



Ecosystem

a member of the ECHAlliance International Ecosystem Network

Dr Louise Hopper, Assistant Professor, Psychology/Dementia Studies



Data and the National Dementia Registry

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Centre for eIntegrated Care

November 1st 2018

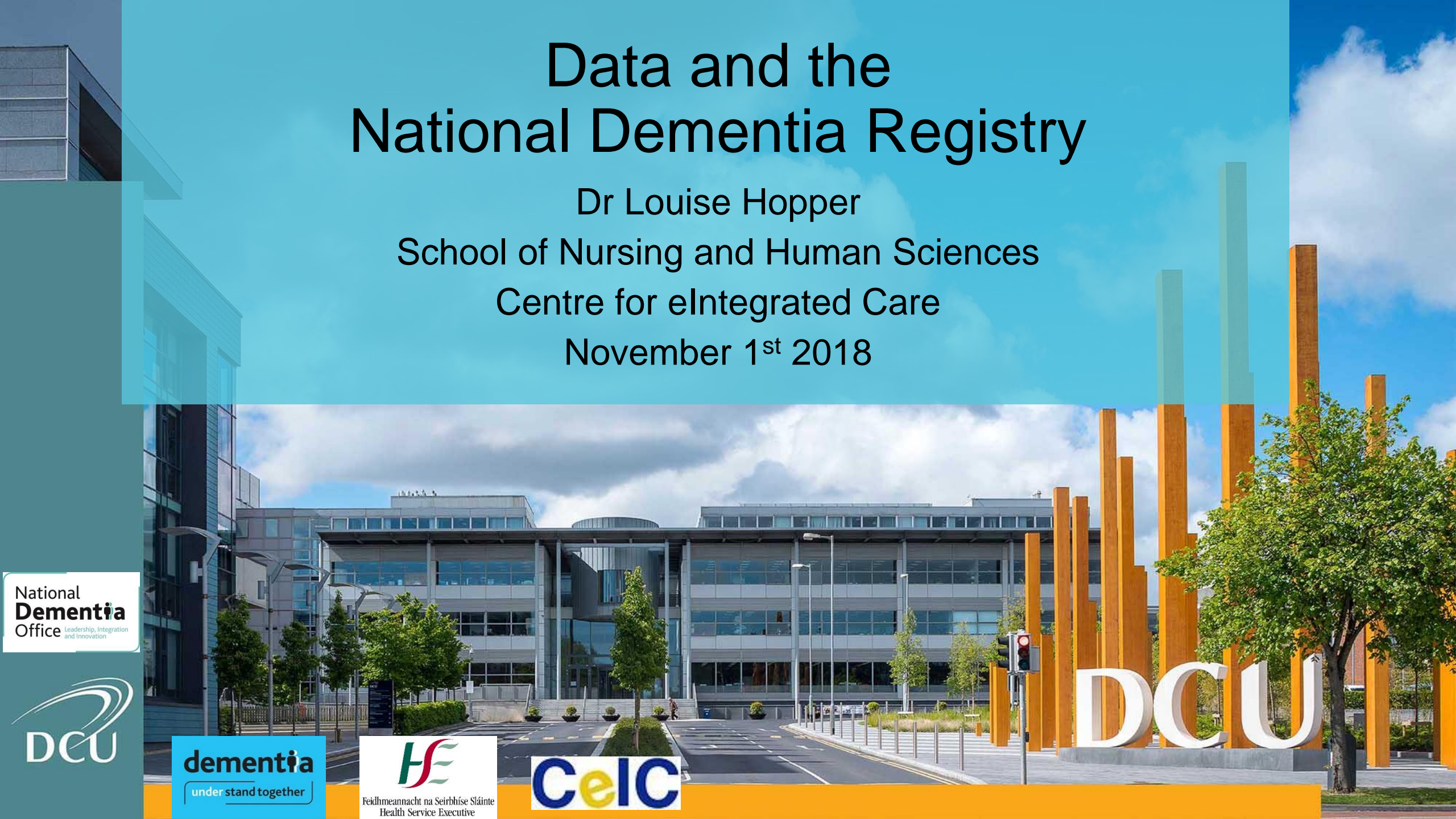
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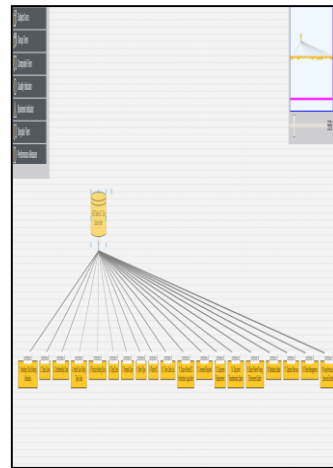
dementia
under stand together

