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Palliative and End-of-Life Care in Ireland (PELCI)

Establishing the state of the nation, mapping future direction

Peter May[1,2] on behalf of the PELCI team

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[2] The Irish Longitudinal Study on Ageing (TILDA)

Author's note

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- *These slides represent a shortened version of those presented at Wynn's Hotel on December 5th, 2023*

- *No content has been altered but some slides have been removed to protect work that is currently undergoing peer review from allegations of self-plagiarism*

- *Please contact me if you have questions about material that has been edited out*

    - *Peter May (mayp2@tcd.ie)*

Team and collaborators

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Palliative & End-of-Life Care in Ireland

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HSE

AIIHPC
All Ireland Institute of Hospice and Palliative Care
VOICES 4 CARE
Improving the Palliative Care Experience

Irish Hospice Foundation
To die and grieve well wherever the place

Healthcare Pricing Office

tilda
Staidéar Fadaimseartha na hÉireann um Dhul in Aois
The Irish Longitudinal Study on Ageing

HRB
An Bord Taighde Sláinte

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Introduction

Background: death and taxes

- End-of-life care a core function of any health system
- Ireland ranked highly by EAPC, Economist but…
  - … modifiable poor experiences
  - geographical inequities

The Economist Intelligence Unit

The 2015 Quality of Death Index

Ranking palliative care across the world

A report by The Economist Intelligence Unit

THE IRISH TIMES

Wed, Aug 29, 201

NEWS | SPORT | BUSINESS | OPINION | LIFE & STYLE | CULTURE

Social Affairs › Religion & Beliefs | Papal Visit

How Irish people die: many suffer unnecessarily in final year

Tilda survey of relatives shows high prevalence of pain and depression before death

Tue, Dec 12, 2017, 00.00

- Updated national PC policy in draft
  - Fast-growing population health needs
    - ➢ Urgent need for funding, workforce planning

End-of-life care needs will nearly double over next 30 years

Posted on: 10 February 2020

New research at Trinity College Dublin shows that the number of people dying in Ireland with palliative care needs will increase 84% to the year 2046 and highlights the urgent need for funding and workforce.

Introduction

HRB Secondary Data Analysis Projects (SDAP)

- Strong data is key to better health care, health policy & health
  - An era of big data
  - Routine data key to PC/EOLC
- SDAP (2019-present)
  - Answer policy/practice-relevant questions with secondary data
  - Explicitly linked to the documented evidence needs of knowledge-users
    - PELCI
      - *"Establish the state of the nation"*
      - *"Map future direction"*

Work packages

Three principle areas

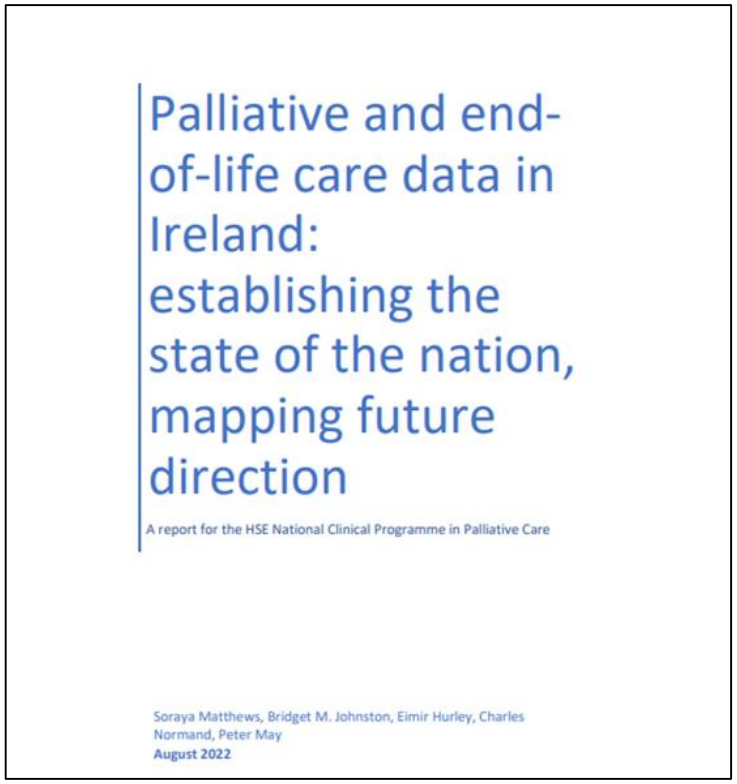
- **WP1:** Routine data in palliative care: review of practice in Ireland
  - What data are collected, by whom?
- **WP2:** Routine data in palliative care: review of international practice
  - How do other countries do it, what can we learn?
- **WP3:** Economics of palliative and end-of-life care in Ireland
  - Cost of care for serious illness, models of palliative care

