

Trinity Centre  
for Ageing and  
Intellectual Disability

# STRATEGY 2023–2028


## ADDING LIFE TO YEARS

BUILDING BETTER LIVES FOR PEOPLE AGEING WITH AN  
INTELLECTUAL DISABILITY THROUGH RESEARCH AND PARTNERSHIP



Trinity College Dublin  
Coláiste na Tríonóide, Baile Átha Cliath  
The University of Dublin

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# ADDING LIFE TO YEARS

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## ACKNOWLEDGMENTS

Professor McCarron would like to thank all colleagues and external advisors who were members of the various strategic planning groups, each of the thematic leads, people with an intellectual disability and their families who drove the development of this plan. Particular thanks to the contributions from Professor Eilish Burke, Associate Director of TCAID, Professor Philip McCallion, Senior Academic Advisor to TCAID, June O'Reilly, Strategic Development Officer, Gavin Dann, Administrative Officer and Michael Foley, Programme Manager for Trinity's PPI Ignite Office. We would also like to acknowledge the ongoing support and commitment from the School of Nursing and Midwifery Executive and the Faculty of Health Sciences.



Professor Mary McCarron

# DIRECTORS MESSAGE

This Strategic Plan will shape the future of the Trinity Centre for Ageing and Intellectual Disability (TCAID) to benefit people who are ageing with an intellectual disability, their caregivers, Irish society, and the wider world.

The plan's title, 'Adding Life to Years: Building better lives for people ageing with an intellectual disability through research and partnership' contributes to Trinity College Dublin's mission to respond with creativity and imagination to the formidable challenges faced by people with an intellectual disability in leading longer healthier lives. Most importantly this strategy challenges the health inequities for people with an intellectual disability as they age by shining a light on health and well-being issues. We offer early-career researchers unparalleled mentorship, career development, and research opportunities.

This strategy's ambition is to reshape the future of care for people with an intellectual disability by addressing the following **nine strategic priorities**:

1. Put the voice of people with an intellectual disability at the heart of strategy
2. End avoidable mortality (treatable and preventable)
3. Create care pathways for poorly understood diseases such as cancer, dementia, and frailty
4. Increase quality of life through medicines optimisation and non-pharmacological interventions
5. Oral Health
6. Understand and positively influence social determinants of health
7. Understand and positively influence mental health and well being
8. Create new service and financing models that support ageing in place and family carers
9. Death, dying and end of life care



## Adding Life to Years: Building better lives for people ageing with an intellectual disability through research and partnership



People ageing with an intellectual disability often lack the political capital to voice and to advocate for their own needs. Research generated at TCAID is an engine to drive reform, and to produce reliable knowledge to give us the opportunity to solve problems. Longitudinal studies such as the Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (IDS-TILDA) are the platform to enable us to do this.

Informed by people with an intellectual disability and their caregivers, this strategy advances our responses to the complex interplay between the physical and social determinations of health, and targets specific disease conditions such as dementia and cancers, women's health, disease prevention and health literacy, inappropriate prescribing, community connectedness, ageing family caregivers, end-of-life care and the spiraling cost of health and disability services. The strategy builds on our strengths and accomplishments, enables achievement of a vision to enhance lives for people with an intellectual disability as they age, and advances research, knowledge, leadership, and internationalisation.

I am delighted to launch this five-year strategy for TCAID. I look forward to working with TCAID, its wider school and college community, and all our national and international collaborators to make its ambitious goals a reality.

*Prof. Mary McCarron*

Professor Mary McCarron  
Director of Trinity Centre for Ageing and Intellectual Disability



# VISION

Enhanced health, wellbeing and quality of life for people with intellectual disability as they age.

*"Thank you for being so kind to us and for making me feel so welcome whenever we met, virtually or otherwise. I wish you the very best of luck with all your work... our loved ones with an intellectual disability and in particular, Down syndrome, are so blessed to have you working on their behalf. Their world and ours is so much better for it".*

Quote from family member, September 2022

# MISSION

Our Centre aims to address the inequalities and health disparities that occur for people with an intellectual disability as they age. We do this by conducting rigorous engaged research on the physical and social determinants of health and well-being, and translating findings to inform models of policy and practice





# VALUES

## **INCLUSION AND DIVERSITY**

Operating from beliefs that people with an intellectual disability are equal citizens and that the work of TCAID champions and demonstrates that differences must and can be included.

## **COMPASSION AND RESPECT**

Work that is driven by principles of “nothing about us without us”, focused on building understanding and subsequently reduction of health and social concerns that challenge healthy ageing and enjoyment of desired lives and conducted in a manner that values every participant.

## **PARTNERSHIP AND COLLABORATION**

Realizing an ethos of interdisciplinary practice at all levels and in all activities that includes genuine public patient involvement, engagement with policy makers, governmental and funding agencies, and providers and complementary alignment with related national and international research groups.

## **INTEGRITY AND ETHICAL PRACTICE**

Pursuing research, knowledge and programme development in collaboration with and guided by people with an intellectual disability and their families adhering to all applicable ethical, consent and data protection guidelines ensuring equal access to potentially beneficial participation.

## **INNOVATION AND IMPACT**

Advancing new and novel approaches, translating findings to produce the highest level of impact for people ageing with an intellectual disability and their caregivers.