 **HSE**
Feidhmeannacht na Seirbhíse Sláinte
Health Service Executive

ceic



Why develop a National Dementia Registry?



Urgent need to gather valid epidemiological data to:

- Provide **accurate and reliable national estimates** of current and future dementia prevalence
 - Facilitate the development of **robust and effective health and social care policy** relating to dementia
 - Enable the **provision of services** nationally and at a local level
 - Improve **patient care** and **quality of life** for people with dementia
 - Facilitate **health technology assessment**
 - Support health and social care **research**
- Acknowledged in the **National Dementia Strategy** (2014, p33)



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The National Dementia Registry Project

Funded by the National Dementia Office, HSE and the Department of Health (Dormant Accounts)

Commenced May 1st 2018; 18 months duration

“The development of an appropriate model for a registry or national database that will support the roll-out of the National Dementia Strategy and has the potential to improve dementia care management and inform and improve clinical outcomes for individuals living with the condition”

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Broad Scope

Policy

Clinical

Data

Technical

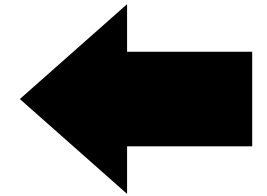
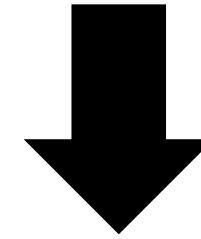
Legal and Ethical

Ownership Governance

Cost and Sustainability

Research

Proof of Concept



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We know successful registries....

- capture data from the patient's point of entry into the health system across all subsequent interactions
- Illustrates the clear need for collaboration and data sharing

BUT we must avoid trying to be all things to all people

- Minimise essential data
- Build on the data that we already have as well as identifying (and filling) our data gaps.