➢ Lessons for policy and data, lessons for research

Important caveat

Today's presentation necessarily a summary

- **Full report and lots of further reading to follow!**



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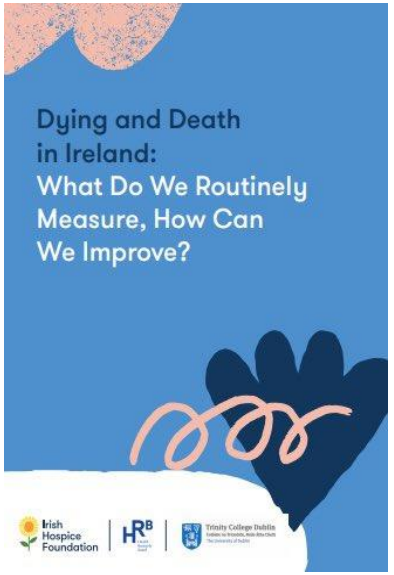
WP1: Routine PEOLC data

A review of current practice in Ireland



WP1: Results

Place of death

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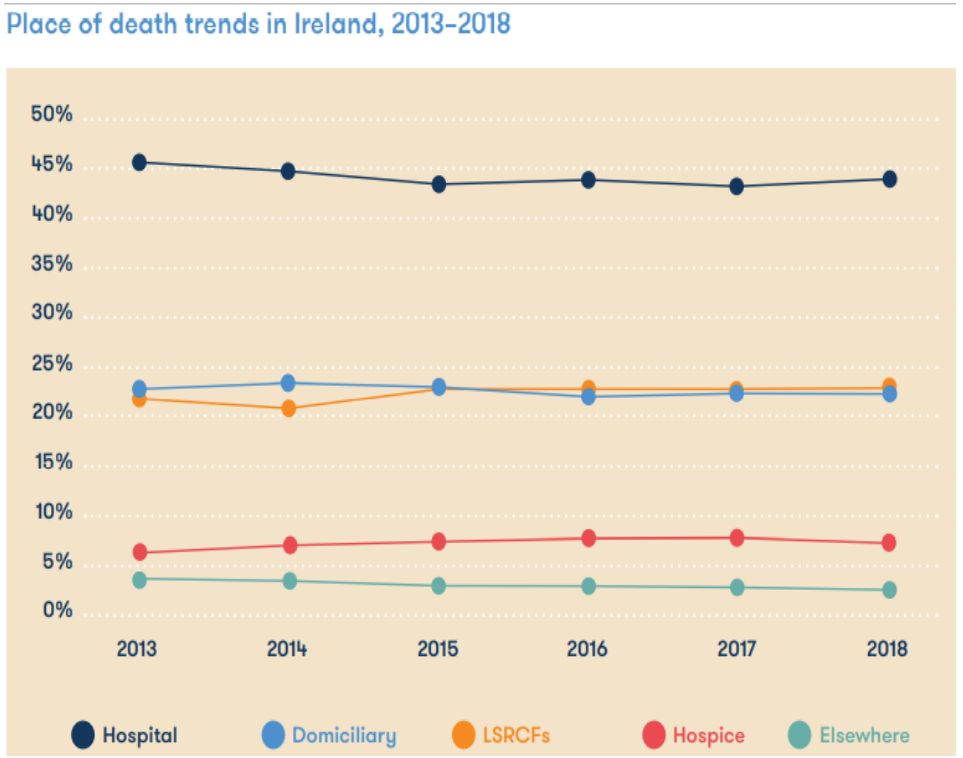
- Central Statistics Office (CSO) data between 2013-2018.
- Hospitals (40%<) the most common place of death across the six-year period.
- All trends largely stable
- Small increases in deaths in hospices and in long-stay residential care facilities (LSRCF)



