Secondary Data Analysis Projects (SDAP)

Seminar 2025

26 Mar 2025

Health Research Board

Research. Evidence. Action.

& Thank you!

HRB Health Research Board

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Agenda

Session 1 SDAP Experience		
13:00	SDAP 2025 Scheme	Mr Gavin Lawler, *Programme Manager*
13:20	Informing Youth Suicide Prevention and Mental Health Promotion through Secondary Analysis of the Planet Youth Datasets (Inform - YSP)	Dr Bernadine Brady, *University of Galway*
13:35	Disparities in Heath Outcomes of Chronic Kidney Disease Between Men & Women in the Irish Health System	Prof Austin Stack, *University of Limerick*
13:50	The DXA (Dual-energy X-ray Absorptiometry) Management Application Project (MAP): A Personalised Patient-centred Tool for Osteoporosis Screening & Fracture Prediction	Prof John Carey, *University of Galway*
14:05	Q&A SDAP Grant Holders' Experience	
14:15	**Break**	

Session 2 Data		
14:30	HRB Policy on Management & Sharing of Research Data	Sudipta Saha, *Project Officer*
14:40	HRB Open Research Publishing Platform	Dr Irene Castellano, *Project Officer*
14:45	The Irish Longitudinal Study on Ageing (TILDA)	Dr Siobhan Scarlett, *TILDA*
15:00	CSO Health Research Data Centre	Anthony Macken, *Central Statistics Office*
15:15	National Care Experience Programme	Dr Conor Foley, *HIQA*
15:30	HRB National Health Information Systems	Dr Sarah Craig, *Head of National Health Information Systems*
15:25	Q&A	

Secondary Data Analysis Projects 2025 Call

26 March 2025

Gavin Lawler

Programme Manager

Research & Innovation Infrastructures Unit

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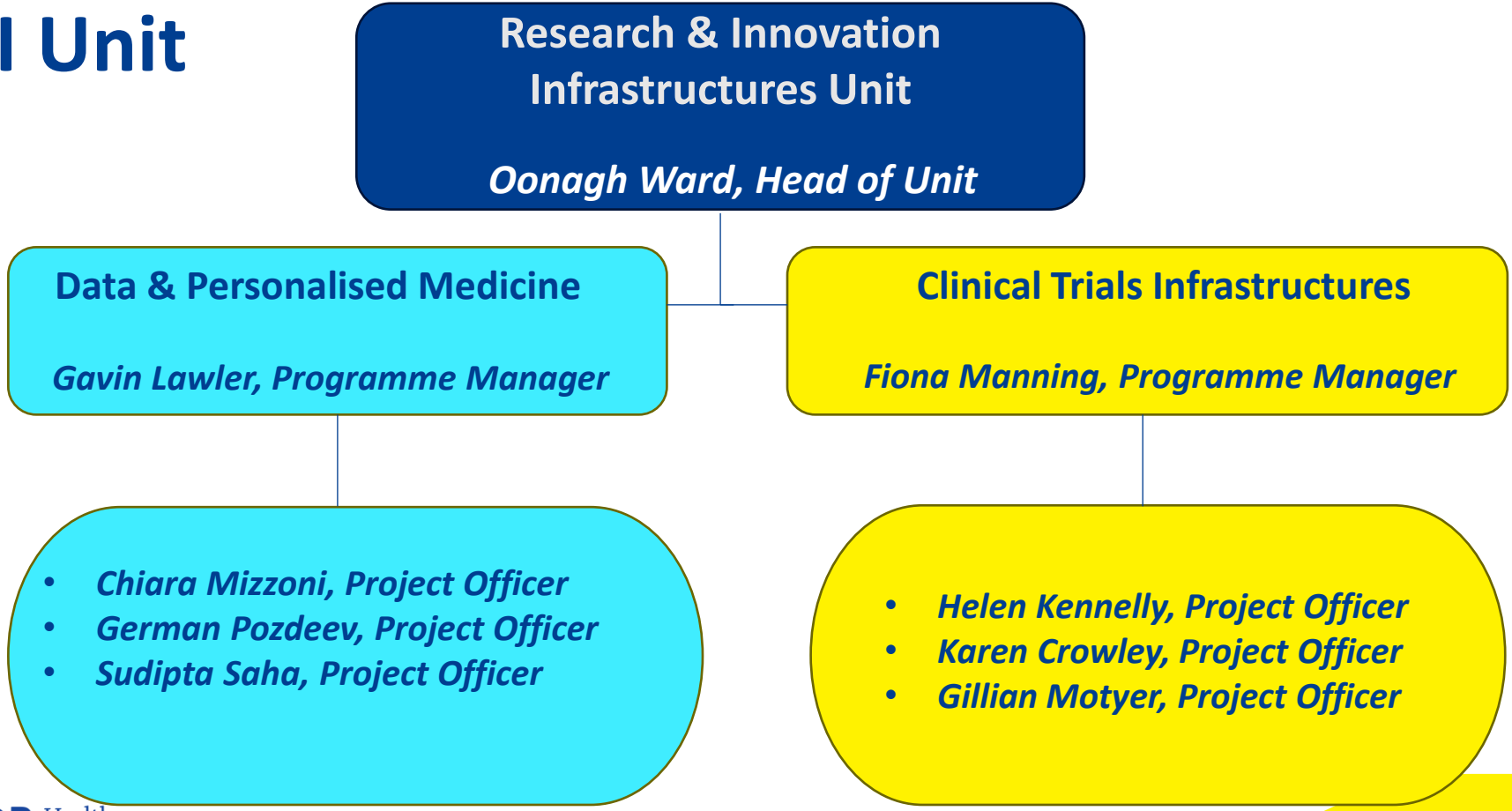
RAII Unit


Research & Innovation Infrastructures Unit
Oonagh Ward, Head of Unit
Data & Personalised Medicine
Gavin Lawler, Programme Manager
Clinical Trials Infrastructures
Fiona Manning, Programme Manager
Chiara Mizzoni, Project Officer
German Pozdeev, Project Officer
Sudipta Saha, Project Officer
Helen Kennelly, Project Officer
Karen Crowley, Project Officer
Gillian Motyer, Project Officer

Irish Data Context

- **No existing centralised data infrastructures, or EHRs**

  -Multiple data silos/systems, fragmented approach across different government/regulatory agencies

  -CSO Covid-19 Data Hub established during pandemic for access to specific health data sets

- **Data Access Storage Sharing and Linkage (DASSL)** Proof of Concept funded by HRB in 2019 & published 2023

- Work progressing to establish an Irish Health Data Access Body(HDAB) via Department of Health and **Health Information Bill**

- **Individual Health Identifiers**(IHIs) being rolled out by the Health Service Executive

HRB Strategy 2021-2025

Strategic Objective 3. Trusted data

Promote and enable the use of data to shape health policy, enhance healthcare delivery, and drive broader research and innovation initiatives

- **Key Action 3.1.** Play a leading role with other stakeholders to promote and enable the infrastructure and environment for the optimal use of health and social care data and statistical data for research.
- **Implementation action 3.1.4** Invest in research projects which employ secondary data analysis and record linkage.

SDAP 2025 Call

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Secondary Data Analysis Projects (SDAP) 2025

Aim: To optimise the use of existing health and social care data sources to deliver high-quality, high-impact evidence for policy and/or practice

Objectives:

i. To answer policy and/or practice-relevant questions using secondary data

ii. To develop and strengthen partnerships between researchers, data controllers & knowledge users in the area of secondary data analysis

iii. To enhance capacity for further research of this nature in Ireland through upskilling, training and education of team members where possible.

Overview of HRB investment in SDAP

SDAP 2019	36 Applications	7 Funded €1.75M
SDAP 2021	34 Applications	10 Funded €2.25M
SDAP 2023 Cycle 1 Cycle 2	14 Apps 29 Apps	5 Funded €1.2M 10 Funded €2.0M
SDAP 2025	€4M	

Scope

- Findings will have direct relevance to policy and/or practice in the Irish health and social care system
- Research should be explicitly linked to the documented evidence needs of the Knowledge User organisation
- Development of tools to make data sets accessible and/or more widely available
- Proposals must include at least one existing **Irish or International dataset**
- Applications may be related to, but must be distinct from, the specific aims of the original data collection

Out of Scope

- Projects involving additional primary data collection studies or bio-specimen analysis

- Projects seeking to design and evaluate a trial or intervention

Applications which are solely/predominately:

  - Literature reviews, audits, service improvements, surveys or needs assessments
  - Health service developments/evaluations (although these elements may form part of a wider research study)
  - Developing the infrastructure for bio banking, databases or patient registers

Dataset Requirements

- Require to meet **HIQA Information Management Standards for Health and Social Care Data Collections**
- Randomised controlled trials (RCTs) generally seek to answer one specific question under certain conditions, with limited scope outside the specific trial parameters. Data from **RCTs are <u>not</u> appropriate** when seeking to make more generalised policy and practice decisions and should ideally be avoided as dataset sources without specific justification
- **Data Controller(s) must agree to provide access to the dataset**. Exceptions:
  - Where a dataset is publicly available, details must be included in the application. A separate letter of support from the data controller is not required.
  - For datasets held by the CSO where permission to access data is under review, a 'letter of comfort' indicating access has been applied for is sufficient at the application stage. Confirmation of access will be required at contracting for successful grants.
- Where the process to allow access to data only commences once research funding has been secured, correspondence from the data controller that the data is available for access is required

Applicant Team

- Applications should be made on behalf of a team made up of **Researchers, data controllers/processors and knowledge users**:
  - Lead Applicant
  - Co-Applicants (up to 10)
  - Collaborators (up to 10)
- Public and Patient Involvement (PPI) encouraged as appropriate

Changes for SDAP 2025

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Key Changes For 2025 Call

1. Grant Budget

- Increasing from **€250,000 to €350,000** enhanced budget empowers capacity building across the system enhancing data expertise & skillsets

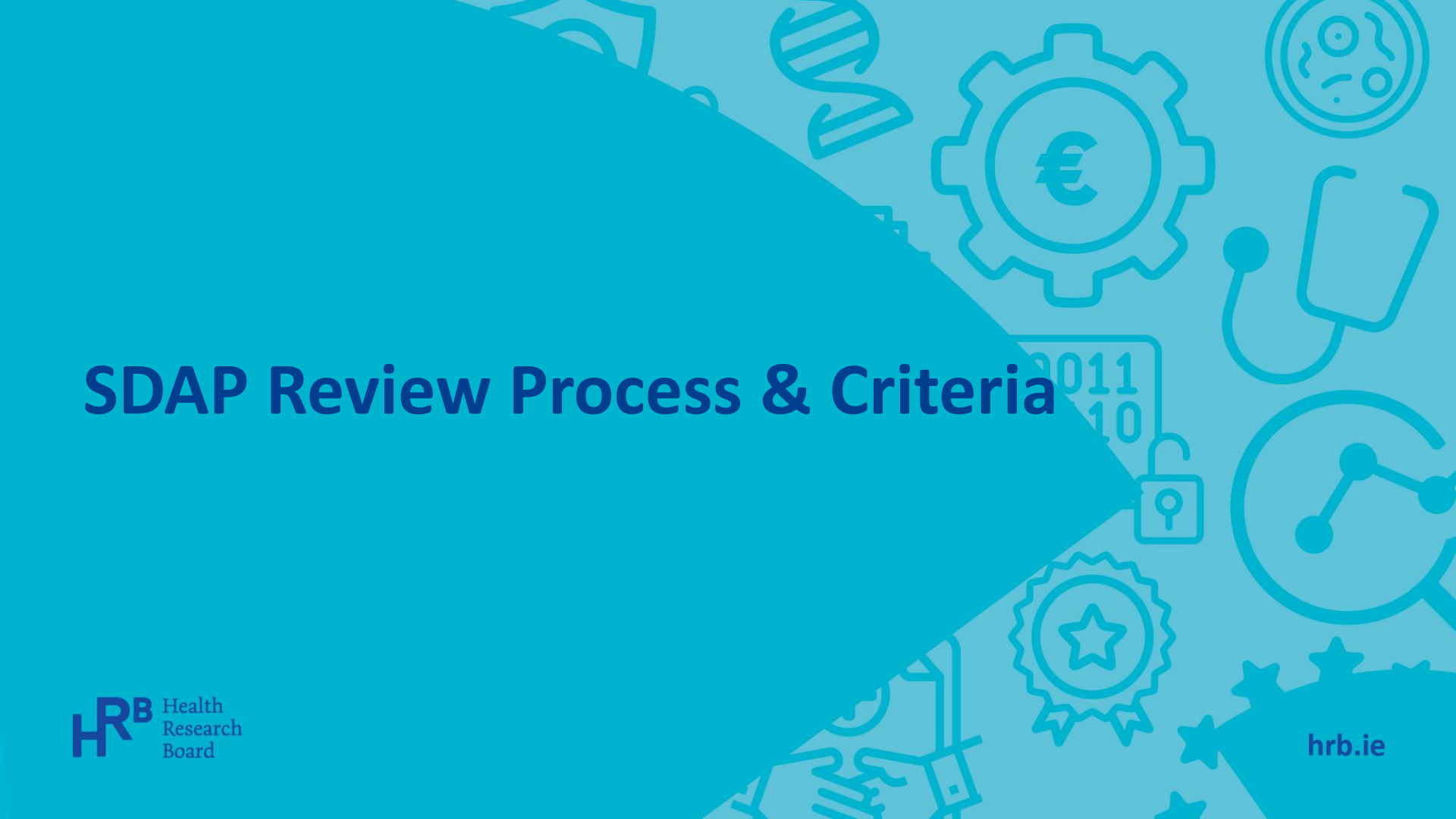
2. Project Duration

- Grant duration will increase to a minimum of **36 months or up to 42 months if developing a tool** in recognition of potential challenges regarding data curation, hiring of suitable personnel and dissemination activities to conduct SDAP. This should reduce the requirement for NCE

3. PPI & Identify Knowledge Translation Framework to Implement

- The HRB encourages PPI to be actively considered for inclusion in all proposals where appropriate. In the event of PPI being excluded in a proposed project appropriate justification will be needed and this will be considered by the review Panel

SDAP Review Process & Criteria



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2 Stage Review Process

STAGE 1

Peer & Public Review

- International academic experts in content area: Scientific Criteria
- Public Reviewers: Quality of the PPI

Right to Respond

- Shortlisted applicants following peer review only
- Response from the Lead Applicant to Reviewers' Comments (Peer & Public)

STAGE 2

Panel Review

- Consider Applications, Reviews and Lead Applicant Response
- Examine Scientific Criteria & Knowledge Translation Criterion
- Successful Applications expected to score highly on both criteria

Scientific Review Criteria

- Does the research address a policy or practice question/s relevant to the Irish health & SC system?
- Will the research design & methodology answer the research question/s?
- Does the research team have the expertise & experience to deliver on the proposed project?
- Do the proposed processes, protocols & safeguards reflect best practice data governance?
- Is it a genuine partnership between researchers, data controllers/processors, PPI contributors and knowledge users?
- Where possible, are there plans for relevant education & training in skills relevant to SDA?