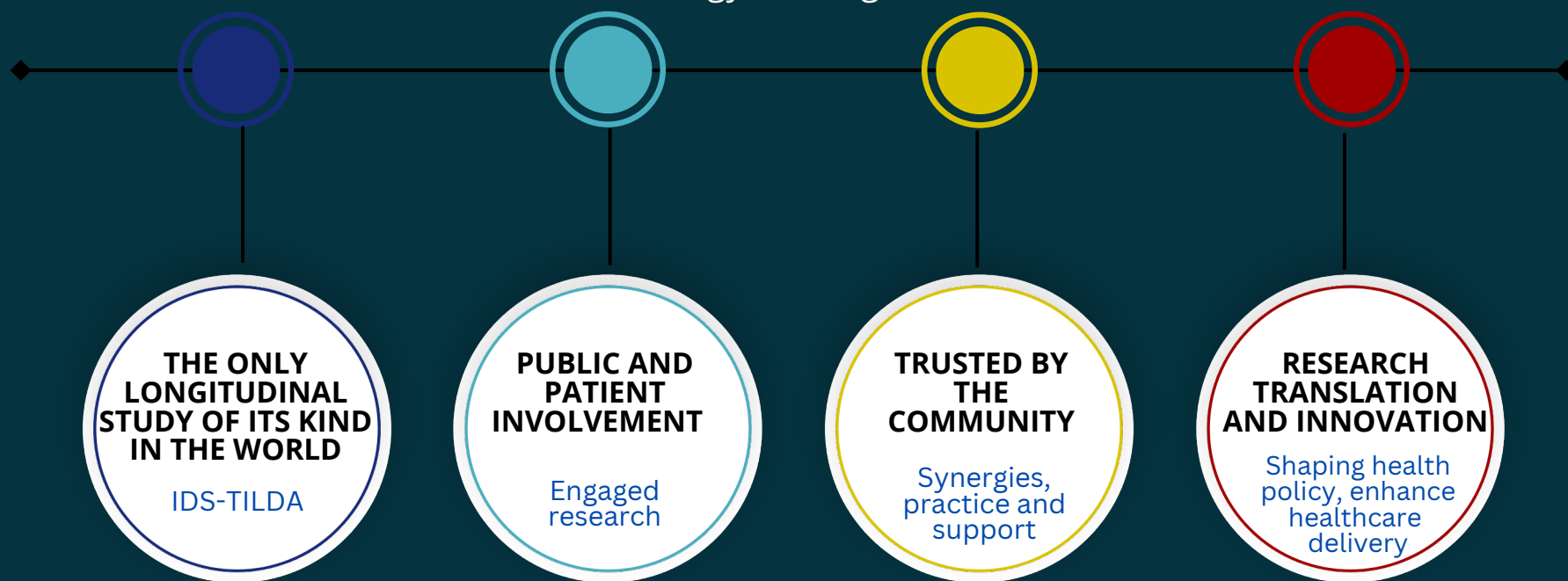
## **RIGOUR AND SCIENTIFIC EXCELLENCE**

Utilising cutting edge, highly rigorous methods to answer pressing questions for the ageing of people with an intellectual disability.

# STRATEGIC INFRASTRUCTURE

TCAID has laid **solid foundations** for lasting impact in an ever-changing landscape

In preparing for the strategic plan for 2023-2028, TCAID has laid solid foundations in developing human, physical, research, and clinical infrastructure required to advance our strategic priorities. TCAID has very strong engagement with decision-makers, advancing evidence-informed policies and strategies to create a more equitable policy landscape across sectors. TCAID has grown its networks nationally and globally by joining networks and consortia aligned with our strategic priorities to identify opportunities, leverage efforts, and maximise impact from which we build our next strategy to bring us to 2028.



## WHAT WE DO

We deliver  
**IMPACT**

We advance  
big  
**IDEAS**



The Intellectual Disability Supplement to  
The Irish Longitudinal Study on Ageing  
(IDS-TILDA)

We exemplify  
and build  
**PARTNERSHIP**





# STRATEGIC PLANNING PROCESS

## Pre-planning

Established internal Strategic Planning Group to coordinate and manage the process and inform the early phase of the planning effort.

Conducted in-depth review and evaluation of the progress made in 2017-2022 strategy.

Reviewed relevant national and international strategies, fundamental policy and legislative developments.

Extensive consultation with internal and external stakeholders.

## Extensive Stakeholder Consultation

Substantive and informed discussions were carried out with TCAID's stakeholders focusing on emerging priority areas, objectives, and associated actions.



## Strategy Planning Day

TCAID held a strategy planning day on 22nd September 2022. A review of achievements and KPIS for the previous 5-year strategy 2017-2022 as well as the future vision and directions for TCAID were presented. Responses and perspectives were given by invited panelists. A collective intelligence workshop engaging TCAID colleagues was held to inspire innovative thinking, harness diversity of people's perspectives and experiences and enable all team members to contribute to new ideas, provide new insights and future directions for TCAID.

## Implementation and Evaluation

Implementation and evaluation will be overseen by members of the TCAID management team.

A mid-term review of strategic goals, actions and KPIS will be undertaken.

In a rapidly evolving external environment and research landscape, this will be a dynamic plan which will require agility and responsiveness, while maintaining the stated strategic priorities.