An Phríomh-Oifig Staidrimh Central Statistics Office

WP1: Results

Cause of death

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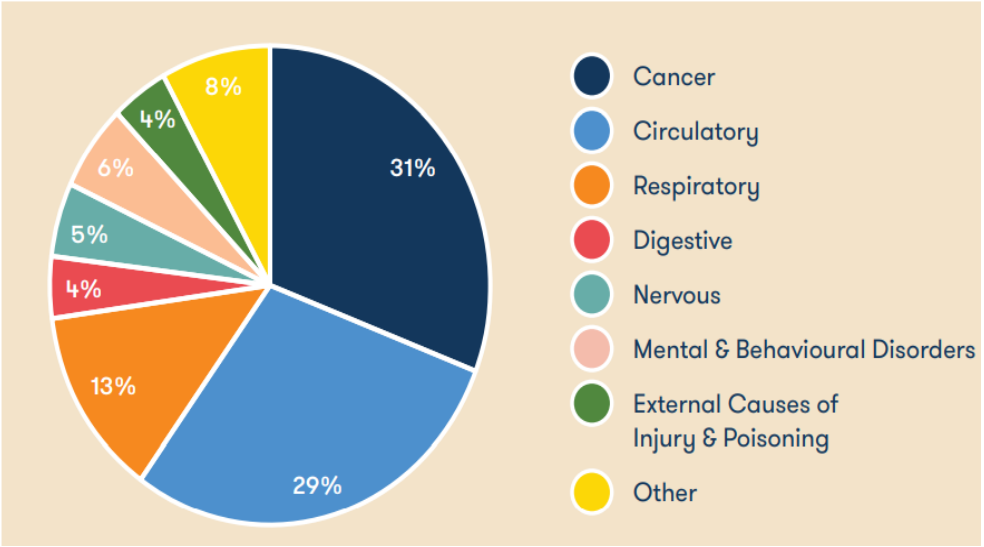
- Central Statistics Office (CSO) data between 2013-2018.
- We grouped 1,780 different causes of death into eight main categories.
- Between 2013 and 2018, cancer replaced diseases of the circulatory system as the leading cause of death.
- **<u>Deaths caused by mental and behavioural disorders increased 61% (4%-6%) as both prevalence and identification of dementia grew.</u>**

All deaths in Ireland by cause of death, 2018 (%)



An Phríomh-Oifig Staidrimh
Central Statistics Office

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WP1: Results

Health care use data

Hospital Inpatient Enquiry (HIPE)

- People with incurable illness make up **approximately half** of all adult emergency admissions to acute hospitals.
- These admissions account disproportionately for both **length of stay** and **discharges ending in death**.
- On any given day, among all adults in an acute public hospital in Ireland we estimate that **one in five is in last year of life**.