Knowledge Translation Criteria

- Is there potential for impact policy and/or practice in Ireland and beyond within 1-2 years post project?
- Are there credible plans described to enable ongoing deliberation between researchers and knowledge users and to translate findings and learnings into policy and/or practice throughout the project (not just at the end)?
- Is there appropriate justification for the KT approach being proposed?

Review Criteria-Protocols, Practices & Tools

- Will the project contribute to improving the future accessibility of a dataset for research purposes in accordance with best practice and transparent data governance processes?

- Panel members will be advised to take PPI approaches into consideration under any of the assessment criteria if considered relevant beyond the specific reference under partnership.

Public Review Criteria

Public Reviewers will only assess the quality of PPI in the application and will provide comments and an overall rating which will be shared with the Panel. Public Reviewers will not provide a score.

Public Reviewers are asked to comment on the following:

- The plain English summary (Lay Summary)
- Relevance of the proposed research question
- PPI in development of and throughout the project
- Making it straightforward for research

GEMS Application Process

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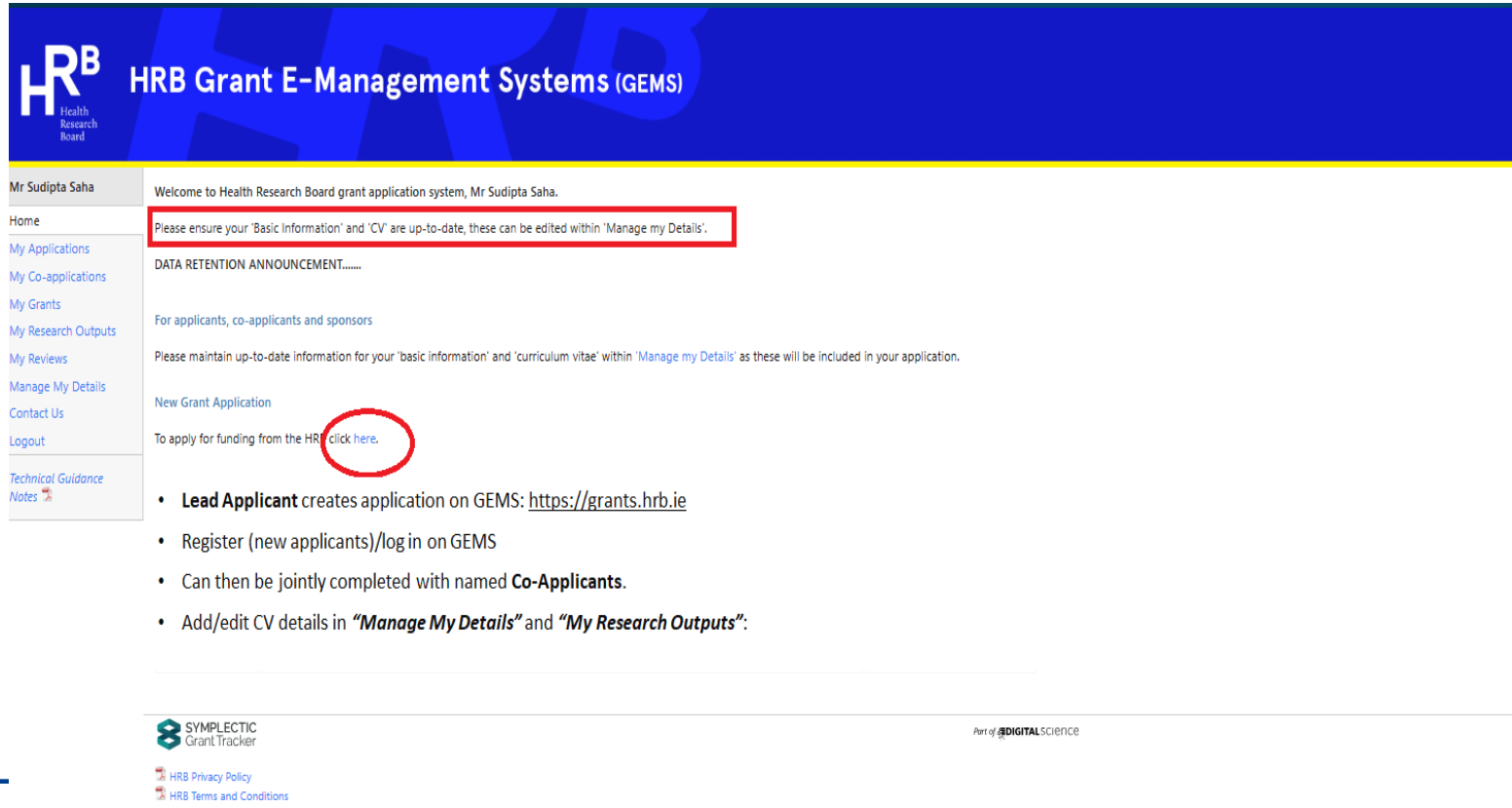
Create or Update your GEMS Profile



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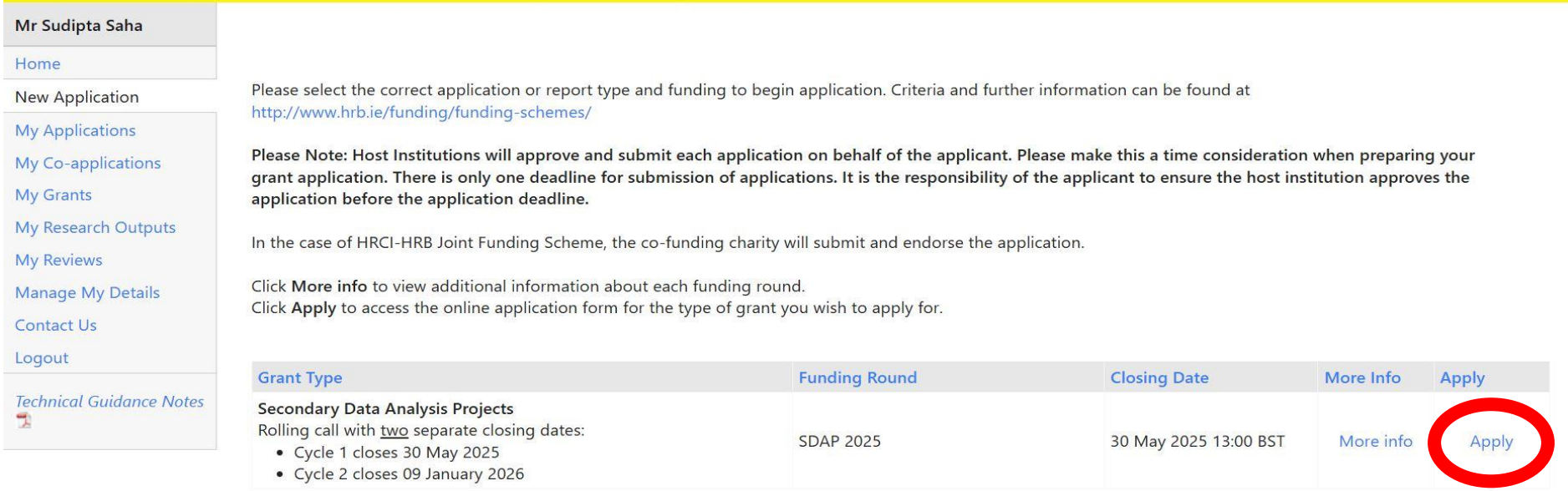
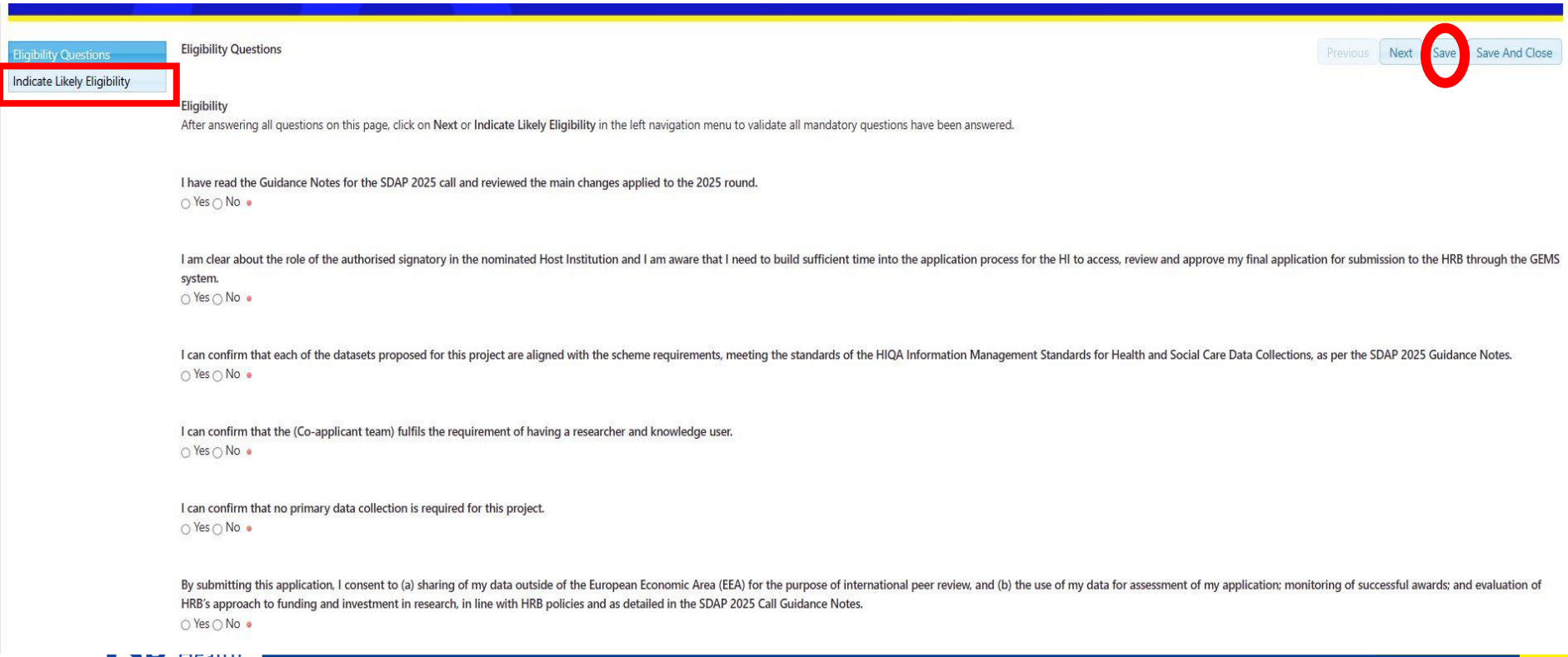
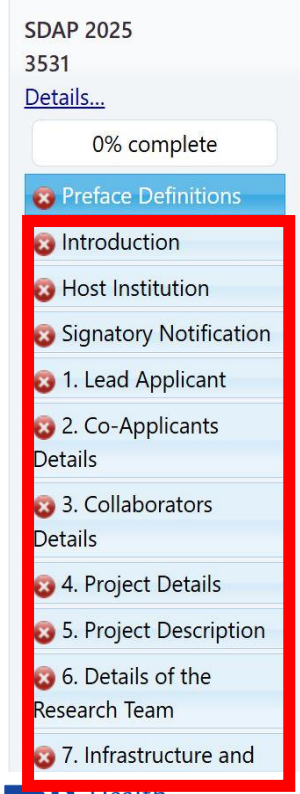
Select SDAP 2025

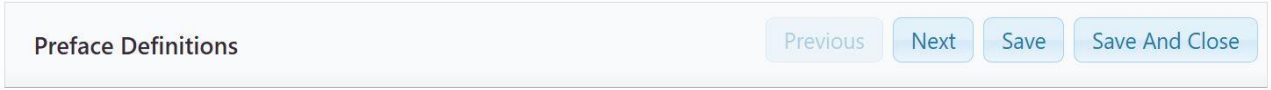


Complete Eligibility Questions



View & Navigate the Application Form



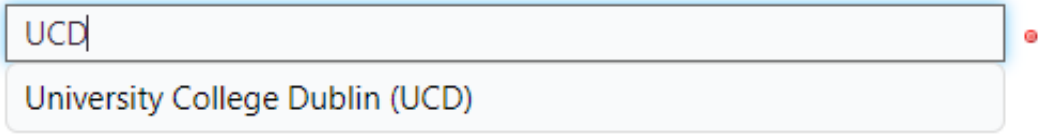


Key to form symbols:

Previous	This button will take you to the previous available page and save all content on the current page
Next	This button will take you to the next available page and save all content on the current page
Save	This button will save all content within the form and allow further editing
Save And Close	This button will save all contents of the form and return to the previous area
	This icon indicates that a question is mandatory
	Clicking this icon will display help information related to this question
	Click and drag the green arrow to move items up and down in a list
	Page Read and Complete
	Page read however some actions remain
	Unread page

Identify HI & Notify Signatory

other Irish institutions listed on GEMS, only the recognised host institutions listed on the PDF should be selected. If your Host Institution does not appear in this list, please contact the HRB at gemshelp@hrb.ie.



- **Signatory Notification**
  The signatory's details are pre-populated. Click ***'Notify'***

  **Prior to submission, applications must be reviewed and approved by the HI. Leave sufficient time for this prior to the submission date. Be aware of any internal HI deadlines for review and approval, distinct from the HRB deadline.*

Validation

SDAP 2025
3524
Details...

98.9% complete

- Preface Definitions
- Introduction
- Host Institution
- Signatory Notification
- 1. Lead Applicant
- 2. Co-Applicants Details
- 3. Collaborators Details
- 4. Project Details
- 5. Project Description
- 6. Details of the Research Team
- 7. Infrastructure and Support
- 8. Project Budget
- 9. Ethical Approval
- Supporting Documentation
- Validation Summary

Validation Summary

Previous | Next | Save | Save And Close

Please complete the validation checks below before submitting this application.

Signatory Notification

- Please notify the Dean of Research.

2. Co-Applicants Details

- Co Applicant - Sudipta Saha must confirm their participation before submitting.