# STRATEGIC PRIORITIES

Trinity Centre  
for Ageing and  
Intellectual Disability

PUT THE VOICE OF  
PEOPLE WITH AN  
INTELLECTUAL  
DISABILITY AT THE  
HEART OF  
STRATEGY

END AVOIDABLE  
MORTALITY  
(preventable and  
treatable)

CREATE CARE  
PATHWAYS FOR  
POORLY  
UNDERSTOOD  
DISEASES

MEDICINES  
OPTIMISATION &  
NON-  
PHARMACOLOGICAL  
INTERVENTIONS TO  
INCREASE QUALITY  
OF LIFE

ORAL HEALTH

UNDERSTAND AND  
POSITIVELY  
INFLUENCE SOCIAL  
DETERMINANTS OF  
HEALTH

UNDERSTAND AND  
POSITIVELY  
INFLUENCE MENTAL  
HEALTH AND  
WELLBEING

CREATE NEW SERVICE  
AND FINANCING  
MODELS THAT  
SUPPORT AGEING IN  
PLACE AND FAMILY  
CARERS

DEATH, DYING AND  
END OF LIFE CARE

# STRATEGIC PRIORITIES

## Put the voice of people with an intellectual disability at the heart of this strategy

**TCAID puts the voice of the experts at the heart of every element of this strategy.**

TCAID will ensure that the voices of 'experts by experience' such as people with an intellectual disability themselves, their carers and supporters, will shape our approach to all aspects of the strategy, providing insights on the research agenda as well as working with us to drive impact.

TCAID has a proud tradition of Public and Patient Involvement (PPI) in all of its activities and, during this strategy, it will continue to create opportunities for people with an intellectual disability to be staff members within TCAID and to serve on its oversight boards. It will continue to support and develop TCAID's PPI panel of people with an intellectual disability so that they, in turn, can support researchers to plan, design, conduct, analyse and disseminate research projects.

*"You have given me a platform and a voice to advocate for people like me"*

Ms Mei Lin Yap, TCAID Ambassador Liaison Officer

PUT THE VOICE OF  
PEOPLE WITH AN  
INTELLECTUAL  
DISABILITY AT  
THE HEART OF  
STRATEGY



Provost of Trinity College Linda Doyle in conversation with TCAID Research Assistant Christina Corr, TCAID Ambassador Liaison Officer Mei Lin Yap on International Day of People with Disabilities



# STRATEGIC PRIORITIES



## End Avoidable Mortality

**TCAID will strategically focus on preventable and treatable mortality in areas including women's health, cancer, diseases of the respiratory, circulatory, neurological, and endocrine system.**

People with an intellectual disability continue to die younger than their peers in the general population with no evidence that the gap in death rates is closing, with females having a death rate that is over two-thirds higher than for the general female population.

TCAID will use IDS-TILDA and other large data sets to strategically focus on preventable mortality defined as causes of death that can be mainly avoided through effective public health and primary prevention interventions i.e. before the onset of diseases/injuries, to reduce incidence. Treatable (or amenable) mortality defined as causes of death that can be mainly avoided through timely and effective health assessment and care interventions, including secondary prevention and treatment i.e. after the onset of diseases, to reduce case-fatality rates (\*2019 OECD/Eurostat).

Health assessment supports the maintenance of health, prevents diagnostic overshadowing and detects conditions which otherwise would be missed, further contributing to mortality. IDS-TILDA will focus on furthering the development of accessible and comprehensive health assessment as part of its strategic approach to end avoidable mortality.

\*OECD/Eurostat (2019), "Avoidable mortality: OECD/Eurostat lists of preventable and treatable causes of death", <http://www.oecd.org/health/health-systems/Avoidable-mortality-2019-Joint-OECD-Eurostat-List-preventable-treatable-causes-of-death>.

END  
AVOIDABLE  
MORTALITY  
(preventable  
and treatable)





# STRATEGIC PRIORITIES



## Create care pathways for poorly understood diseases

TCAID will take a leadership role in creating new knowledge, evidence and care pathways for poorly understood diseases such as cancer, dementia, women's health and frailty.

Using IDS-TILDA data, we will develop new understandings on the **epidemiology of cancer**, what drives **cancer-related deaths** and what is different for people with an intellectual disability compared to the general population. We will create an evidence base on living and dying with cancer for this population.

We will collaborate with the Horizon 21 consortium, the National Intellectual Disability Memory Clinic, and other groups and leverage our clinical trial network to drive a range of pharmacological and non-pharmacological trials in **dementia prevention and treatment**.

We will provide the highest-quality evidence as to approaches to reduce **premature morbidity and mortality in women**. We will leverage our clinical trial network to definitively establish the evidence base to address premature mortality and improve health outcomes for women.

We will improve our understanding and **measurement of frailty** in older adults with an intellectual disability and test and evaluate frailty prevention and treatment interventions.

