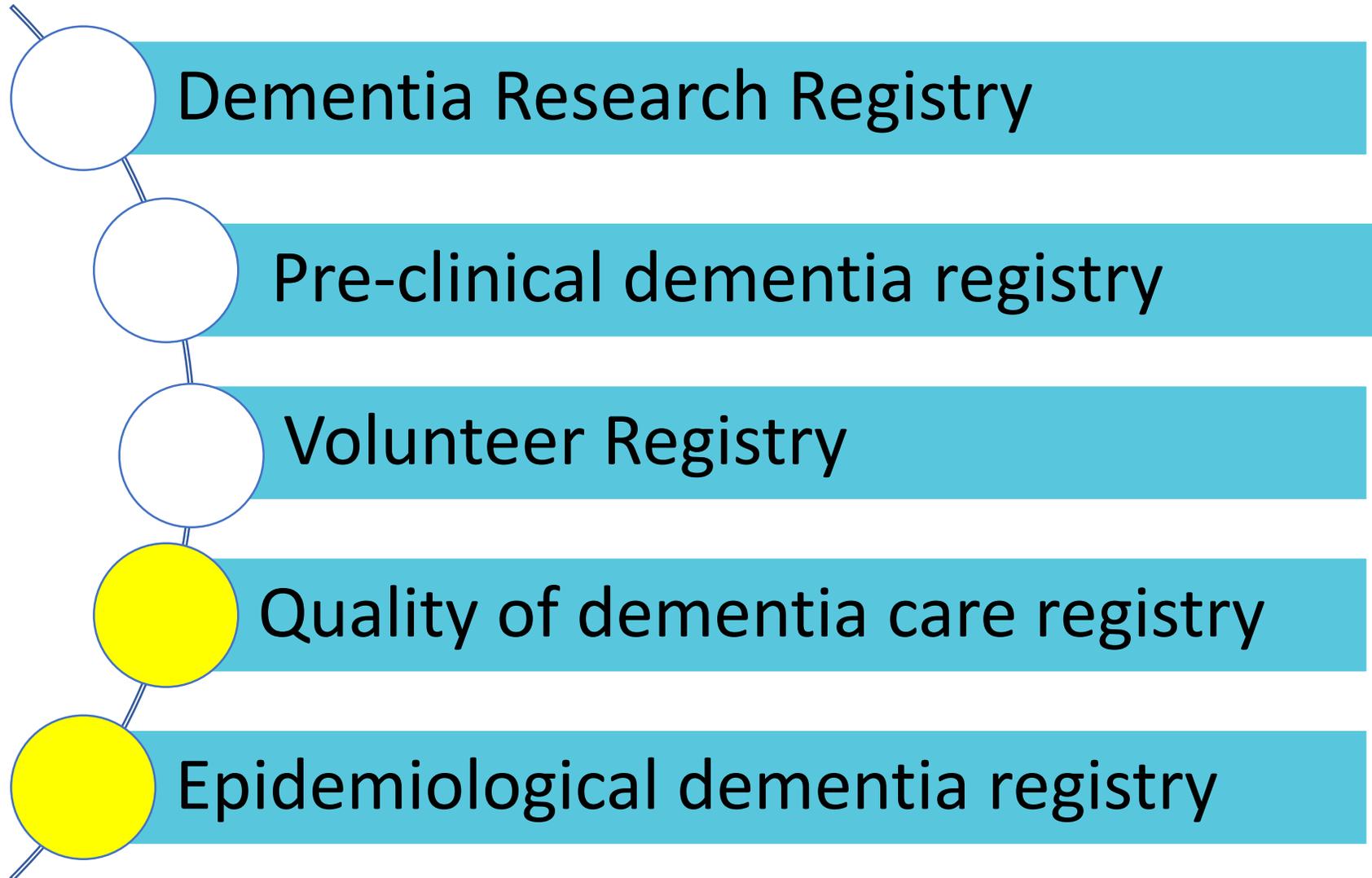


DCU

Ollscoil Chathair  
Bhaile Átha Cliath  
Dublin City University

National  
**Dementia**  
Office