Previous | Next | Save | Save And Close

SDAP 2025 Call Timeframe

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Key Dates

Cycle 1	
Call Opens	03 February 2025 @ 13:00
Closing Date	30 May 2025 @ 13:00
Peer Review Period	May – July 2025
Applicant Response	Late July 2025
Panel Meeting	Sep 2025
Grant Must Start Before	15 December 2025
Earliest Start Date	01 November 2025
Cycle 2	
Call Opens	01 September 2025 @13:00
Closing Date	09 January 2026 @ 13:00
Peer Review Period	Jan – March 2026
Applicant Response	Early April 2026
Panel Meeting	May 2026
Earliest Start Date	01 June 2026
Grant Must Start Before	14 Dec 2026

Contact Details

Gavin Lawler

Programme Manager

glawler@hrb.ie

Sudipta Saha

Project Officer

ssaha@hrb.ie

Ollscoil na Gaillimhe
University of Galway

Informing Youth Suicide Prevention and Mental Health Promotion through Secondary Analysis of the Planet Youth datasets – *Inform-YSP*

Dr Bernadine Brady
HRB SDAP seminar
March 26th 2025

University *of* Galway.ie

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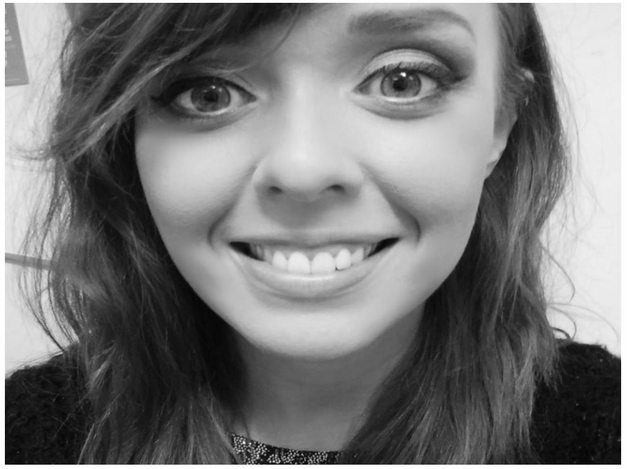
University of Galway

HRB Health Research Board



Dr Charlotte Silke, Postdoctoral Researcher,
UNESCO Child & Family Research Centre

Dr Bernadine Brady, Co-PI, UNESCO Child & Family Research Centre, University of Galway

Dr Caroline Heary, Co-PI,
School of Psychology, University of Galway

Co-applicants: Annmarie Groarke; Cliodhna O'Connor, Carmel Devaney, Emmet Major, Micheal Durcan, Gemma Cox, Olwyn McWeeney

National Office for Suicide Prevention

Western Region Drug & Alcohol Task Force
Meitheal Drugaí an Iarthair

Planet Youth Partner Ireland

National Suicide Research Foundation
NSRF

HSE

Our Dataset

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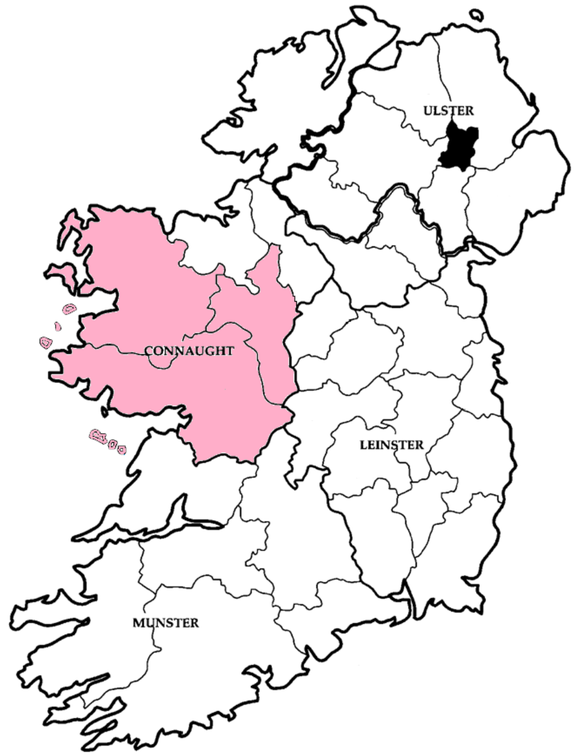
Planet Youth conducts in-depth surveys with young people to understand risk & protective factors and inform preventative interventions

- ❑ *Non-clinical sample of adolescents*
- ❑ *Bi-annual surveys: 2018, 2020 and 2022 (and now 2024)*
- ❑ *Measures – demographics, wellbeing, behaviour, experiences, adversity*
- ❑ *100% response rate from schools*
- ❑ *15,129 secondary school students completed the 2018, 2020 or 2022 Planet Youth surveys*



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HRB SDAP 2021 requirements

Research Focus: Youth Mental Health & Self-harm

Policy Need: Identifying youth most at-risk of experiencing suicidality and self-harm is a key policy objective (World Health Organisation, 2021).

HSE/NOSP *Connecting For Life* national strategy:

- To design effective supports, high quality research is needed to better understand suicidal behaviour, mental wellbeing, and associated risk and protective factors in Ireland.
- Youth a priority group.

Connecting for Life

Ireland's National Strategy to Reduce Suicide 2015-2020

Research Gaps:

How do patterns of adversity impact youth self-harm and suicidality? (Gobel & Cohdres, 2021).

Need for evidence of wellbeing trends before, during and after Covid-19 pandemic.

National Office for Suicide Prevention

Project Partners

National Office for Suicide Prevention (NOSP)

National Suicide Research Foundation

HSE CHO Area 2

WESTERN REGION Drug & Alcohol Task Force Meitheal Drugaí an Iarthair

PLANET Youth PARTNER Ireland

Project Structure

PI's: Dr Bernadine Brady, Dr Caroline Heary

Post-Doctoral Researcher: Dr Charlotte Silke

Project Steering Group: All partners – met quarterly

- Knowledge translation sub-group
- Research sub-group

Youth Advisory Panel: 8 members, 6 meetings over two years

Research Aims

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1. Prevalence Rates

Examine youth self-harm & mental health

2. Trends & Demographics

Identify trends over time and across key demographics

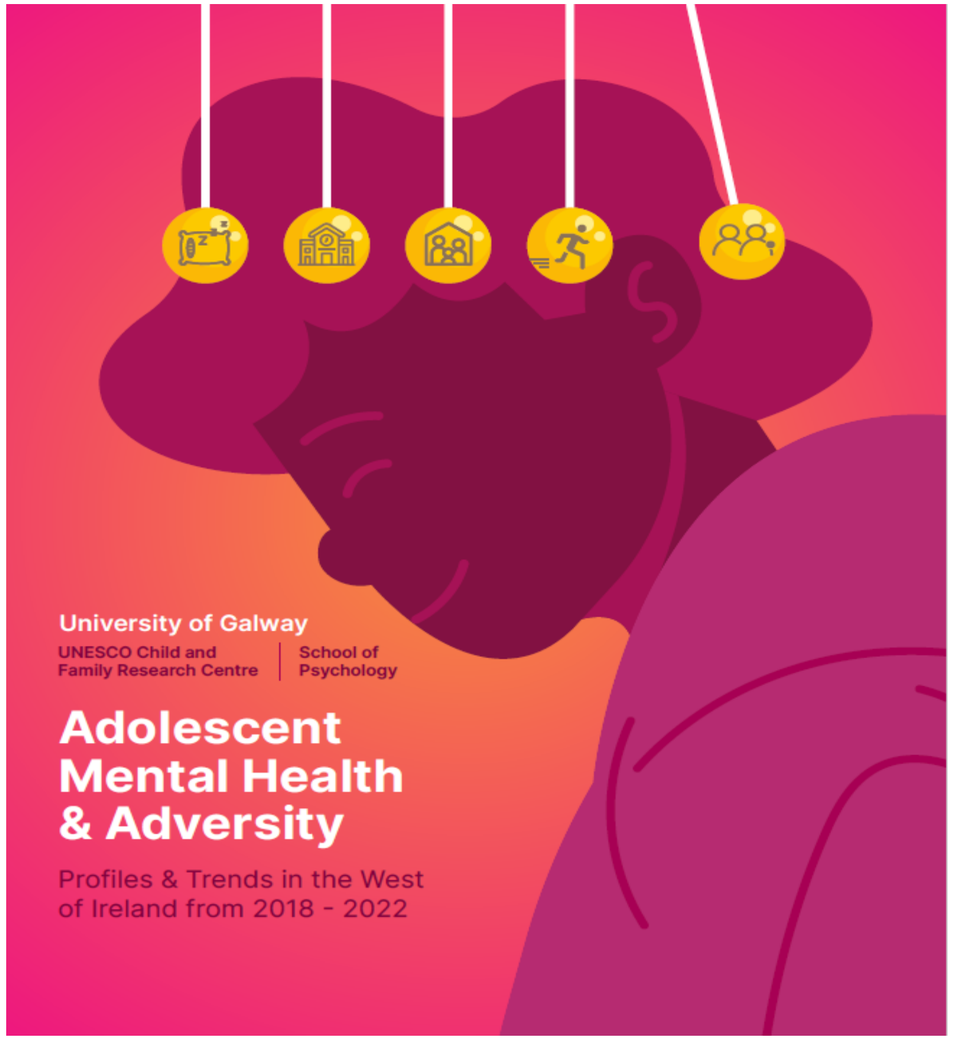
3. Adversity Related Risk

Understand the link between youth adversity & mental health

4. Protective Factors

Determine whether social supports & health behaviours act as protective factors

Key Findings



- Declines in youth mental health outcomes over time were evident.
- Four dominant patterns of adversity were identified.
- Youth who experience adversity are at greater risk of experiencing poor outcomes.
- Protective factors operate at both the community and individual level.

Patterns of Adversity

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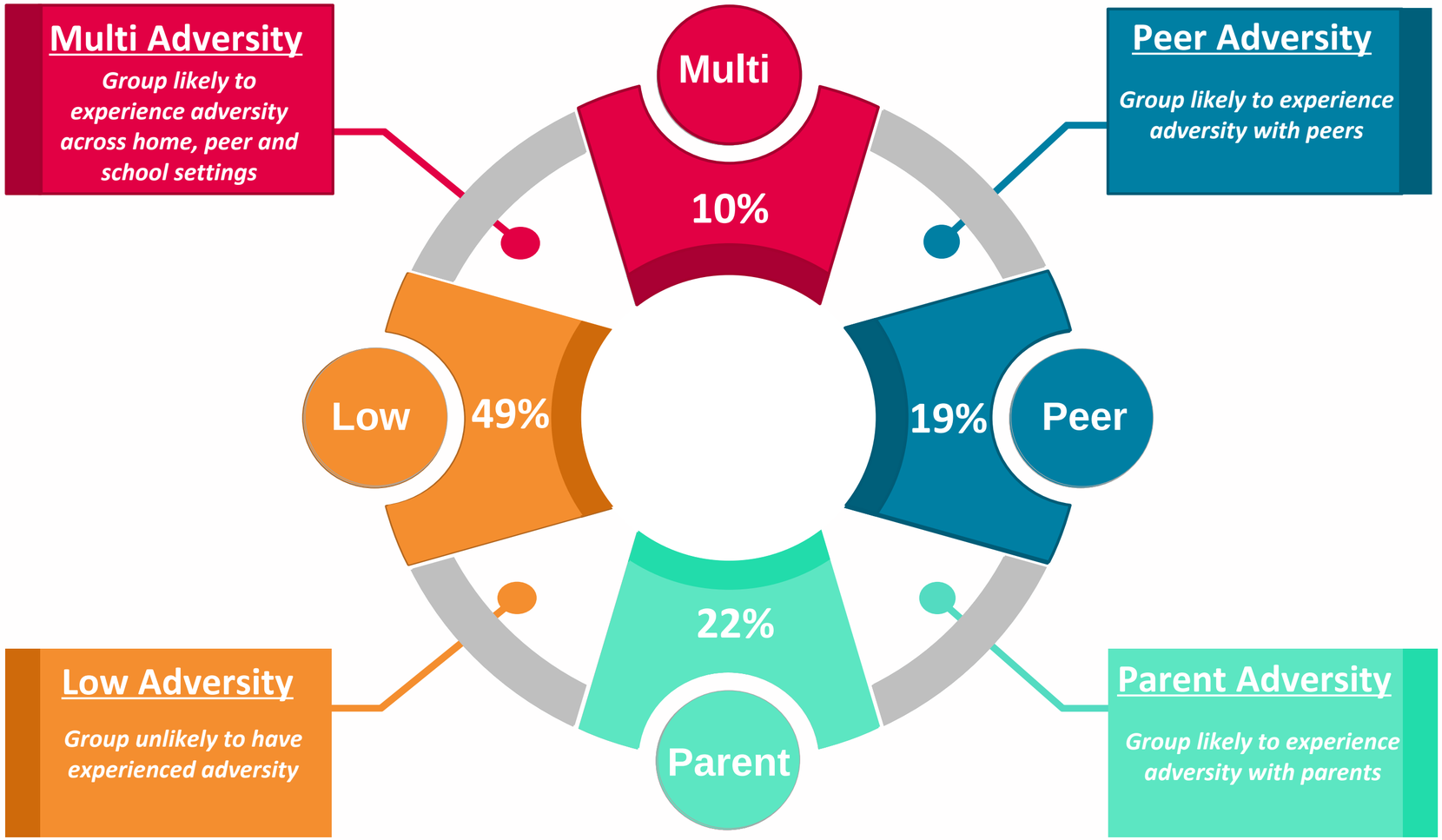

Clustered, multi-group LCA with BCH training weights, identified a 4-class solution as the best fitting model. Average latent class probabilities ranged from .76-.90

* Findings based on 2020 & 2022 data

Adversity groups and self-harm

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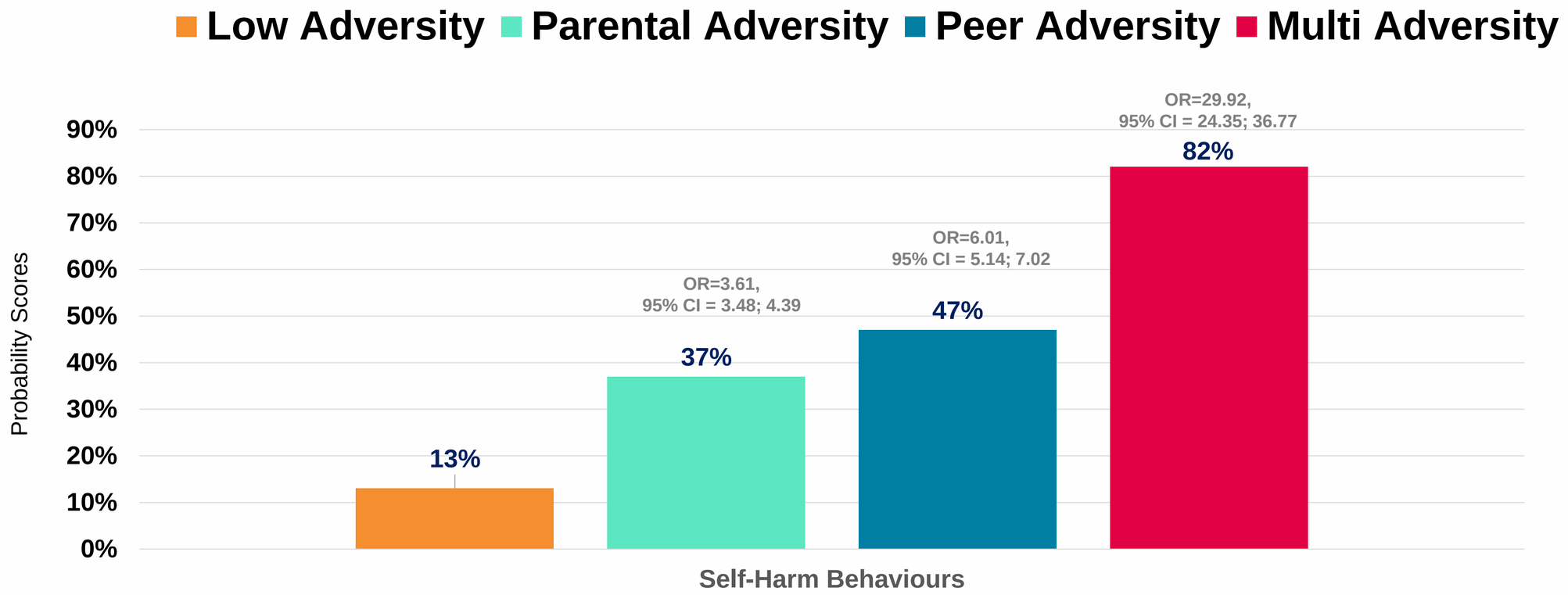

There were significant differences in self-harm behaviours between the four adversity groups.