CREATE CARE  
PATHWAYS FOR  
POORLY  
UNDERSTOOD  
DISEASES





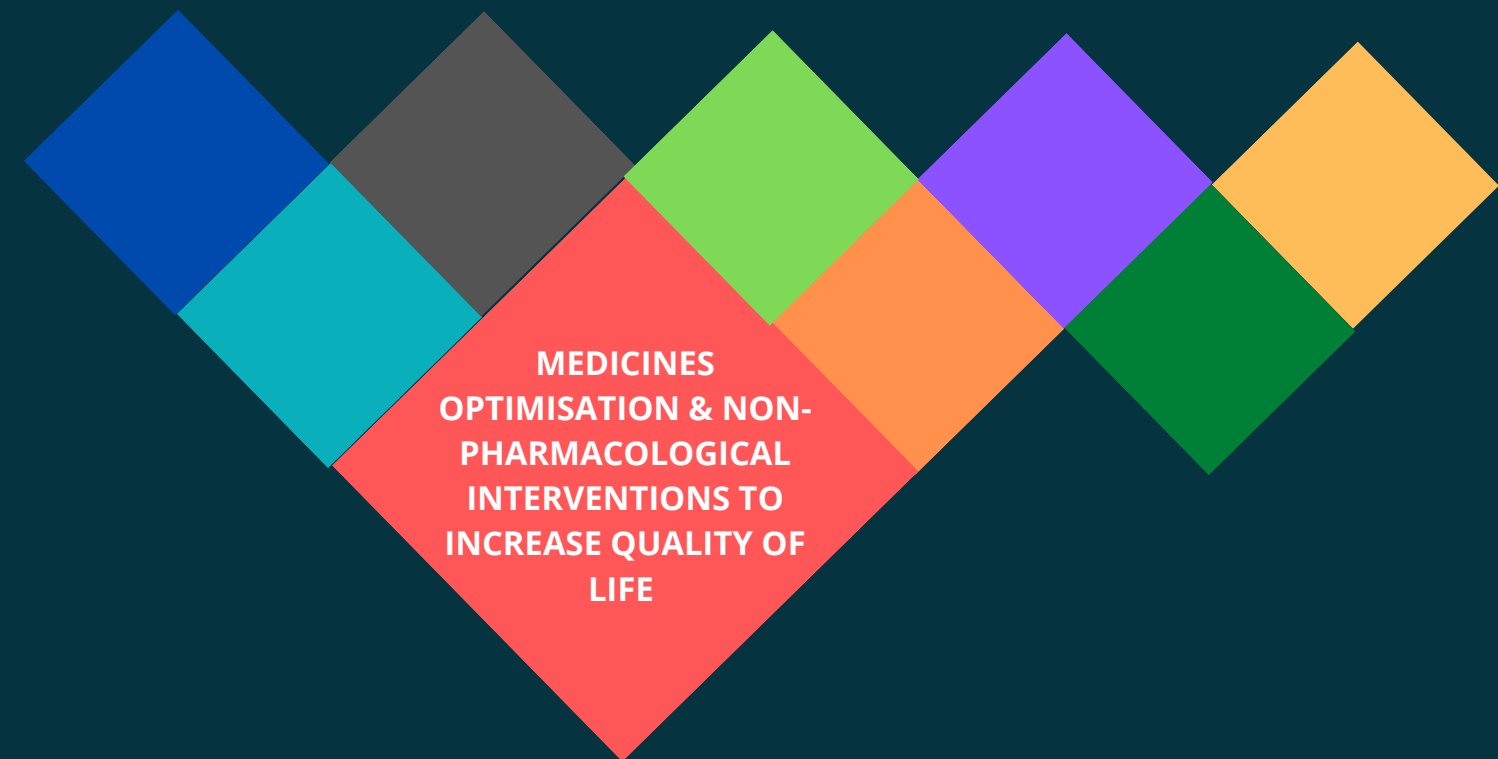
# STRATEGIC PRIORITIES



## Medicines optimisation & non-pharmacological interventions to increase quality of life

**TCAID will lead the development of prescribing guidelines to optimise psychotropic medicine use for people with intellectual disability, reducing harm from medicines.**

Five waves of IDS-TILDA have highlighted significantly higher levels of polypharmacy (multiple medicines) compared to the general population. In particular research to date from TCAID highlighted high levels of psychotropic medicines use which may cause adverse effects such as falls, constipation and sedation. TCAID will continue to take a leadership role to further examine the long-term benefits and risks of polypharmacy and develop ground-breaking interventions to optimise medicine use and improve quality of life. Working together with clinical practice, policy-makers, and patient stakeholders, for example the College of Psychiatrists of Ireland and the HSE Clinical Programme for Disability, TCAID will lead the development of prescribing guidelines to optimise psychotropic medicine use for people with intellectual disability, reducing harm from medicines.



# STRATEGIC PRIORITIES



## Improving oral health for longer, better living

**TCAID research will break ground in understanding what it is to have a healthy mouth for people with intellectual disabilities.**

It will develop inclusive approaches to measuring oral health and oral function. Underpinned by IDS-TILDA data it will establish the determinants of oral health and the relationship between oral health and general health.

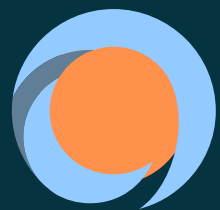
Particular priority areas will be understanding the relationship with pneumonia and dementia, oral health service use and experience for people with an intellectual disability, allowing better service design and a better understanding of the intersection of disability with other marginalizing conditions as they relate to oral healthcare utilisation.

Working together with partners, TCAID will develop and evaluate an evidence based national program for oral health promotion specifically aimed at people with an intellectual disability across Ireland that will lead to empowered, trained, motivated carers, dental teams, and people themselves. Ultimately this will lead to better oral care, reduced disease burden, reduced health inequality and innovation in evidence-informed practice.