Specialist Palliative Care Minimum Dataset (2013-2019)

- SPC in-patient beds: increased but still below recommended level.
- Diagnoses: majority of new patients had cancer.
    - But, proportion of non-cancer diagnoses receiving SPC have increased

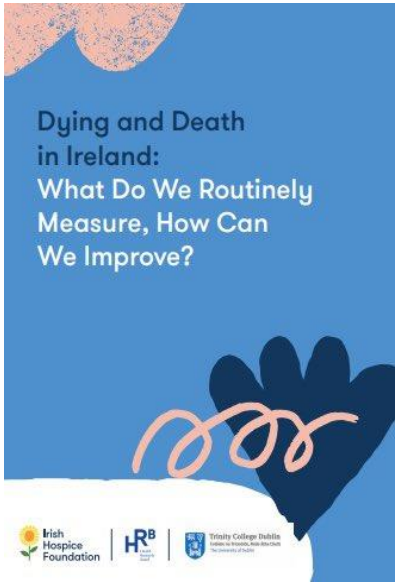
WP1: Key conclusions

Full report launched with IHF 25/11/21

- Some encouraging trends:
  - Deaths from cardiovascular disease falling
  - Deaths in hospital low compared to other countries
  - Access to specialist palliative care is relatively high and growing

- Important issues to address:
  - The number of deaths from dementia is rising rapidly (and we don't really know *how* rapidly)
  - Equity and capacity issues still visible
  - Data access is unnecessarily difficult
  - **Data gaps on end-of-life experience limit our ability to plan and fund the required services**

- Further reading:
  - Full report with IHF



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WP2: Routine data in palliative care

A review of practice in 16 countries

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WP2: Objectives

International review of data practice

Aim: to synthesise international best practice with routine data in palliative care planning and evaluation

- 16 high-income countries with established services

1. **To describe PC data infrastructure in these countries;**
2. **To examine how these databases are used, including governance;**
3. **To document limitations, and chart efforts to address limitations;**
4. **To identify factors that influence the implementation/sustainability.**

WP2: Methods

International review of data practice

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- Identified 15 countries relevant to Ireland
  - Well-established PC services (per EAPC, Economist)
  - Australia, Austria, Belgium, Canada, Denmark, Finland, France, Germany, Japan, The Netherlands, New Zealand, Norway, Sweden, Switzerland and the UK
- For each country:
  - Searched academic, grey, government literature
  - Compiled narrative synthesis
  - Described relevant databases: purpose, use, limitations
  - Reviewed with/by a local expert
- Combined the 16 country documents using thematic synthesis

WP2: Key conclusions

Full review launched available to HSE at project's end

- Critical to take broad, integrated approach:
  - Noncancer patients; generalist and community PC
- New data collection essential
  - Routine data addresses a minority of relevant domains
- Mixture of necessary ingredients
  - Resources, clinical leadership, staff engagement, feedback to services, limiting administrative burden, expert analytic support, stepwise implementation, ongoing review and refinement…
- Further reading:
  - Full review to the HSE
  - Paper (under review)

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WP3: Economics of palliative and end-of-life care in Ireland

Estimating formal health care costs

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WP3: Objectives

Costs of PC/EOLC in Ireland

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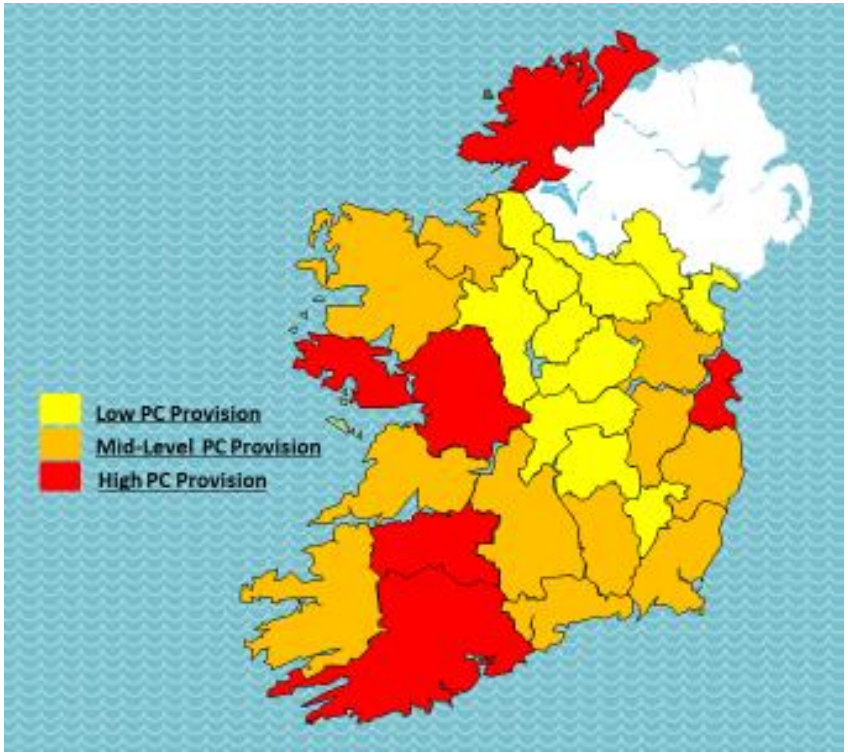
Aim: to estimate costs associated with EOLC in Ireland, and to analyse variation by PC provision