* Findings based on 2020 & 2022 data

Outputs & dissemination

Academic: 4 peer reviewed journal articles (2 published, 2 under review)
5 academic conference presentations

Summary Report and Infographic

One day seminar entitled *'Broadening the Debate: Understanding the Social Context of Youth Mental Health'* – attended by 150 people

Local & national media coverage

Presented findings to more than 100 policy / practice / research stakeholders via:

- HSE Connecting for Life (CFL) NGO partners & Expert Advisory Group
- NSRF/ NOSP staff meeting

Academic & policy impact of the project

Addressed the need for **timely research** examining mental health functioning and behaviours among community-based samples of adolescents over time.

Provided new insights about the patterns of adversity youth experience across various social contexts (e.g., at home or with peers) and about the **relationship between adversity and youth mental health** in an Irish context.

Helped to advance understanding of **how adversity is defined and measured**, broadening the focus from individual contexts to include family, community and school influences.

Identified **personal health behaviours and community/relational supports** that are linked to lower risk of self-harm and better mental health functioning.

What worked well...

- Dedicated funding for full-time excellent Researcher
- Youth Advisory Panel – brought valuable insights and energy, contributed to KT activities
- Having policy partners, data controllers, academic disciplines as part of steering group
- HRB reporting requirements were not burdensome
- Institutional support – with data management plan, funding, event management, etc.

Key challenges

Secondary data:
- Coverage of measures
- Publishing cross-sectional data in higher ranking journals

Knowledge translation:
- Timing and format of outputs
- Personnel changes among partners

Impact:
- Balancing academic rigour with policy needs / real world impact
- Maintaining momentum after project ends

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Further Information:
https://www.universityofgalway.ie/cfrc/projects/currentprojects/inform-ysp/

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Disparities in Health Outcomes of Chronic Kidney Disease between Men and Women in the Irish Health System

Austin Stack
University of Limerick & University Hospital Limerick

HRB-Funded SDAP-2019-036

austin.stack@ul.ie
https://www.nkdss.ie

SDAP HRB Seminar
26th March 2025

Outline

- The Project
- The Findings
- Challenges, Struggles & Solutions
- The Impact

Goals

This project seeks to test whether sex disparities in relation to the morbidity and mortality exist for patients with chronic kidney disease

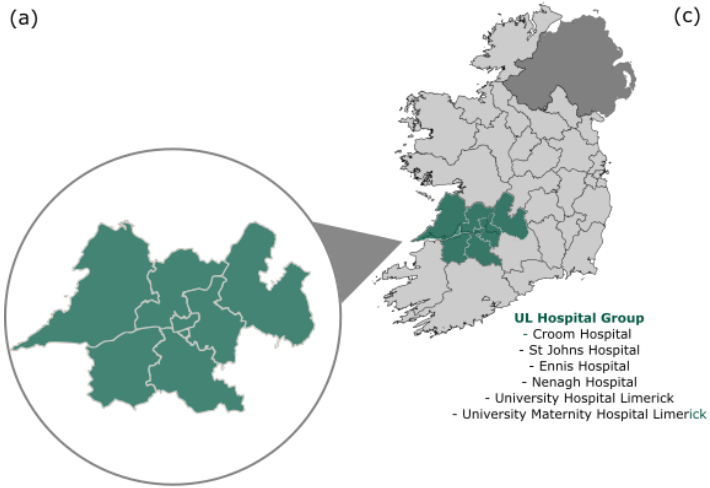
1. Compare the burden of CKD between men and women
2. Compare hospitalisation rates between men and women
3. Compare mortality rates between men and women

and

determine whether any observed differences could be explained by baseline health status or health care delivery

Figure 1: National Kidney Disease Surveillance System illustrating a) geographical coverage in the Midwest Community Healthcare Network of Ireland, b) percent of population included c) Data sources and information characteristics that converge to create a Surveillance System

(a)

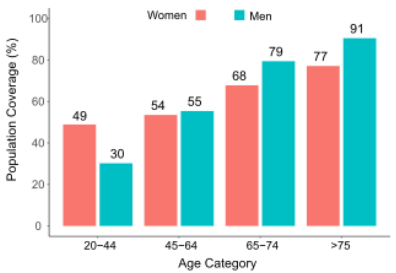


UL Hospital Group
- Croom Hospital
- St Johns Hospital
- Ennis Hospital
- Nenagh Hospital
- University Hospital Limerick
- University Maternity Hospital Limerick

HSE Mid West
Community Healthcare Network

(b)

The NKDSS includes laboratory and healthcare information of patients in the Midwest region that underwent creatinine or albuminuria testing in connection to a healthcare consultation.
In 2016, 175K persons over the age of 20 years with linked data had a laboratory investigation (52% of the Census population for the Midwest region N=341,800)



(c)

UL Hospital Group: Routine Laboratory measurements

-Inclusion criteria: >=1 creatinine / albuminuria test

- Age >=18 years

- Biochemistry, Haematology and Serology tests

- Demographics, Residency, Date of request, center and medical department, patient type

- Laboratory source, units, reference interval

- Speciality, primary, outpatient, emergency an inpatient consultations

Central Statistics Office: Vital Statistcs

- Demographics, Address, Civil Status,
- Date of death, Underlying Cause of death (ICD-10-AM), associated causes of death (ICD-10-AM)

Kidney Disease Patient Management system/ Renal Register

National electronic medical record for all Nephrology referred CKD stage-4 patients on wards.

- Demographics, Renal Centre, Hospital Group

- Primary /Underlying cause of Kidney Disease

-Transplant status

-Dialysis characteristics

-Clinical Data: Laboratory and Comorbidity Data
-Kidney Replacement Therapy and modality

POBAL Deprivation index: Socioeconomic area

The Pobal HP Deprivation index is Ireland's most widely used social gradient metric, which scores each small area (50 – 200 households) in terms of affluence or disadvantage.

- Small area, Electoral Division

- 2006 , 2011, 2016 Absolute Index Score and Relative index Score

ULHG: Hospital In-Patient Enquiry (HIPE) data

-Demographics, Hospital Number, Area of Residence, Civil Status, Consultant Speciality

-Clinical Diagnoses (ICD-10-AM), Major Diagnostic category, Australian Refined

- Diagnosis Related Group (AR-DRG) and Australian Classification of Health Interventions (ACHI) procedure codes.

- Source of admission, admission type, elective type, date of admission , date of discharge, length of stay, ITU length of stay, day case indicator, date of diagnoses,date of procedure , discharge type, insurer.

Primary Care Reimbursement Service (PCRS)

- Demographics, LHO area

-Trade name, Anatomical Therapeutic Chemical (ATC) classification system Name, ATC CODE

- Date claimed, Prescribed dose/ Strength.

- Cost, Scheme Name

Primary Care: Chronic Disease Management

-Demographics (Age, sex, Ethncicity), Patieint type

-Scheme Type, Registration date, review date

-Comorbidity Data (ICD-10, ICPC-2)

-Medciation Data: Date of prescription,trade name, strength/ dose,quantity, issue, type, number of issues, scheme

-Anthropometric and clinical measurements: Weight, Height, BMI, Blood Pressure

-Health behaviours: Smoking, physical activity, alcohol

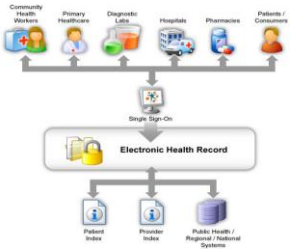
Area	Laboratory tests
Kidney Function	Serum creatinine, eGFR, Urea, Blood Urea Nitrogen (BUN),Urine Protein,Microalbuminuria,Urine Creatinine
Electrolytes/ Minerals	sodium (Na), potassium (K), chloride (Cl), Bicoarbante(HC03) , Phospohate (PO4) carbon dioxide (CO2), Magnesium, Iron , Serum -Lithium
Bone Mineral Metabolism	PTH, Alakaline Phosphatase, Calcium, Phosphate,Albumin , Vitamin D
Diabetes	Hba1C, Fasting plasma Glcuose, Random plasma glucose
Cardiology	BNP, Cardiac Troponins, D-Dimer,
Nutriton-Anaemia	Albumin, haemoglobin, ferritin, transferrin saturation
Hormones	Thyroid Hormones, Sex Hormones, PSA, aldosterene
Lipids	Total cholesterol, triglycerides, LDL, HDL
Urine tests	Proteinuria, Albumin to creatinine ratio (ACR)
Liver Function	Alanine transaminase (ALT),Aspartate transaminase (AST),Alkaline phosphatase (ALP),Albumin and total protein,Bilirubin,Gamma-glutamyltransferase (GGT),L-lactate dehydrogenase (LD),Prothrombin time (PT)
Full Blood Count	Haemoglobin (Hb),White Blood Count (WBC), Platelet Count (Plt),Red Cell Count (RBC), Haematocrit (HCT),Mean Cell Volume - Red cell (MCV), Mean Cell Haemoglobin (MCH),Neutrophils, Lymphocytes,Monocytes, Eosinophils, Basophils
Rheumatoid arthritis	C-reactive protein (CRP) , ESR, Full Blood count, Rheumatoid factor(RF), ANA (Antinuclear Antibody) Test, Anti-DNA and Anti-Sm, Complement,Uric acid

A Framework for Disease Surveillance Stsyem

Integrated Informatics Engine to capture key health information data from Primary Care to Secondary care

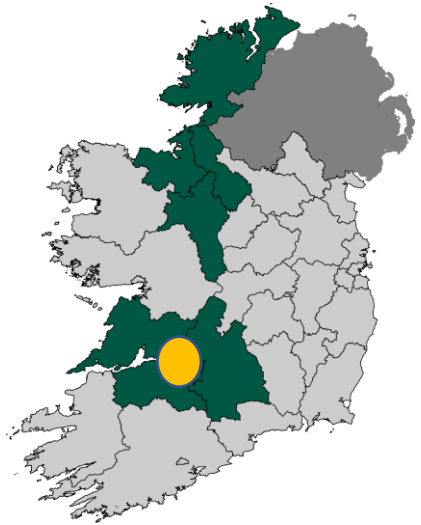
Blood tests
(HSE Laboratory Data Systems)

Mortality
(CSO National)



Hospitalisations
(HIPE)

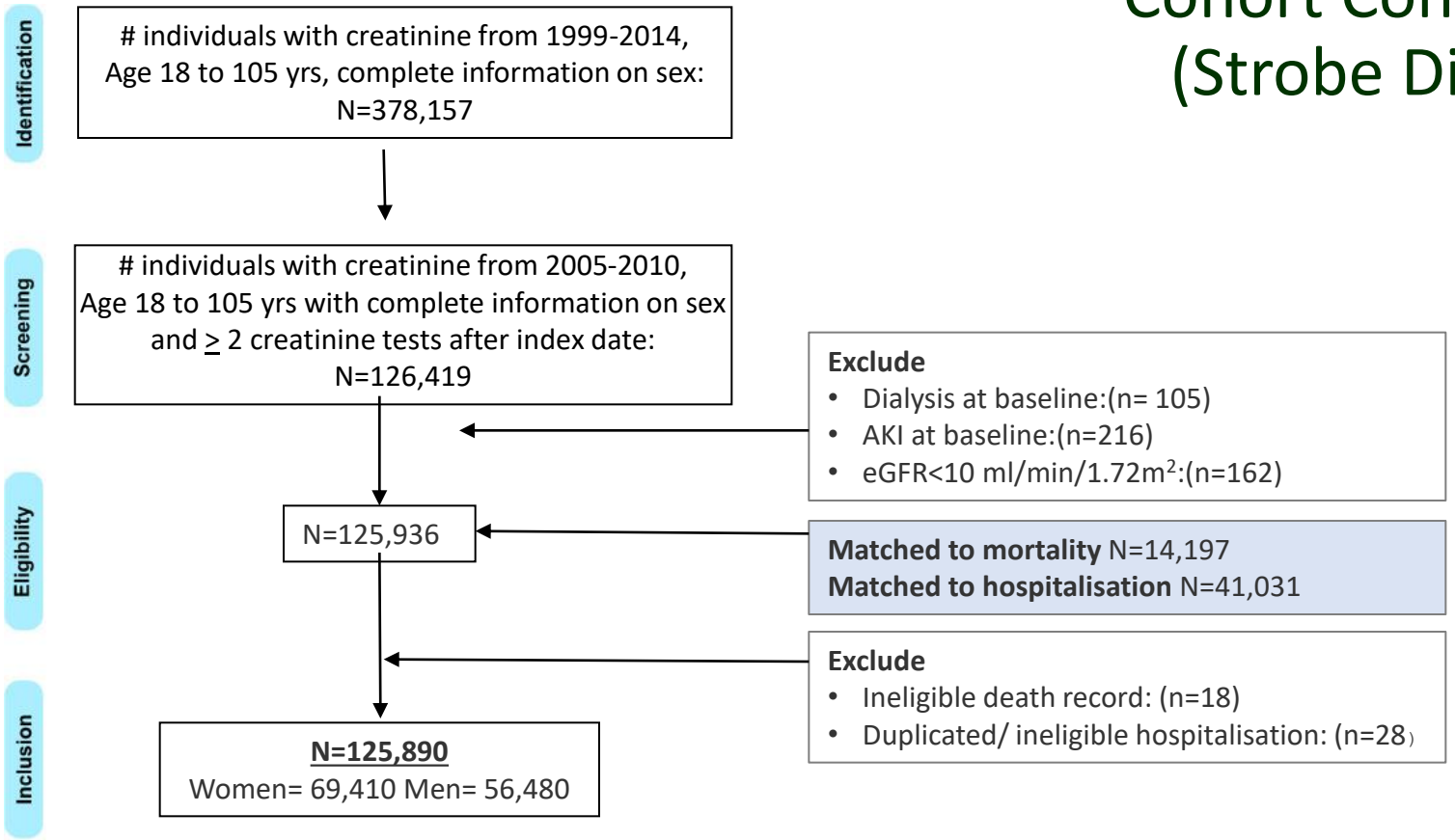
Kidney Replacement Therapy
(National)