# STRATEGIC PRIORITIES

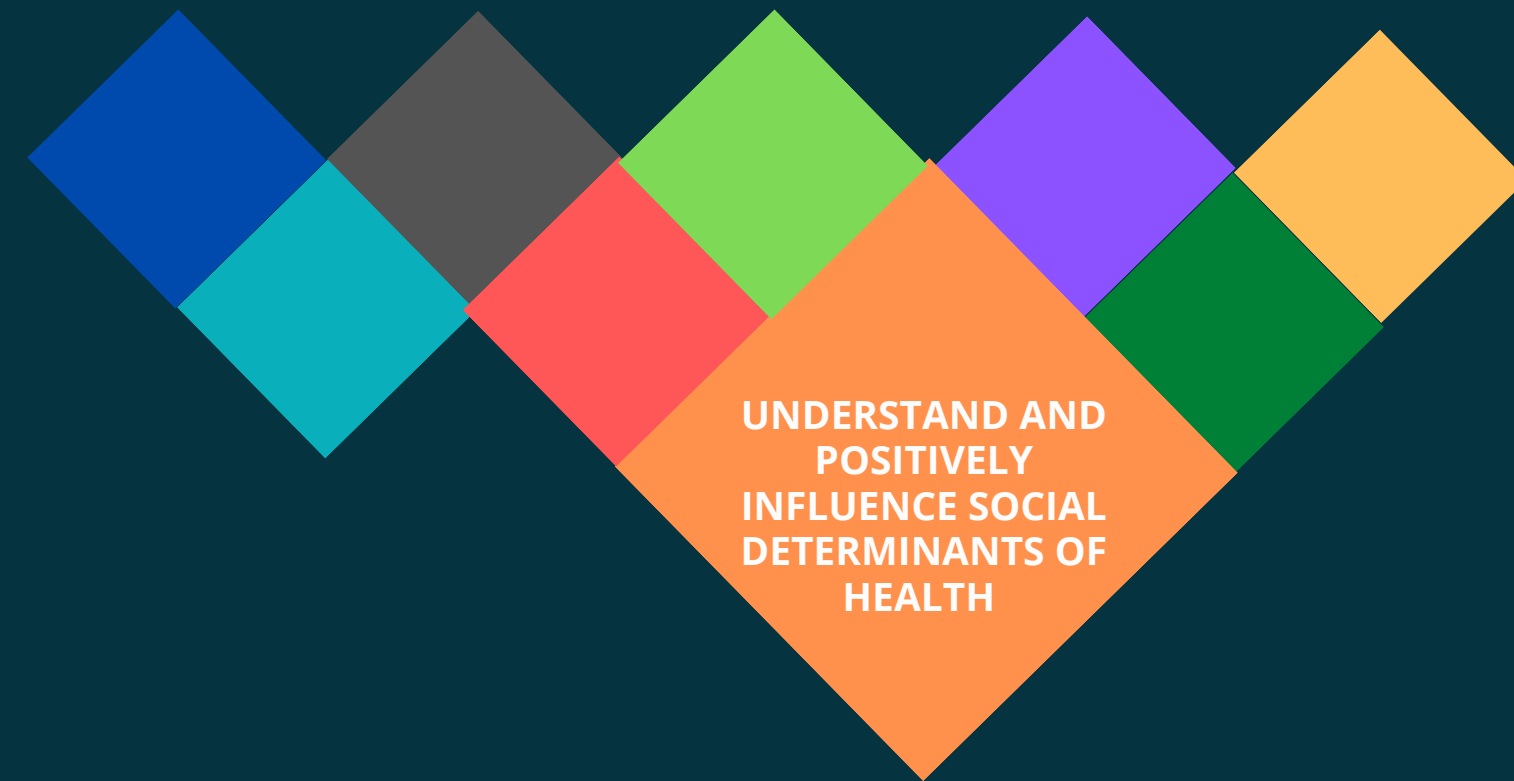


## Understand and positively influence social determinants of health

**Underpinned by longitudinal data from IDS-TILDA, TCAID will apply a social determinants of health lens to better understand the micro and macro processes and structures which have a bearing on the health of this population.**

Five waves of the IDS-TILDA data have shone a light on the multidimensional nature of health for adults with an intellectual disability, with wide-ranging factors combining to influence healthy ageing throughout the life course.

By better understanding factors influencing social networks, interpersonal relationships, community participation, civic engagement and other critical areas of life, we will positively influence policy and service delivery to support better quality of life outcomes for people as they age.



# STRATEGIC PRIORITIES



## Understand and positively influence mental health and well being

**TCAID will continue to converge knowledge from diverse disciplines to improve our understanding on the root cause, risk and protective factors for mental health concerns for people ageing with an intellectual disability.**

Longitudinal data from IDS-TILDA will create new understanding of the nature and development of mental disorders, explore intergenerational differences, and inform more effective psychosocial and pharmacological interventions to improve mental health and well-being.

This data will be used to inform health system and policy responses, improve treatments and access to care.

Qualitative data from people with an intellectual disability will help us to understand their perspectives on, and ways of maintaining, good mental health.