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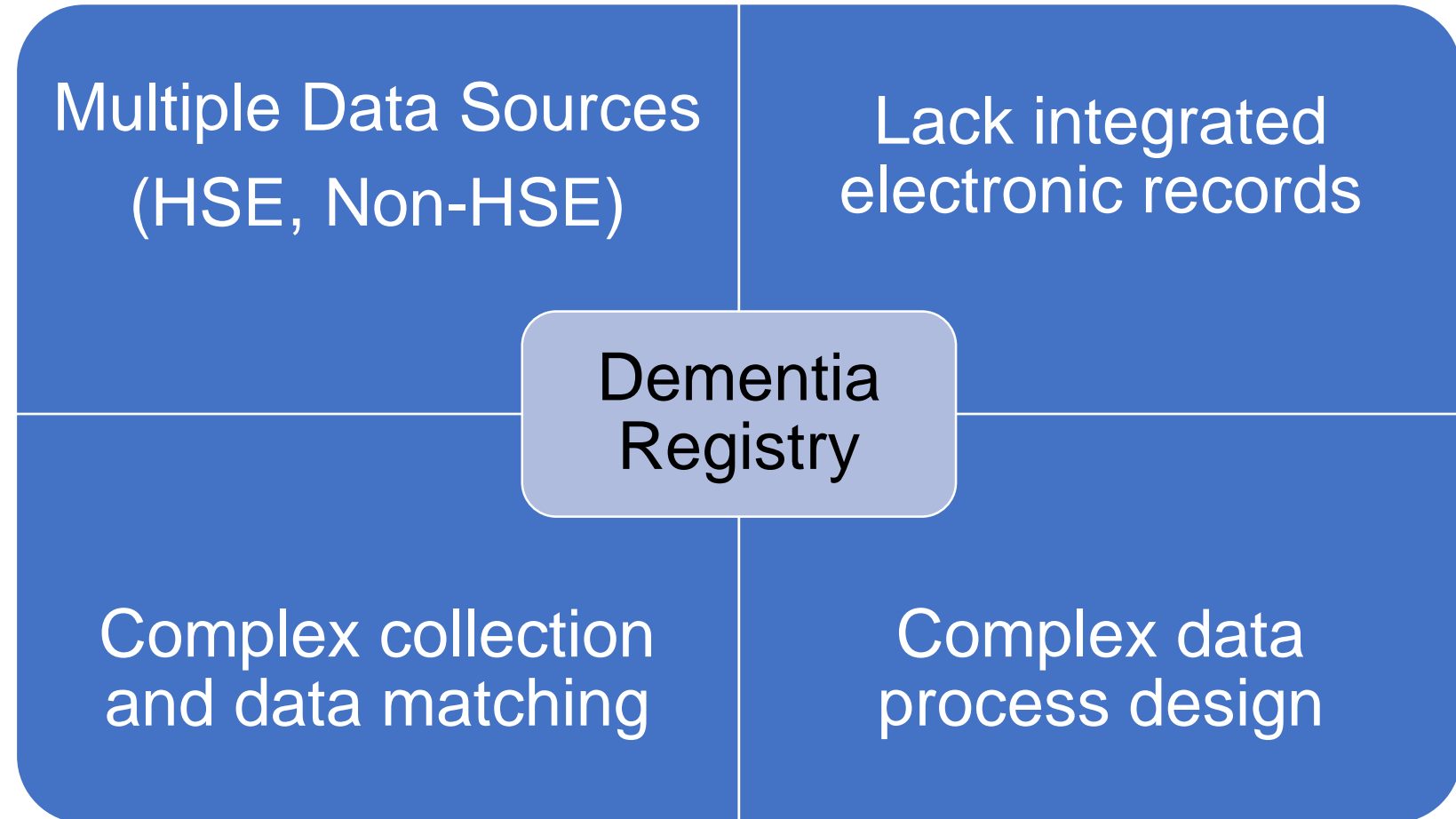
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Where is
our
dementia
data?



Our data challenges



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Next Steps

First steering group meeting on November 5th.



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Name	Role / Expertise	Organisation
Dr Emer Begley	Chairperson	National Dementia Office, HSE
Dr Louise Hopper	Project Lead	Dublin City University
Ms Christina Bowen	Project Manager; Secretary	Dublin City University
Dr Suzanne Timmons	Clinical Lead	National Dementia Office, HSE
Dr Tony Cox	General Practitioner	GP; Medical Director, ICGP
Dr Aishling Denihan	Consultant Psychiatrist	HSE, Older Peoples Services, Co. Meath
Dr Sean Kennelly	Consultant Physician Geriatrics and Stroke Medicine	Tallaght Hospital; Department of Medical Gerontology, Trinity College Dublin
Mr Martin Tully	Head of Information Architecture	HSE OoCIO
Mr Howard Johnson	Clinical Lead Health Intelligence	Health & Wellbeing Directorate, HSE
Dr Carole Glynn	Director of Innovation	HSE CCIO
Prof Roger O’Sullivan	Director Ageing Research and Development Division	Institute of Public Health
Mr PJ Hartnett	Senior Programme Manager	Integrated Care Programme for Older People (ICPOP), HSE
Ms Mairead Creed	Services for Older People	Department of Health
Ms Eilis Hession	General Manager Social Care	HSE Services for Older People
Dr Bernadette Rock	Research and Policy Manager	Alzheimer Society of Ireland
Mr Frank Burton	Irish Dementia Working Group	Alzheimer Society of Ireland
To be confirmed	Irish Patient Registries	National Cancer Registry of Ireland
Dr Dorota Reglia	Swedish Dementia Registry	Division for Clinical Geriatrics, Karolinska Institutet



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Next Steps

First steering group meeting on November 5th.

- Currently, we are:
 - Linking in with stakeholders in the various domains
 - Examining potential data sources
 - Examining existing registry models and processes in more detail

Expect to hear more from us soon!

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