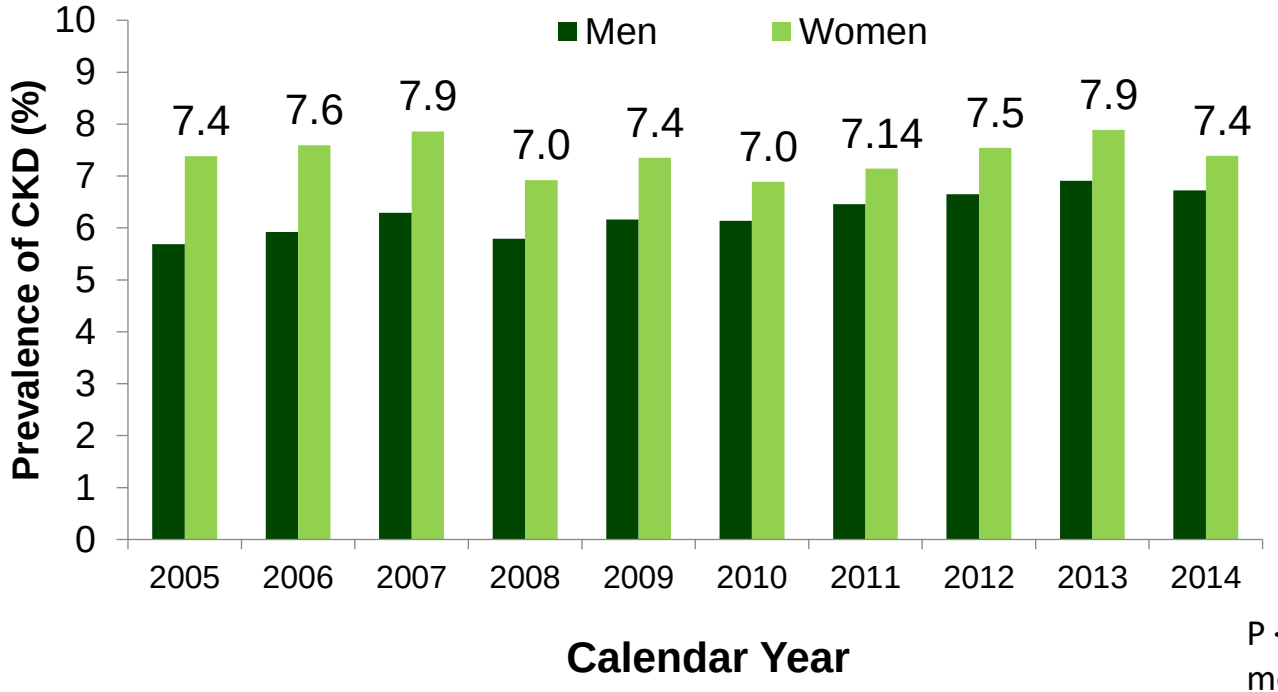
PCRS: https://data.ehealthireland.ie/group/pcrs
HIPE: https://data.ehealthireland.ie/group/about/hpo-hipe
KDCPMS: Hussein et al Kidney360 June 2021
CSO: https://www.cso.ie/en/statistics/birthsdeathsandmarriages/mortalitydifferentialsinireland/

Stack et al: Irish Kidney Disease Surveillance System

Cohort Construction (Strobe Diagram)



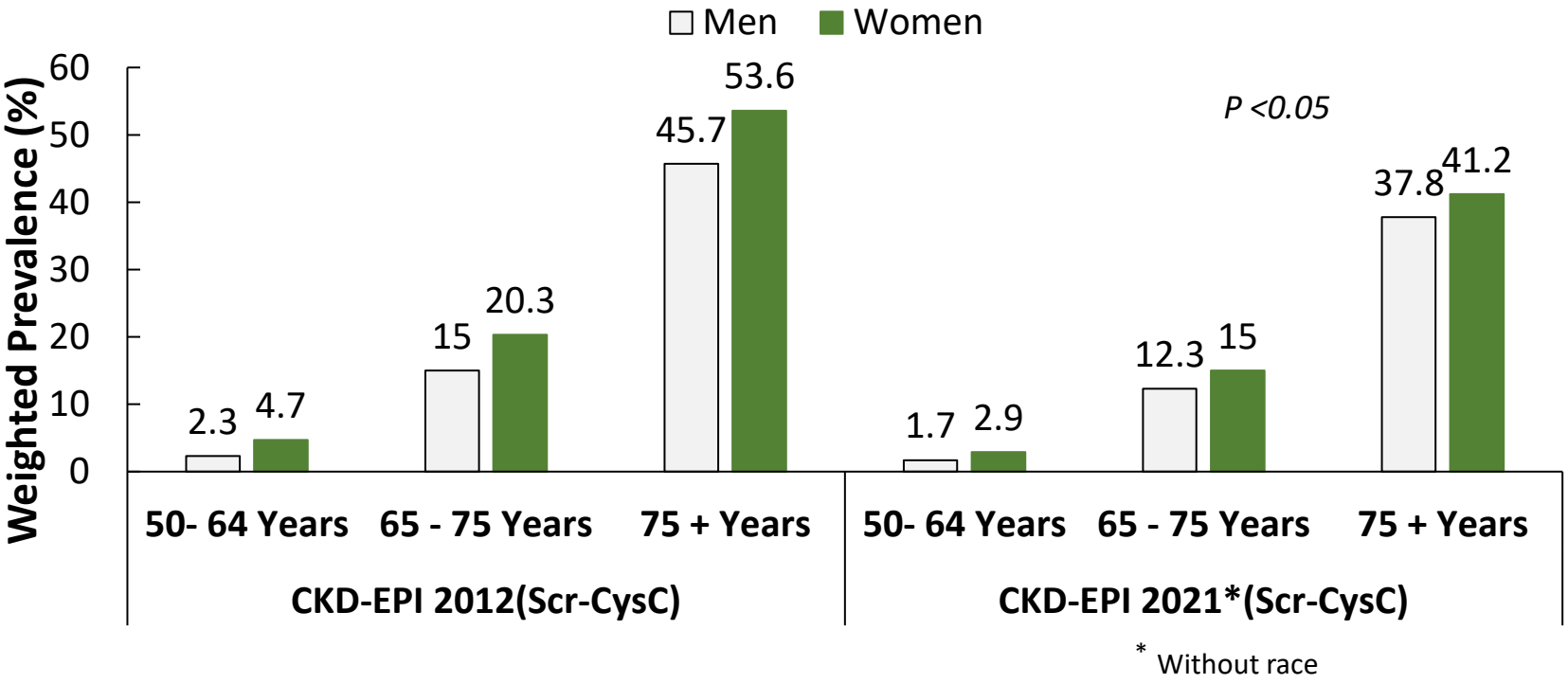
Higher prevalence of CKD in Women than Men



P <0.001 for trend in men only

CKD defined as mean eGFR <60 ml/min/1.73 m², using CKD-EPI
Population estimates derived from 2012 and 2016 census data

Replicated Findings in TILDA

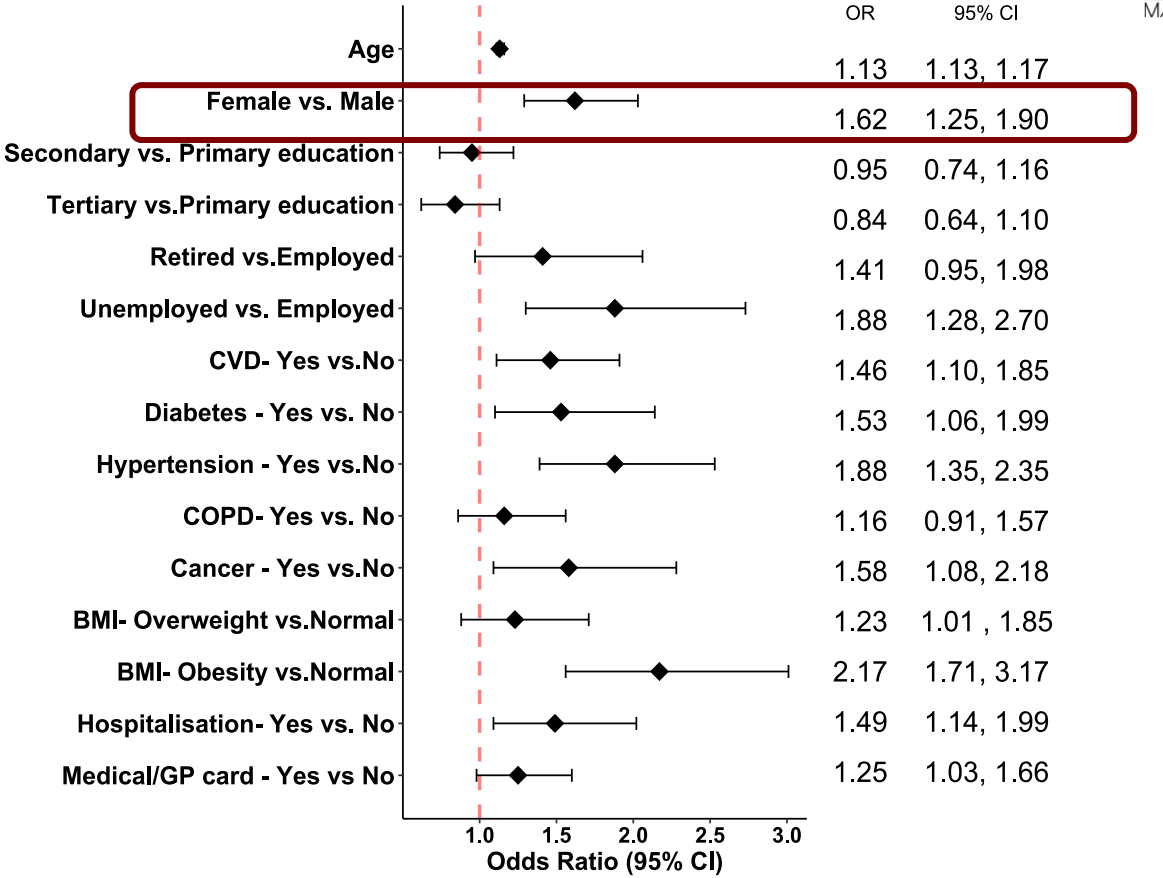


* Without race

TILDA Wave 1
N=5,386

Tandan et al CKJ 2025

Factors Associated with CKD in TILDA

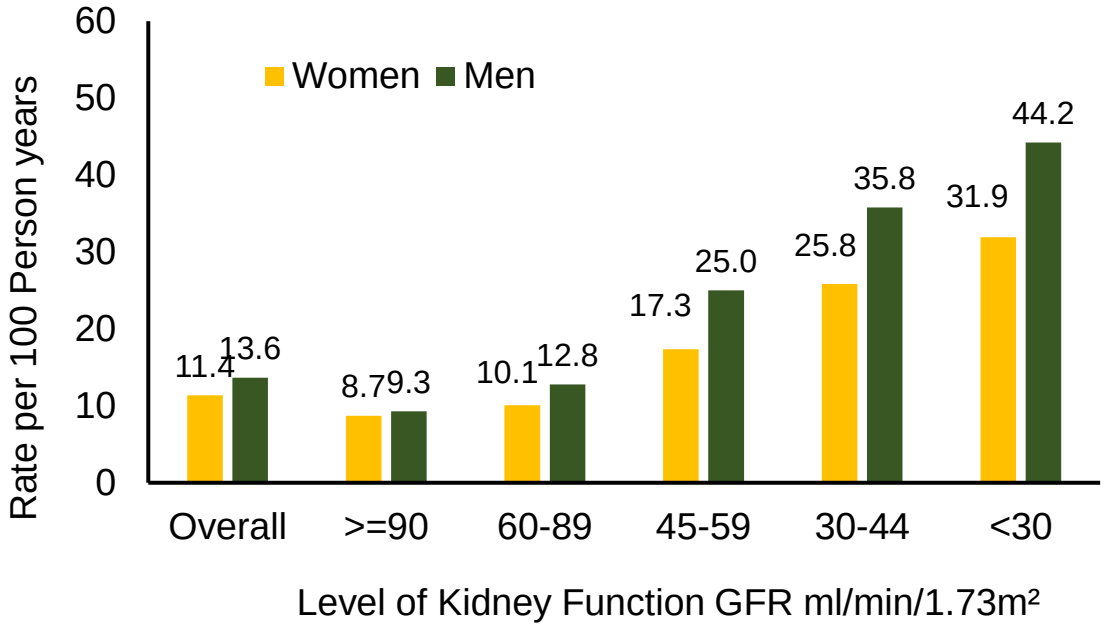


Model adjusted for
Socio-demographic factors, comorbid conditions, and
health care utilisation

Tandan et al CKJ 2025

Women had lower rates of hospitalisation than Men

All-cause hospitalisation by level of kidney function



P< 0.001
for women vs men

GFR categories in ml/min/1.73m² using CKD-EPI equation
N= 125, 890 patients
N= 93, 515 hospitalisations

Relative Risk for Hospitalisation for Men vs Women[1]