UNDERSTAND AND  
POSITIVELY  
INFLUENCE MENTAL  
HEALTH AND  
WELLBEING





# STRATEGIC PRIORITIES

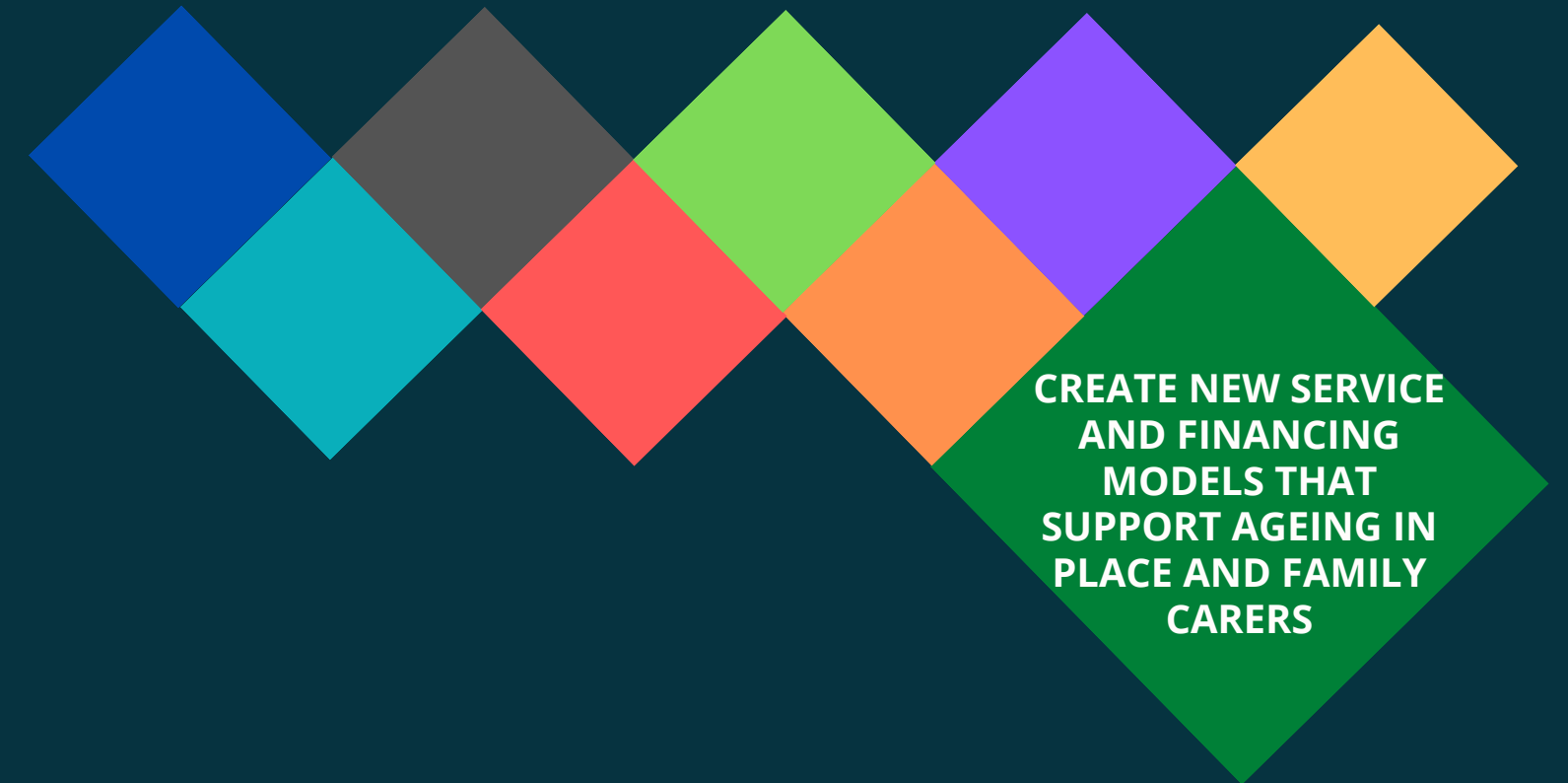


## Create new service and financing models that support ageing in place and family carers

Building on the research conducted to date, TCAID will take a leadership role to better understand the financial, social and policy impact of provision of models of care. This will serve to inform and anticipate social policy challenges and avoid crisis responses to care needs.

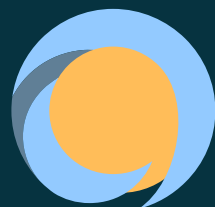
Much of TCAID's work to date has been focused upon adults living in group homes, campuses, and other residential care. Three contemporary changes are occurring: More people are continuing to live long-term with family members; others are living independently for extended periods and some in older age are moving into nursing homes.

TCAID will generate an evidence base to better understand the impact of such models of care provision to inform and anticipate social policy challenges and avoid crisis responses to care needs.





# STRATEGIC PRIORITIES



## Death, dying and end of life care

**Research on end of life is designed to better understand both quality of life and quality of dying for people with intellectual disabilities.**

Research on end of life is also designed to better understand pain, fatigue and other physical symptoms during terminal illness; the genuine inclusion of the person in planning their care; the unique issues of caring when there may be family, staff carers who have been important in the lives of the person with an intellectual disability for many years and peers who have shared a home; and optimal approaches to accessing and blending supports from intellectual disability, healthcare and hospice/palliative care providers.

Longitudinal data from IDS-TILDA will also addresses gaps in research through a greater focus on psychological and spiritual issues, understanding and addressing co-occurring psychiatric disorders and co-morbidities and the effectiveness of the treatment of such disorders and responding to social and cultural diversity.