Research questions:

1. What is the cost of end-of-life care in Ireland?
2. Does it vary by regional PC access?



WP3: Methods

Costs of PC/EOLC in Ireland

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Methods:

- The Irish Longitudinal Study on Ageing (TILDA)
- For LYOL, TILDA EOL interviews (n=892 total)
- For everyone else, regular TILDA interviews (n=5,205 at Wave 5)
- Age, sex, place of residence, diagnoses from all interviews
- Costs: we combine health care use in TILDA (e.g. how many GP visits in the last year?) and unit costs for each type of use

WP3: Key conclusions

Two papers in draft; summary analyses for the HSE

- Mean LYOL costs among 50+ €65,000 -> €2bn annually
  - ~1% of people account for ~10% of spending
- Hospital PMS reduces LOS
  - Most effective early -> identification critical
- However,
  - 'PC access' ≠ lower health care costs
  - Hospice costs absorb hospital savings
  - Differing patterns of hospital and nursing home use
- PC services offer potential value but not huge cost-savings
  - PROMs and other measures key to that understanding
  - Models of care that suit rural populations in particular
- People living with serious illness 3.5*costs of those without
  - This group has PC needs, doubling in size to 2050

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Lessons for policy, data and research

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PPI Feedback

AIIHPC Voices 4 Care network, 24/2/22

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- We invited PPI participants to discuss experiences of data collection in PC/EOLC (i.e. WP1, 2)
- Feedback from this event resulted in six key themes being highlighted:

1. Requests for information, what's fair?

2. Transparency of data collection objectives

3. Are data collection methods effective or exhaustive?

4. How do we measure what's not reported or reports that have potential biases?

5. Who steers the ship of evaluation – service providers or service user?

6. Positive feedback is important, not just complaints

'…how much are they recording and how much goes in a file? Is it casual conversation or is it collection of data, and is that data retained?.... We really don't know what data is out there on us.'

- PPI feedback on WP3 to follow

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Improving the Palliative Care Experience

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All Ireland Institute of Hospice and Palliative Care

Lessons for policymakers

Challenges and policy implications

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Theme	Key Points
Reliable indicators, outcome measures	• **Beyond place of death:** proactive collection of PEOLC quality measures • **Beyond death certificates:** a partial picture, a value judgement, diminishing value with age, frailty, multimorbidity • **Reliable SPC indicator:** essential for service evaluation
Classification & coding practices	• **Ambiguity over some places of death**, 'community hospitals' and 'nursing homes' • **Dementia identification** requires urgent action
Absence of unique patient identifier	• PEOLC analyses require data at **multiple time points from multiple locations** • **Unique ID** to understand how trajectory of disease and need changes, how people use and access services, and how people die. • Essential for a **dedicated patient-level PC database**
Key trends	• Wide **regional variations** in use of SPC, diagnostic inequities narrowing • Place and cause of death are relatively **stable over time** • **EOL care a core responsibility** of any health system – needs growing in a high-cost subset of the population - **€2bn annually and rising fast**
Accessing secondary data	• We had hoped to use NCRI and CSO, but access not achieved due to **capacity issues** • Other data access was **burdensome** (and all data linkable) • **Better systems essential** to improve access to, and use of, secondary data