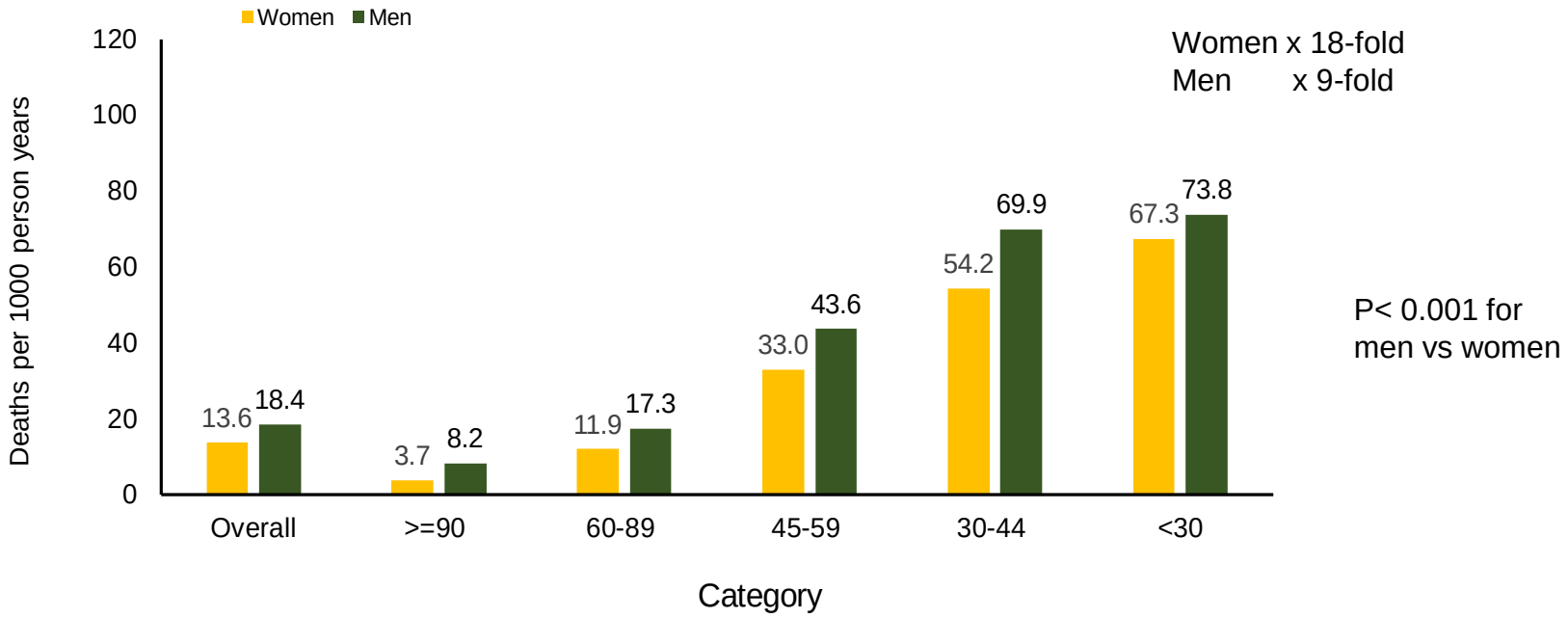
Men (vs Women)	Risk Ratio	95% CI	
Unadjusted Model	1.20	1.16	1.24
plus age	1.15	1.12	1.19
plus age, diabetes	1.13	1.19	1.17
plus age, diabetes, eGFR	1.14	1.10	1.17
plus age, diabetes, eGFR, location of supervision	1.07	1.04	1.11
plus age, diabetes, eGFR, location of supervision, year	1.07	1.03	1.10

P-value for interaction for sex and eGFR with hospitalisation: P< 0.001

eGFR (ml/min/1.73m^2)
N=125, 890 patients
N= 93,515 hospitalisations
Location of medical supervision: inpatient, outpatient, general practice, emergency department
[1]Negative binomial model better fit than Poisson regression

Stack et al EDTA 2022

Women had higher than expected mortality rates than Men by GFR Group



N= 14, 179 deaths (11.3 %)

Hazard Ratios for Death for Men and Women stratified by GFR Group

Group	$HR_{unadjusted}$	$HR_{adjusted}$
Overall Cohort	1.36	1.62 (1.55-1.70)
GFR Category		
>=90	2.20	2.16 (1.89-2.46)
60-89	1.46	1.64 (1.53-1.76)
45-59	1.33	1.52 (1.38-1.67)
30-44	1.30	1.40 (1.24-1.59)
<30	1.10	1.22 (1.00-1.49)

N= 14, 179 deaths (11.3 %)
GFR ml/min/1.73m²
Final model: was adjusted for baseline age, sex, eGFR, ,haemoglobin, white blood cells, serum, potassium, alanine aminotransferase (ALT), alkaline phosphatase(ALP), and location of supervision

Conclusion

1. Irish women have higher burden of CKD than Irish men
   - They experience lower rates of hospitalisation than men
   - Some of these differences are explained by age, diabetes, GFR

2. Women with CKD experience mortality rates that are similar to men
   - They loose the normal survival advantage

3. These would suggest that CKD does influence the outcomes of women either due to change in the biology of the disease or in the extent to which women are assessed and treated

Expected Challenges

Governance and Legislation, Organisational framework , Technical

1. No single entity of organisation to guide or facilitate
2. No blueprint to follow in this country (National Cancer Registry)
3. No unique identifier
4. No Data linkage centre (capacity, capability, expertise)
5. Lots of silos of health information

Learning Opportunities

NKSS

Data Controllers, Access & Data Sharing

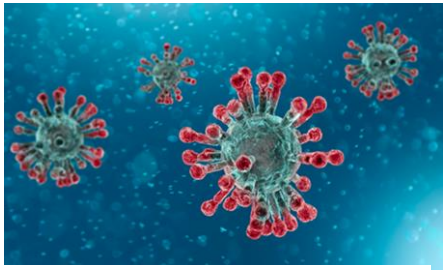
Information Governance/Data Controllers/Data Processors

1. Where is the health data?
2. Who is the data controller?
3. **Will you share the data?**
4. Have you authority to link data?
5. Have you spoken with CEO?
6. Has the Data Protection Office approved data?
7. Have you ethical approval?
8. Have you consent?

Another Learning Opportunity

NKSS

Unexpected Challenges



COVID Pandemic
2020-2023

HSE Cyber Attack
May 2021

Researchers learning to adapt

CSO Corporate Governance
2022

The Impact

to

Individuals, health systems & society

1. Contribute to Local & Global Policy
Advance our understanding of a major chronic disease

- Invitation to national strategy & Policy events
- Global health policy: United States: CDC Surveillance of CKD 2023-2024
- National health policy: Department of Health-Evidence for Reform 2023
- Regional health policy: Chronic Disease Surveillance Programme


An Roinn Sláinte
Department of Health

Department of Health Conference

Evidence for Reform: Where Research meets Policy

7 NOVEMBER 2023

08:30 – 09:15

Registration

09:15 – 09:45

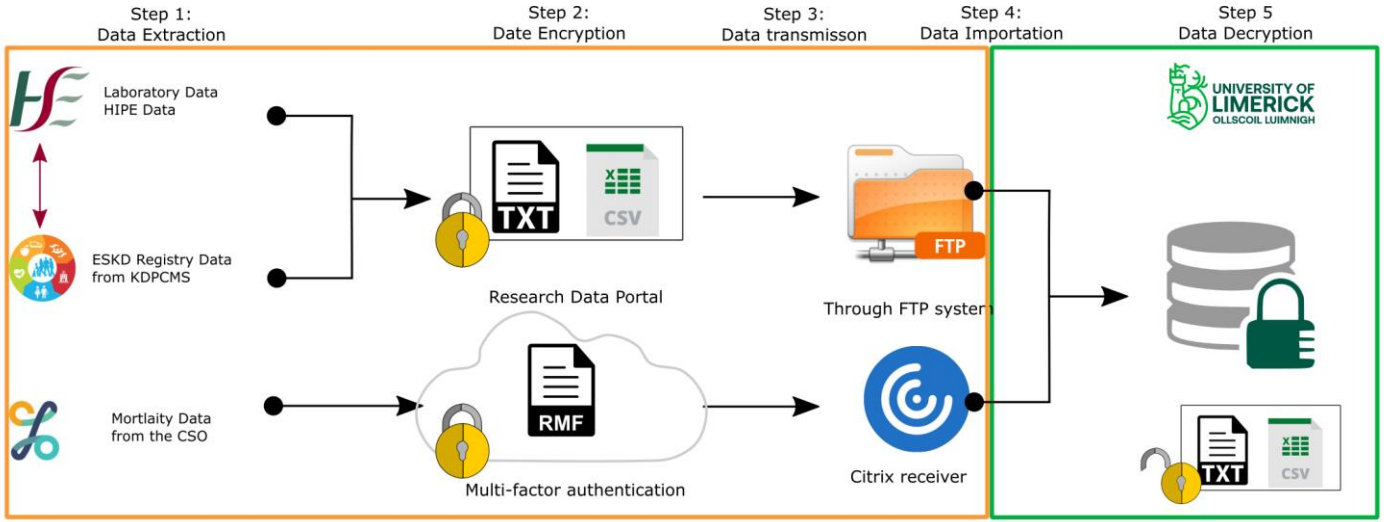
Muiris O'Connor – Assistant Secretary Research & Development and Health Analytics Division, Department of Health

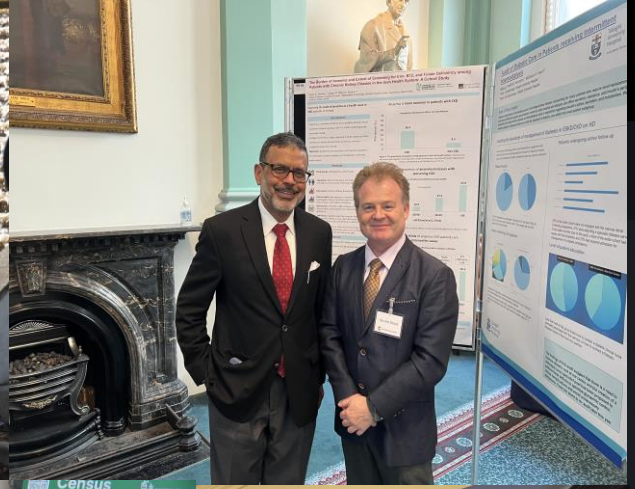
2. Contribute to Key National Initiatives

- National Registry for Kidney Disease-HSE & Academia
- Chronic Disease Data System – HSE & Academia

3. Establish key Infrastructure for Data Systems to generate real world evidence

- National Kidney Disease Surveillance System (NKDSS)
- Address core issue of data security, data linkage, scalable datasets
- Trusted Research Environment (TRE)





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MENU

RTÉ

RTÉ RADIO 1

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New research finds that women are 50% more likely to have chronic kidney disease than men

CLIP • 5 MINS • 13 MAR • DRIVETIME

00:00 05:39

Share -15 +30

Back to Show Page

Notes

A new study by researchers at the University of Limerick has revealed an extraordinarily high burden of kidney disease in older individuals in Ireland that suffer from common chronic conditions. We hear from Professor Austin Stack, Senior Author on the study and Consultant Nephrologist at UL.

Our greatest Assets

Ospidéil OL
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Scoil an Leighis
School of Medicine

UCC
University College Cork, Ireland
Coláiste na hOllscoile Corcaigh

Ollscoil na Gaillimhe
University of Galway

UCD DUBLIN
School of Medicine

JOHNS HOPKINS
MEDICINE

UNIVERSITY OF MICHIGAN
MEDICAL SCHOOL
MICHIGAN MEDICINE

CDC
CENTERS FOR DISEASE CONTROL AND PREVENTION

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University of Galway

DXA

(Dual-energy X-ray Absorptiometry Project)

HIP[1]

(Health Informatics Prediction)

MAP[2]

(Management Application Process)

Projects

Health Research Board Funded Projects:

1) SDAP_2021_001
2) SDAP_2023_010

University *of* Galway.ie

Global Burden of Disease (GBD)

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University of Galway

- A comprehensive picture of mortality and disability across countries.

- Quantifies health loss from diseases, injuries, and risk factors, so health systems can be improved and disparities eliminated.

- 281,586 data sources to estimate mortality, health outcomes, and risks in 2019;
- >3.5 billion standardized and comprehensive estimates of health outcome and health system measures;
- >350 health outcomes and risk factors;
- >10,000 individuals from >160 countries and territories collaborate.
- Funded by the Bill & Melinda Gates Foundation.

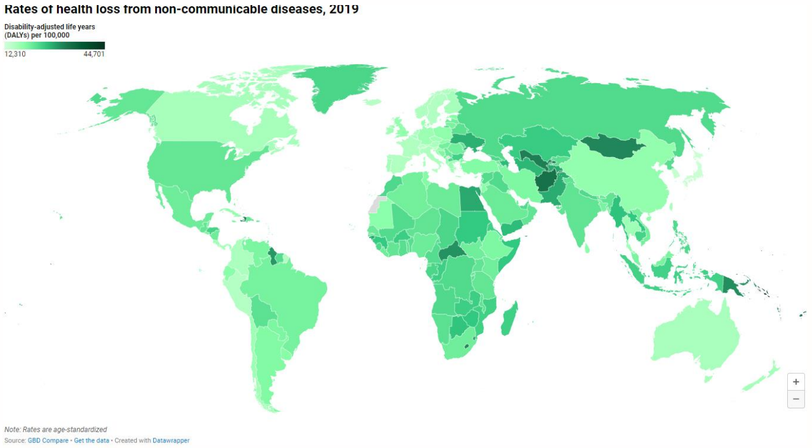
1. https://www.healthdata.org/research-analysis/gbd
2. GBD 2017: A Fragile World. The Lancet 2018; 382: 1683.

2017: Non-communicable Diseases (NCDs)

OLLSCOIL NA GAILLIMHE
UNIVERSITY OF GALWAY

- Global Adult Mortality rates plateaued in 2017!

- NCDs account for 73% of global deaths.
- >50% (29 million) are accounted for by 4 risk factors:
  - High body mass index **(DXA-MAP)**
  - High blood pressure **(DXA-MAP)**
  - High blood glucose **(DXA-MAP)**
  - Smoking **(DXA-MAP)**



- No country is on track to meet all the WHOs sustainable development goals by 2030

1. https://www.healthdata.org/research-analysis/gbd
2. GBD 2017: A Fragile World. The Lancet 2018; 382: 1683.

The Irish Times 16th May 2023

Paul Cullen

- **2022** Government allocated €360M to cut waiting lists;
- Target: 17% - Actual result: 1%

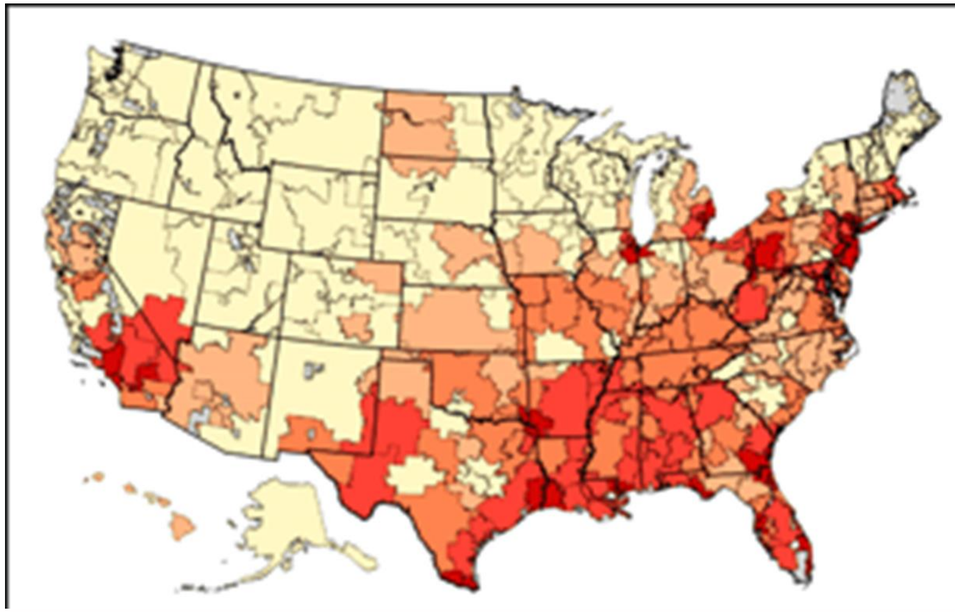
- **2023** Government allocated €443M;
- Target: 10%, but already this number has increased from 870,000 in December 2022 to 888,000 in April 2023.
- Cancellations in April 2023 up almost 70% from April 2022.