Leadership, Integration  
and Innovation

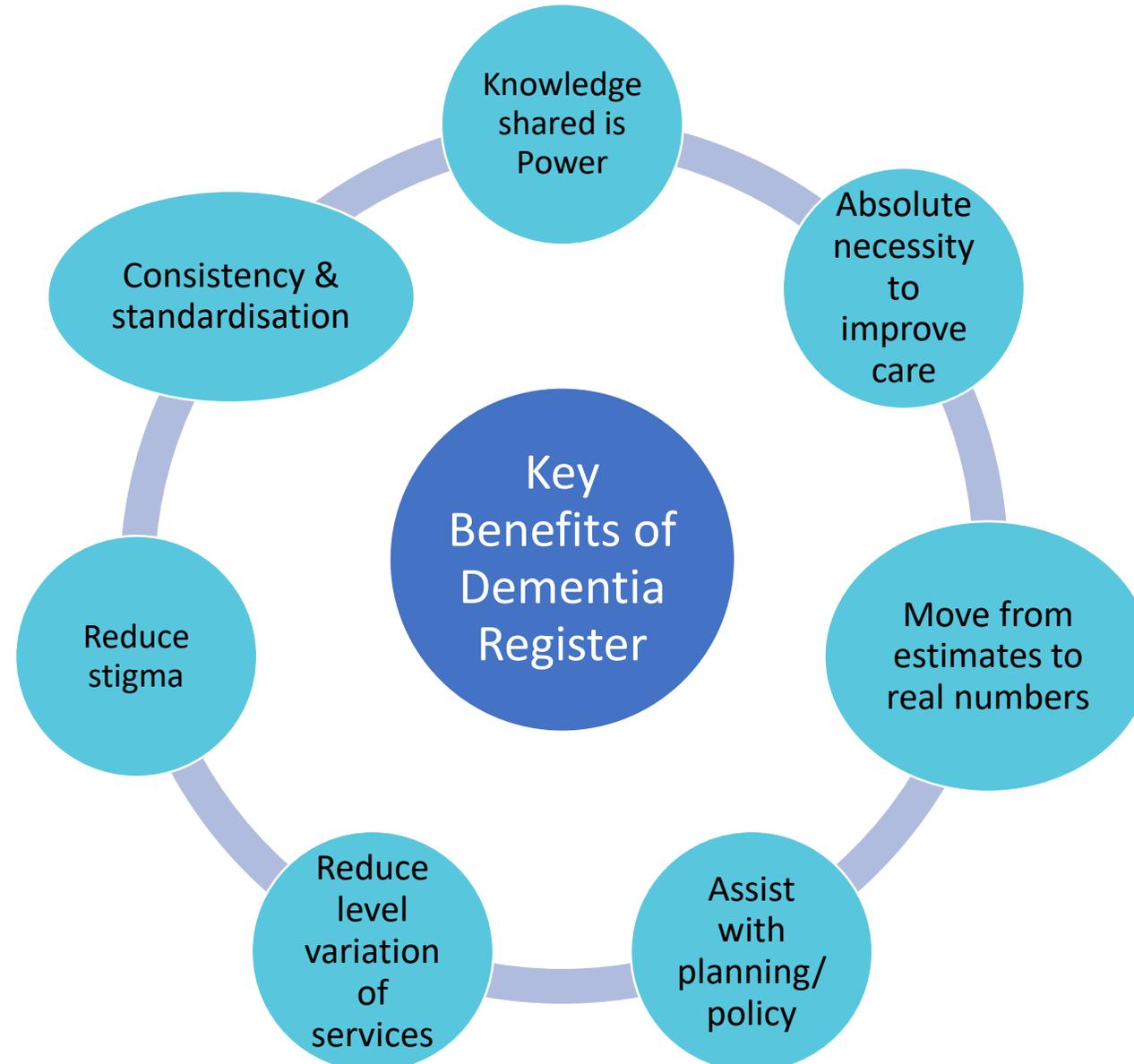
# Type Dementia Registry preferred by Special Interest Group