DEATH, DYING AND  
END OF LIFE CARE

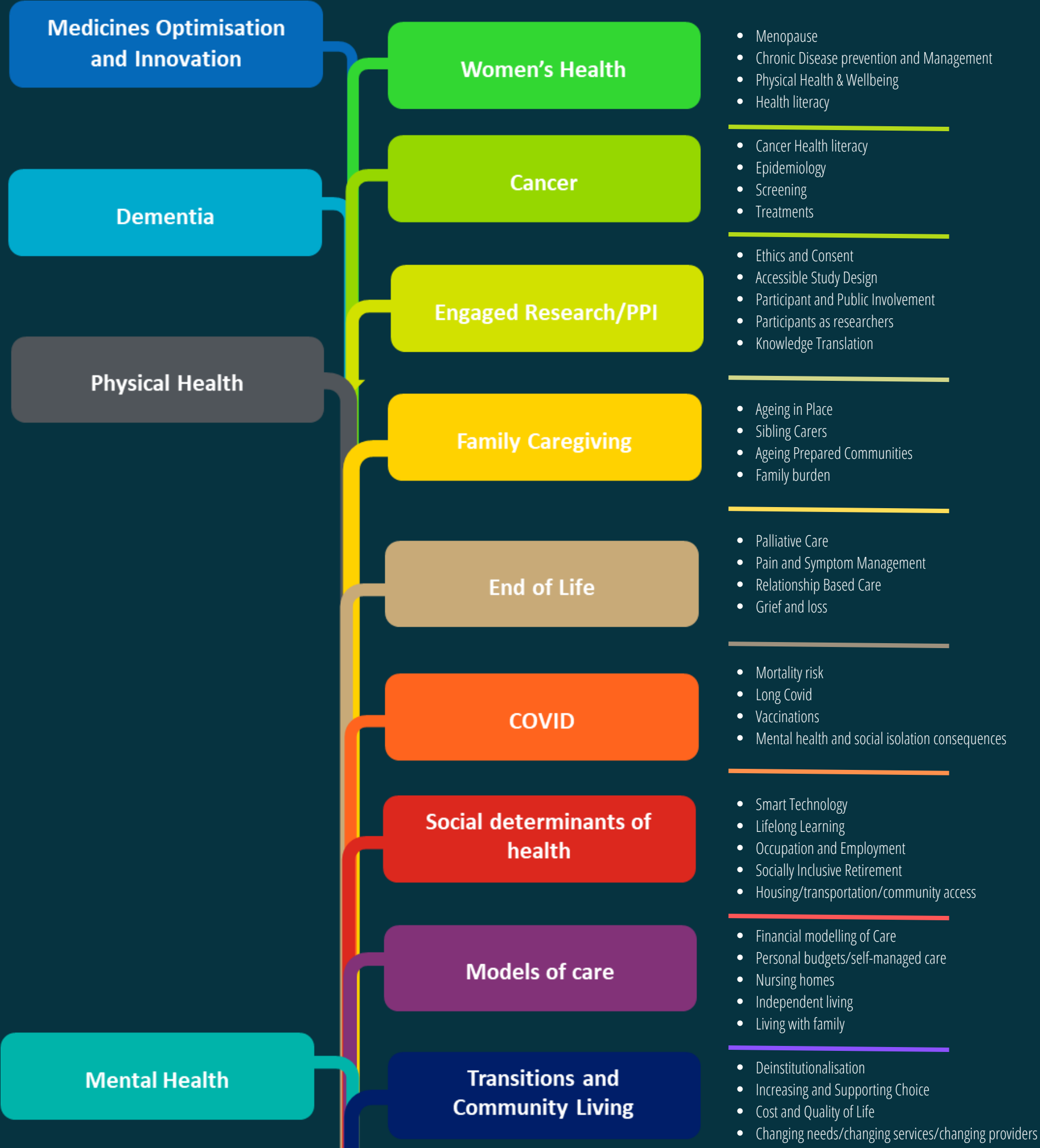


# OPERATIONALISING STRATEGIC PRIORITIES

# RESEARCH THEMES

HIGH QUALITY AND INNOVATIVE RESEARCH AND EDUCATION ADDRESSING THE CHANGING LANDSCAPE OF HEALTH CARE DELIVERY AND OF DAILY LIFE FOR PEOPLE WITH INTELLECTUAL DISABILITY AND THEIR FAMILIES.

- Polypharmacy
  - Appropriate Prescribing
  - Drug Burden
  - Linkage with non-pharmacological interventions
- 
- Brain Health
  - Improving diagnostic accuracy including instrument development, biomarkers etc
  - Pharmacological and non- pharmacological clinical trials
  - Care pathways
  - Living and dying well with dementia
  - The Built Environment
- 
- Frailty**
- Physical, Social and Cognitive
  - Trajectories of frailty
- Health Assessment**
- Facilitating Optimal Health Assessment
  - Instrument development
  - Preparing and Training Health Professionals
  - Accessible Health Information
- Sensory Health**
- Vision and Hearing
  - Sensory profile development
- Bone Health**
- Falls and Fear of Falling
  - Fractures
  - Osteoporosis
  - Physical Activity
  - Sedentary behaviour
- Gastrointestinal Health**
- Diet and Nutrition
  - Obesity
  - Constipation
- Oral Health**
- Teeth for Life
  - Gum health
  - Access and Appropriateness of Care
  - Sedation
  - Oral health assessment
- 
- Depression and Anxiety
  - Sleep
  - Behaviours which Challenge
  - Loneliness and Isolation





# TRANSLATION & INNOVATION

TCAID progresses translational research that is shaping the future of healthcare for people ageing with an intellectual disability to age successfully.