- ***"And we have no idea whether value for money is being achieved"!***

US Study: Is more Healthcare better?

Fisher ES. Ann Intern Med 2003 138(4): 273-287 & 288 – 298.

- Compared Cost of care Vs Outcome for 3 NCDs:
  - Cardiovascular disease
  - Cancer
  - Osteoporosis (Hip Fracture).



- Higher spending regions: More Hospital-based care

- Outcomes in HSRs did NOT shows an increase in:
  - Quantity of life
  - Quality of life
  - Satisfaction with care.

Osteoporosis: A Consensus Definition

Ollscoil na Gaillimhe
University of Galway

"Osteoporosis is defined as a skeletal disorder characterized by compromised bone strength predisposing a person to an increased risk of future fracture.

Bone strength** primarily reflects the integration of **bone density and bone quality.

Bone quality refers to architecture, turnover, damage accumulation and mineralisation."

NIH Consensus Development Panel. JAMA 2001:785-795.

Global Burden of Osteoporosis

- **Osteoporosis is** a complex chronic NCD.[1]
- **M**ost prevalent bone **disease** worldwide, and among the most prevalent diseases.[1-4]
- **Consequence:** skeletal failure.
- **Clinical events:** Fractures / Broken bones.
- **Test:** DXA scan, others.
- 2019 European report of 29 countries.[1]

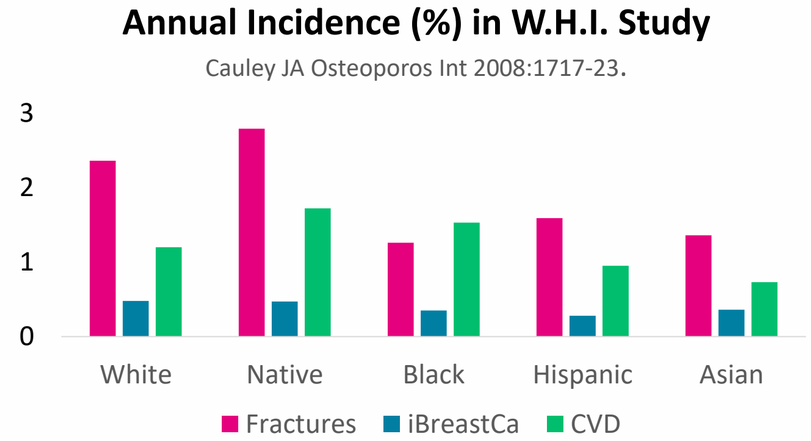
- **Fractures are a global public health issue.**[2]
- 204 countries : 1990 – 2019
- **2019:**
  - 178M new fractures
  - 455M prevalent cases (70% ↑ since 1990)
  - 25.8M YLDs
- Age-specific incidence greatest among older people **= Osteoporosis**

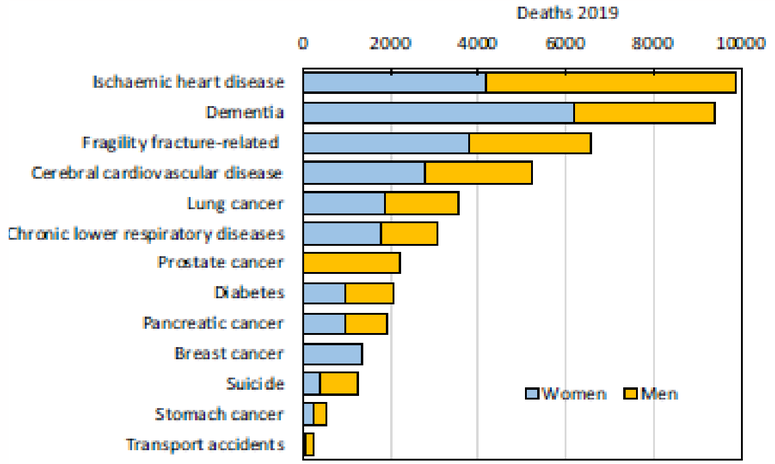
Ollscoil na Gaillimhe
University of Galway

Kanis JA. Arch Osteoporos 2021; 16:82.
GBD 2019 Fracture Collaborators. Lancet Healthy Longev 2021; 2: e580–92.
https://www.osteoporosis.foundation/health-professionals/about-osteoporosis/epidemiology
Khan AA. I.W.G. Mayo Clin Proc 2024; 99(7): 1127-1141.

Global Burden of Osteoporosis

- US Study of 83,724 multiethnic Postmp women 50-79 followed for mean 7.7years (NonVFx);[1]
- **2019**: Europe (EU + UK + Switzerland)[2]
  - Prevalence: >32 million adults;
  - > 4 million fractures;
  - > 250,000 Deaths;
  - Direct Fracture Treatment costs: €60 Billion (€200)





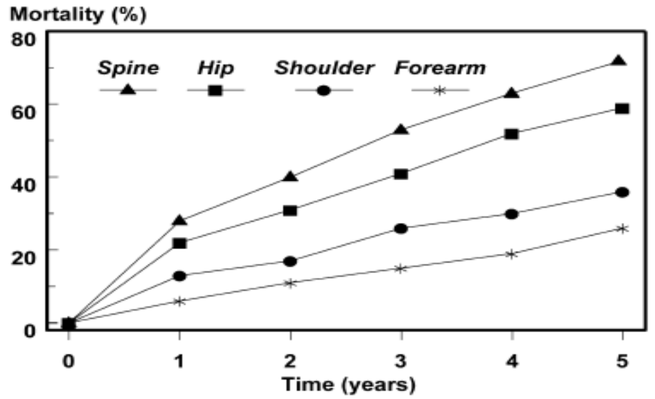


Fig. 1 Cumulative mortality following a fracture at the sites shown

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University of Galway

1) Cauley JA Osteoporos Int 2008; 19: 1717-23.
2) Kanis JA. Arch Osteoporos 2021; 16:82.

Osteoporosis in 2024

Ollscoil na Gaillimhe
University of Galway

Clinical

Central DXA T-score ≤ -2.5

https://iscd.org/official-positions-2023/

Major Osteoporotic Fracture

Hip, Spine, Other?

Mayo Clin Proc 2024: 1127-41.

Gold Standard: T-L Bone Bx

Best Pract Res Clin Rheumatol 2022: 101775.

Public Health

"A Major Health Threat"

JAMA 2001: 785-95.

"Global Public Health Issue"

Lancet Healthy Longev 2021:e580-92.

"Major Public Health Concern"

Mayo Clin Proc 2024: 1127-41.

"A common disease that has a significant impact on patients, healthcare systems and society"

JBMR+ 2023: rkad091.

Patient

"Something that doesn't just shatter your bones, but it also shatters lives".

"A very painful condition".

"A life-altering and very costly disease of the skeleton".

What About Ireland?

Kanis JA. Arch Osteoporos 2021; 16:82.

Scorecard for Osteoporosis in Europe

	Austria	Belgium	Bulgaria	Croatia	Cyprus	Czech Republic	Denmark	Estonia	Finland	France	Germany	Greece	Hungary	Ireland	Italy	Latvia	Lithuania	Luxembourg	Malta	Netherlands	Poland	Portugal	Romania	Slovakia	Slovenia	Spain	Sweden	Switzerland	UK	Description	Units	Score			
Burden of Disease																																			
Hip Fracture Risk																														The age-standardised incidence of hip fracture in women	rate/100,000	<400	400-500	>500	Unknown
Fracture Risk																														All osteoporotic fractures in men and women in 2019	rate/1000 >50 years	<18	18-21	>21	
Lifetime Risk																														Remaining lifetime risk of hip fracture (women aged 50y)	%	<13	13-16	>16	Unknown
FRAX Risk																														Men and women with a > 10% ten-year probability of a major fracture	% in 50-89 y age range	<22.5	22.5-27.5	>27.5	
Fracture Projections																														Increase in fracture number 2019-2034	% >50 years	<25	25-30	>30	
Policy Framework																																			
Quality of Data																														Hip fracture register	Score	3	2	1	Unknown
National Health Priority																														The presence of government backed NHP	Score	3	2	1	Unknown
Care Pathway																														Management in primary care	Score	3	2	1	Unknown
Specialist Training																														Osteoporosis an established specialty	Score	3	2	1	Unknown
Society Support																														Patient support societies	Score	3	2	1	Unknown
Service Provision																																			
Treatment																														Reimbursement and problems that arise	Score	3	2	1	Unknown
Availability of DXA																														Number of DXA units available	Units/million of the general population	>20	10-20	<10	
Access to DXA																														Reimbursement and problems that arise	Score	3	2	1	Unknown
Risk Models																														Availability of country-specific risk models and guidance	Score	3	2	1	Unknown
Guideline Quality																														Quality and scope of guidelines for assessment and treatment	Score	9-10	7-8	<7	Unknown
Liaison Service																														Provision for fracture liaison services (FLS)	Hospitals with FLS (%)	>25	1-25	0	Unknown
Quality Indicators																														Presence and use of quality indicators	Score	3	2	1	Unknown
Service Uptake																																			
FRAX Uptake																														FRAX sessions	Units/million of the general population/year	>2000	500-2000	<500	
Treatment Gap																														Proportion of women at high risk who are untreated	% >50y	<60	60-76	>76	Unknown
Δ Treatment Gap																														Change from 2010	Score	3	2	1	Unknown
Waiting Time Hip Surgery																														Average waiting time for hip surgery	days	<1	1-2	>2	Unknown

* NHP: National Health Priority

IOF International Osteoporosis Foundation

SCOPE '21 ScoreCard for OsteoPorosis in Europe

Ollscoil na Gaillimhe University of Galway

SCOPE '21 ScoreCard for OsteoPorosis in Europe

IRELAND

A NEW SCORECARD FOR OSTEOPOROSIS IN EU 27+2

REVEALS BURDEN OF DISEASE, GAPS, AND INEQUALITIES IN OSTEOPOROSIS & FRACTURE PREVENTION AND CARE

BURDEN OF DISEASE

32,000 NEW FRAGILITY FRACTURES IN 2019

89 FRACTURES PER DAY

3.7 FRACTURES PER HOUR

CHANGE IN COST PER INDIVIDUAL

€55.2 2010 → €95.7 2019

+73%

209,000 INDIVIDUALS WITH OSTEOPOROSIS IN 2019

77.5% WOMEN

22.5% MEN

3.7% OF THE TOTAL POPULATION

€464.3 MILLION SPENT IN 2019

€135.7 MILLION LONG-TERM DISABILITY COSTS

€290.8 MILLION DIRECT COST OF INCIDENT FRACTURES

€37.7 MILLION PHARMACOLOGICAL INTERVENTION

HUGE COST BURDEN FOR OSTEOPOROSIS-RELATED HEALTHCARE

PROJECTED INCREASE IN THE NUMBER OF **FRAGILITY FRACTURES**

51,000 2034

32,000 2019

+58.4%

SERVICE PROVISION & UPTAKE

* REIMBURSEMENT OF OSTEOPOROSIS MEDICATIONS

20.5 AVAILABLE DXA UNITS/MILLION INHABITANTS

2623 FRAX® SESSIONS/ MILLION PEOPLE/YEAR

€120 DXA COST

YES FRAX® RISK ASSESSMENT MODEL IS AVAILABLE

25-50% OF HOSPITALS HAVING FRACTURE LIAISON SERVICES

*LEVEL OF REIMBURSEMENT IS MEANS TESTED

104,000 WOMEN **TREATED** FOR OSTEOPOROSIS

153,000 WOMEN **ELIGIBLE** FOR OSTEOPOROSIS TREATMENT

49,000 WOMEN REMAIN **UNTREATED** FOR OSTEOPOROSIS

32% TREATMENT GAP

POLICY FRAMEWORK

YES ESTABLISHED NATIONAL FRACTURE REGISTRIES

YES OSTEOPOROSIS RECOGNISED AS A SPECIALTY

YES OSTEOPOROSIS PRIMARILY MANAGED IN PRIMARY CARE

OTHER SPECIALTIES INVOLVED IN OSTEOPOROSIS CARE: GERIATRICS, RHEUMATOLOGY, ORTHOPAEDICS

SCORECARD

Policy Framework: Quality of Data; National Health Priority; Care Pathway; Specialist Training; Society Support

Service Uptake: FRAX® Uptake; Treatment Gap; Δ Treatment Gap; Waiting Time for Hip Fracture Surgery

Burden of Disease: Hip Fracture Risk; Fracture Risk; Lifetime Risk; FRAX® Risk; Fracture Projections

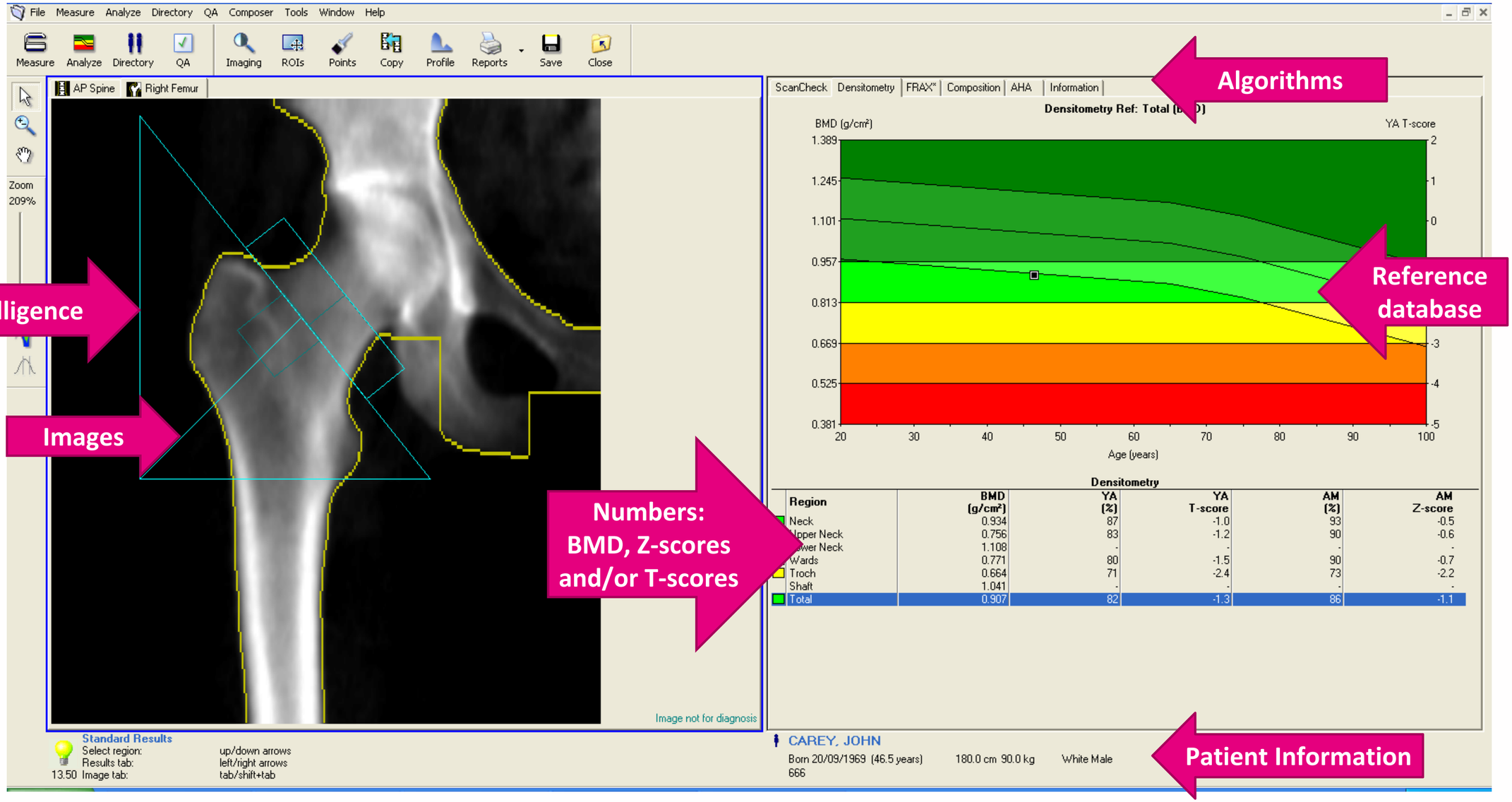
Service Provision: Treatment; Availability of DXA; Access to DXA; Risk Models; Guideline Quality; Liaison Service; Quality Indicators

The elements of each domain in each country were scored and coded using a traffic light system (red, orange, green) and used to synthesise a scorecard.