Ollscoil Chathair  
Bhaile Átha Cliath  
Dublin City University

National  
**Dementia**  
Office Leadership, Integration  
and Innovation

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



Ollscoil Chathair  
Bhaile Átha Cliath  
Dublin City University

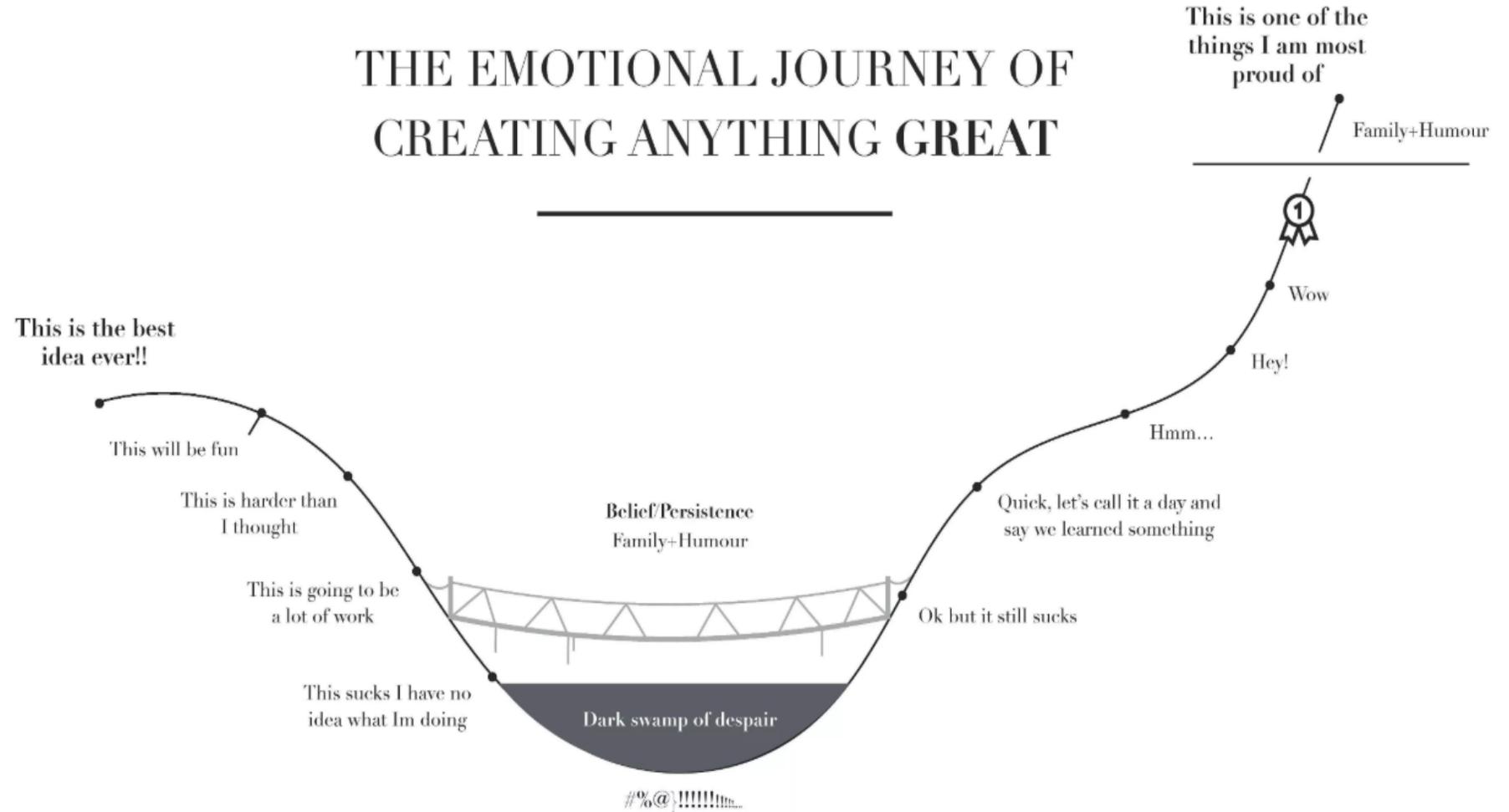
National  
**Dementia**  
Office Leadership, Integration  
and Innovation

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



Ollscoil Chathair  
Bhaile Átha Cliath  
Dublin City University

## THE EMOTIONAL JOURNEY OF CREATING ANYTHING GREAT



THE EMOTIONAL JOURNEY IS INEVITABLE AND PERHAPS NECESSARY

National  
**Dementia**  
Office Leadership, Integration  
and Innovation



Ollscoil Chathair  
Bhaile Átha Cliath  
Dublin City University

## **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.

National  
**Dementia**  
Office Leadership, Integration  
and Innovation

# Contact details

Dr Louise Hopper

Principal Investigator

[Louise.hopper@dcu.ie](mailto:Louise.hopper@dcu.ie)

(01) 700-8540

Christina Bowen

Project Manager

[Christina.bowen@dcu.ie](mailto:Christina.bowen@dcu.ie)

(01) 700-6917