Lessons for research

The untapped power of natural experiments

- Natural experiments -> credible causal estimates with observational data
- With our reliance on routine data (and variable quality of literature), recent developments must be tapped
- Four basic frameworks
  - Interrupted time series
  - Regression discontinuity
  - Difference-in-differences
  - Instrumental variables

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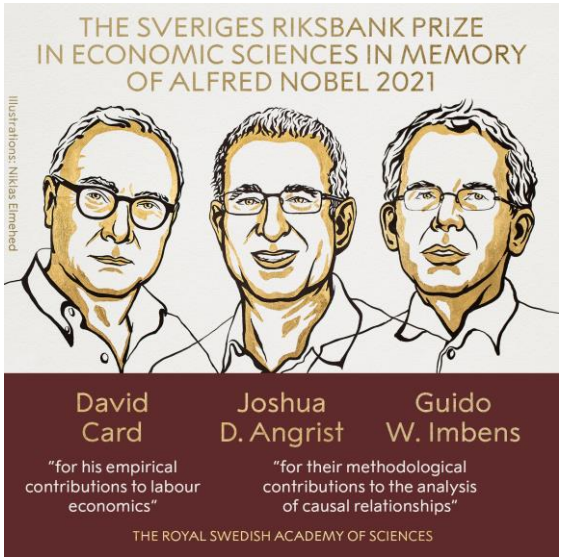
Viewpoint

"Natural Experiments" in Health Care Research

Dhruv Khullar, MD, MPP; Anupam B. Jena, MD, PhD

In "natural experiments," the treatment or intervention is determined by variation not under the control of the researcher. These designs, used in economics and epidemiology to support inferences about causal relationships between interventions and outcomes, are useful tools to help improve the rigor of observational studies in health policy and medicine. Perhaps the first natural experiment

Khullar & Jena. *JAMA Health Forum*. 2021;2(6)



Lessons for research

The untapped power of natural experiments

- Our WP3 PMS evaluation used DiD
  - Leverages **change** in provision
  - More credible estimates of PC effect on HU
  - Not a panacea for data problems!
- Forthcoming systematic review*
  - 17 studies included
  - One in three find no effect…

➢ Challenges and opportunities for the field

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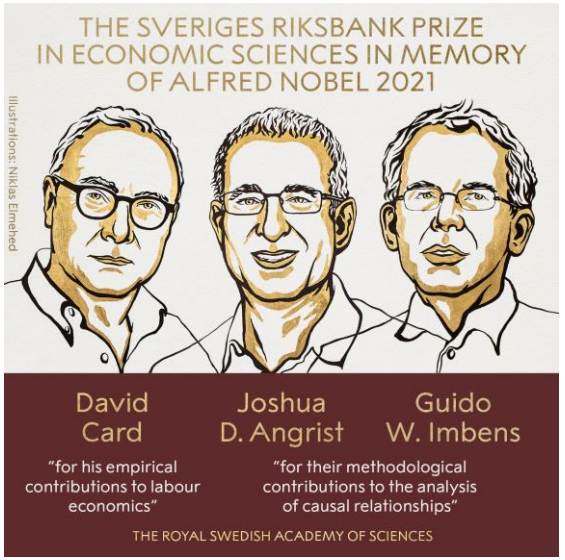

* Not a PELCI paper, funded by GBMF in the United States

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Concluding remarks

Peter May, on behalf of the PELCI team

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Conclusion

Two-and-a-half years and one global pandemic later…

- Ireland leads the EU in PC provision
  - Continuous improvement essential
  - Population health needs growing

  ➢ Better data key to these challenges

- Thanks to all researchers, collaborators and PPI

- Next steps:
  - Two papers out, two more to come
  - One report out, one more to come

  ➢ The conversation hopefully continues…

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Thank you!

Comments, questions, etc

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