READ SCOPE 2021 AT WWW.OSTEOPOROSIS.FOUNDATION

Reference: Hiligsmann C et al. Osteoporosis in Europe: A Compendium of country-specific reports. Arch Osteoporos 2022

Principle Components of DXA Technology



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Ireland:

Almost 80 DXA machines performing 100,000 DXA scans annually

DXA HIP Objectives

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University of Galway

1. Data Management: Extraction, Merging, Cleaning, Anonymization.
2. Calibration of FRAX, Qfracture, Other currently used Algorithms.
3. Use data and ML to Identify optimal thresholds for Irish people.
4. Develop a Personalised Osteoporosis / Fracture Risk Model for Irish people.
5. Disseminate the Findings of the DXA HIP Project

The DXA HIP/MAP Project Team

Researchers

Dr. Attracta Brennan
Ms. Mary Dempsey
Dr. Erjiang E
Dr. Tingyan Wang
Dr. Lan Yang
Professor Máire Connolly
Professor Mary Fitzgerald
Dr. Damian Gonzalez Garza
Dr. John Smyth
Ms. Mina Ibrahimi Erjestan
Professor Ming Yu
Ms. Eléa Thuillier

Clinicians

Professor John J Carey
Professor Bryan Whelan
Dr. Carmel Silke
Dr. Miriam O Sullivan
Dr. Gráinne O'Malley
Dr. Guadalupe Morote Ibarrola
Ms. Bridie Rooney
Ms. Aoife McPartland
Ms. Catherine Armstrong
Ms. Fiona Heaney
Ms. Rebecca Egan
Ms. Kelly Gorham
Ms. Aoife Dempsey

Patients & Public

Mrs. Marie Caffrey
Mrs. Catherine Hickey-O'Maoláin

The Coffee Morning Crew

GUH staff and Patients

SUH and MH Staff and Patients

GPs in Galway and Sligo

Collaborators

Professor Wing Chan, Taiwan
Professor Manju Chandran, Singapore
Professor Andrea Singer, USA
Professor Joshua Lewis, Australia?

Output from DXA HIP and DXA MAP

1. **DXA dataset:** Demographics, biometrics, algorithms, outcomes.

2. 11 Publications:

3. **Oral Presentations:** ISR, WCO; Posters: WCO, ECTS

4. **Workshops and PPI Engagement:** WOD, Workshops, Coffee Mornings, Other

5. **Health Policy:** Engagement, Booklet, Politicians, Media: >10million in 2024!

6. DXA MAP Tool

Publications

Ollscoil na Gaillimhe
University of Galway

1. **The Irish dual-energy X-ray absorptiometry (DXA) Health Informatics Prediction (HIP) for Osteoporosis Project.** PMID: 33371026.
2. **Conceptual design of the dual X-ray absorptiometry health informatics prediction system for osteoporosis care** PMID: 35257612
3. **Machine Learning Can Improve Clinical Detection of Low BMD: The DXA-HIP Study.** PMID: 33187864.
4. **Utility of Osteoporosis Self-Assessment Tool as a Screening Tool for Osteoporosis in Irish Men and Women: Results of the DXA-HIP Project** PMID: 33789806
5. **Vertebral Fractures in Ireland: A Sub-analysis of the DXA HIP Project** PMID: 34085087
6. **How does proximal femur BMD of healthy Irish adults compare to NHANES III? Results of the DXA-HIP Project** PMID: 34773128
7. **Ireland DXA-FRAX may differ significantly and substantially to Web-FRAX** PMID: 36939937
8. **Prevalence of Low Bone Mass and Osteoporosis in Ireland: the Dual-Energy X-Ray Absorptiometry (DXA) Health Informatics Prediction (HIP) Project** PMID: 37808396
9. **Bone mineral density and fractures in patients with rheumatoid arthritis: the DXA-HIP project** PMID: 38025094
10. **Modelling future bone mineral density: Simplicity or complexity?** PMID: 38972532
11. **DXA and Cardiovascular Disease in Rheumatoid Arthritis: A scoping review**. J Clin Densitom, 2025: In Press.

As a result we know

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1. Between 300,000 and 500,000 Irish adults aged ≥ 50 years have osteoporosis;

2. Irish people who suffer an osteoporotic fracture have substantial morbidity and a high mortality too;

3. The majority of Irish patients with, or at risk for, a fracture are not receiving appropriate care, while others not at risk are.

4. We have validated some of the most commonly used osteoporosis clinical algorithms, and identified gaps in knowledge, their use and interpretation among clinicians and patients;

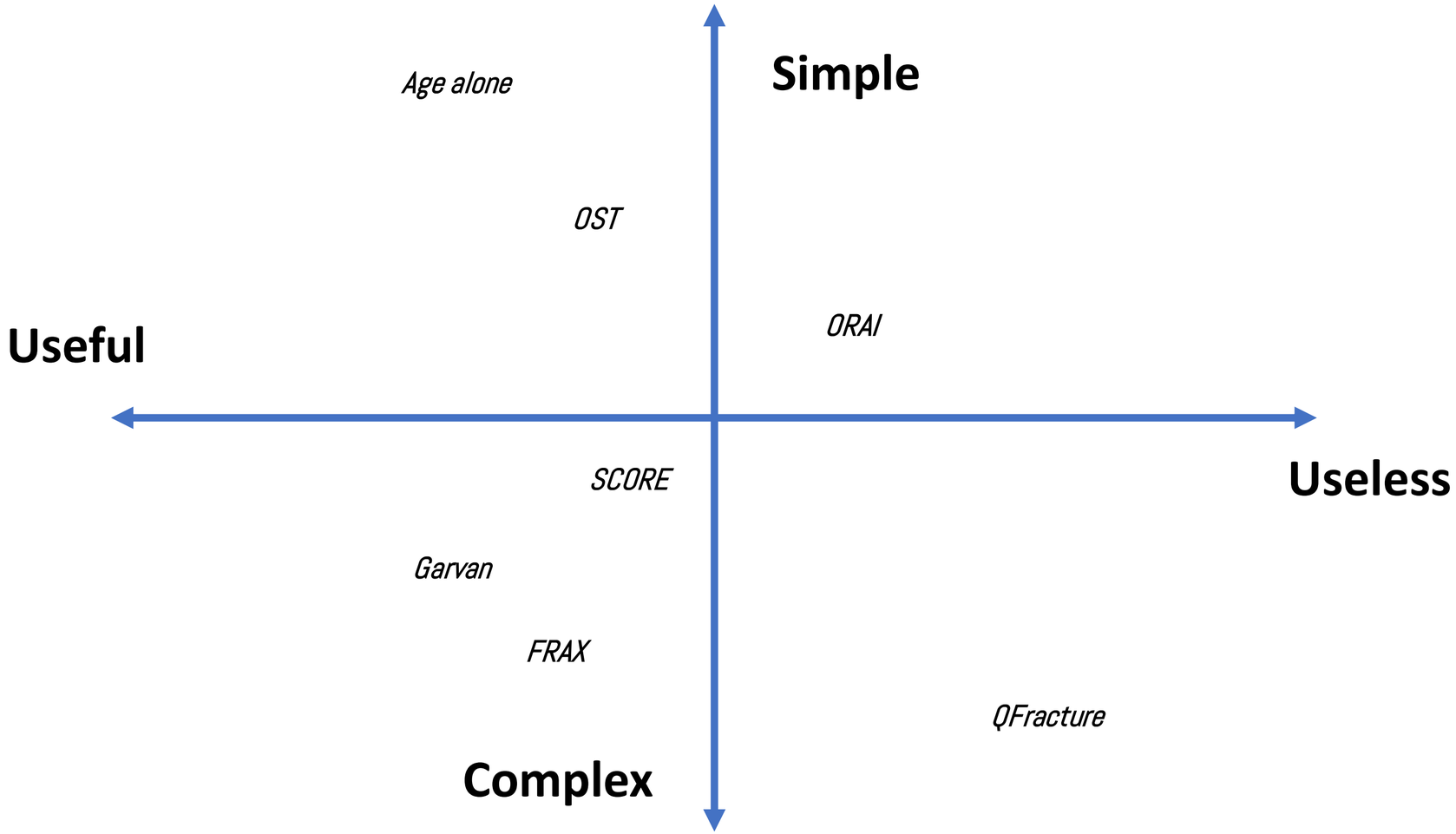
5. We have developed a more user-friendly algorithm to screen Irish adults;

6. We have initiated a policy document to gain traction for a national osteoporosis programme for how to evaluate, treat and manage those at risk based on standards and best practice.

7. This will improve the quality of care and “value for money”.

Current “Osteoporosis” Algorithms

Carey JJ, Brennan AB, in press



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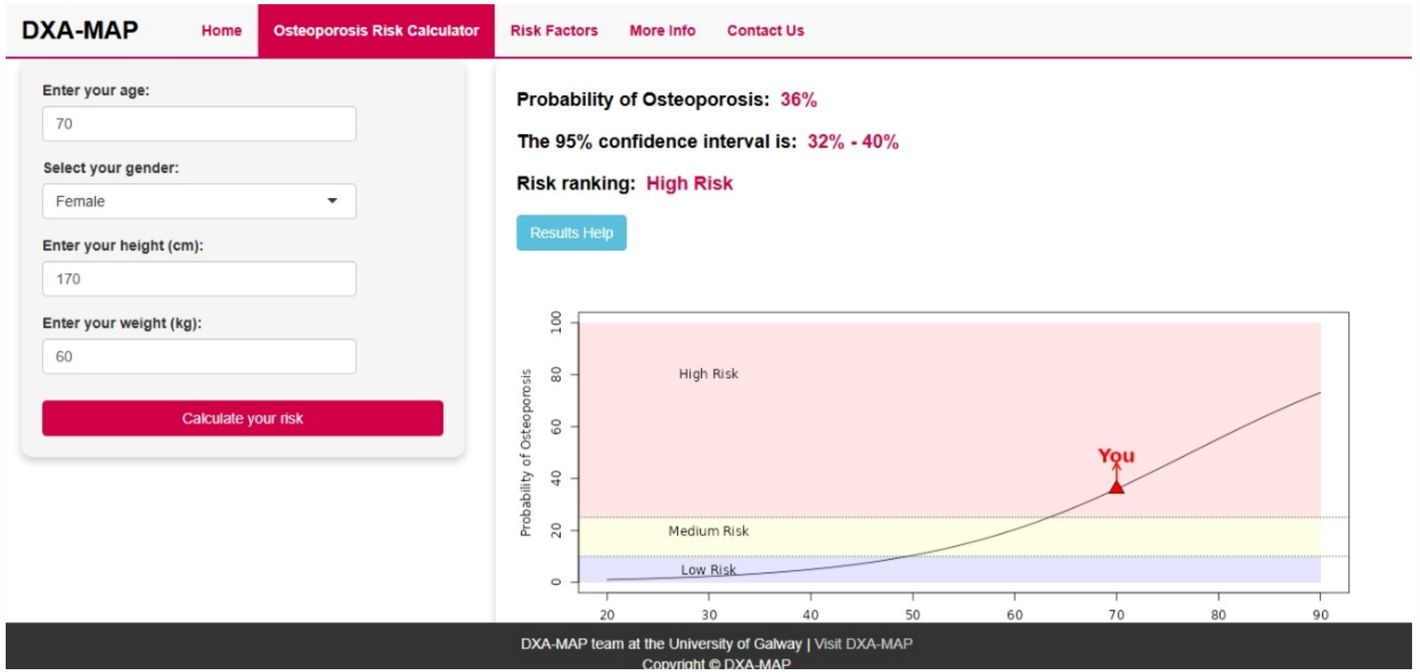
DXA MAP Tool

A Personalised patient-centred tool for osteoporosis screening



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A new Paradigm in Osteoporosis Screening

Carey JJ, Brennan AB, in press

1. Identify those who should be tested

2. Test the person

3. Use the test results to assess their risk and who should be treated

Opportunities and Challenges

- **Working for the HSE**
  - Access to Healthcare **data**
  - Access to DXA **data**
  - Support of patients & staff
  - Lack of Robust Irish **Data**

- **Working for University**
  - Access to Academics
  - **Culture** of Learning & Research
  - International Recognition
  - Research Vs Audit

- **H.R.B. Funding**
  - Staff / Equipment / Meetings
  - Recognition / Support / Knowledge
  - Feedback / Structure / Deadlines
  - Workshops & Meetings

- **HSE**
  - Lack of Expertise & Support
  - Complex pathways to success
  - Inefficiency

- **University**
  - Not the HSE = Governance?
  - Inefficiency
  - Lack of structures / support

- **Research in Irish Healthcare**
  - Lack of Umbrella Policy
  - Waste
  - Lack of Data value
  - Lack of Awareness

- **Administrator Vs Researcher?**

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Go Raibh Míle Maith Agaibh

See https://dxa-map.com