Here are just two examples of TCAID's translational research driving disability innovation and translation to improve lives and imagine new levels of healthcare delivery, support, community engagement and quality of life as people age.

## National Intellectual Disability Memory Service (NIDMS)

Ireland's first ever Centre of excellence in proactive dementia assessment and diagnosis for people with an intellectual disability was launched in 2020.



In the next five years, TCAID will work with and support the NIDMS to drive diagnostic and assessment approaches, and conduct pharmacological and non-pharmacological clinical trials

@nidmsirl

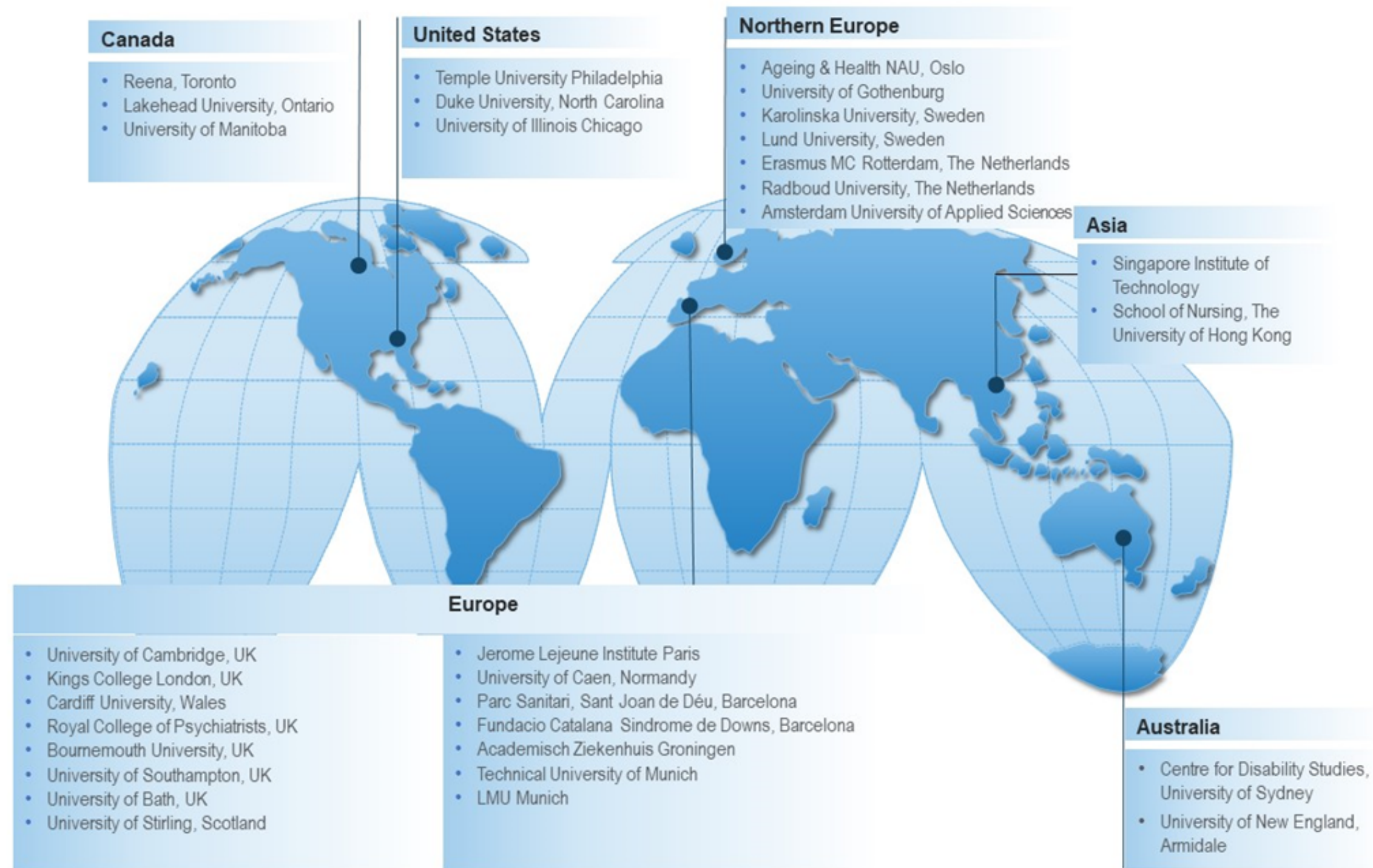
## Disability Innovation and Translation Hub



In the next five years, TCAID will work with key partners to develop a research and practice community driving disability innovation and translation to improve lives and imagine new levels of support, community engagement and quality of life as people age. The HUB will address the persistent inequities in health for people with an intellectual disability and prepare environments, technologies and workforces that advance inclusion, not just respond to the barriers of exclusion.

**PUSH BOUNDARIES AND ACHIEVE MAXIMUM INCLUSION**








# COLLABORATE WITH US

TCAID, continuously develops and advances collaborative initiatives, engaging globally across borders, cultures, multifarious stakeholders and disciplines. Internationally renowned for research expertise and through successful long-standing relationships, we are all working towards the same goal – better lives for people ageing with an intellectual disability.

We welcome expressions of interest to collaborate with TCAID, an international and multi-disciplinary research centre examining key issues in ageing and the life course.

[www.tcd.ie/tcaid](http://www.tcd.ie/tcaid) @ageingwithid





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# ADDING LIFE TO YEARS

## TCAID STRATEGY

### 2023–2028



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