International Cancer Benchmarking Partnership (ICBP)
Inequalities Network Summary Report

Purpose

This document provides an overview of the International Cancer Benchmarking Partnership's (ICBP) Inequalities Network, recognising its achievements, lessons learned, and how the information gathered will inform the next phase of research (Phase 3).

Background and overview

During the Transition Phase of the ICBP (2021-2023), the Programme Board identified the need to bring together a network of health inequality experts. The purpose of this group was to:

- Discuss the feasibility of using demographic data in international comparisons of cancer outcomes to inform future ICBP research.
- Discuss challenges related to data provision, access, and harmonisation.
- Encourage discussion between jurisdictions on how international comparisons can support local decision making.

Previous ICBP analyses collected and assessed data on sex and age, and building on that there was interest across the partnership to explore what further data collection and analysis could be feasible in the future. This network provided an opportunity to gather information from representatives across ICBP countries on available demographic data and what might be possible for international comparisons.

Inequalities Network Leadership

ICBP Programme Board Sponsor

Professor Grant McArthur

Executive Director, Victorian Comprehensive Cancer Centre

Inequalities Network Co-Chair

Dr Ambreen Sayani

Scientist, Women's College Research Institute, Women's College Hospital

Assistant Professor, University of Toronto

Inequalities Network Co-Chair

Dr Sophie Pilleron

Senior Epidemiologist, Group Leader of the Ageing, Cancer and Disparities Research Unit

Luxembourg Institute of Health

The ICBP Inequalities Network is made up of a Leadership team, consisting of a Programme Board sponsor and two co-chairs, as well as 27 network members from across all ICBP jurisdictions.

Overview of Inequalities Network Activities

The Inequalities Network conducted two activities to bring together experts and collate information on the current data landscape and challenges across the ICBP:

1) **Inequalities Network Virtual Event:** This was held in November 2022 to launch the network and discuss jurisdictional priorities related to inequalities.
2) **Inequalities Network Data Landscape Survey:** Following the event, a data collection activity took place to gain insight into demographic data collected across ICBP countries needed to examine inequalities, requesting information on data definitions, sources, linkage, access, and the related strategies in place to address inequalities in cancer care.

Inequalities Network Virtual event

This event was attended by 20 representatives from six ICBP countries[1]. The session was introduced by the Network Leadership which included an overview of the ICBP and Transition Phase by Professor Grant McArthur and a summary of the Inequalities Network aims by Dr Sophie Pilleron. Dr Ambreen Sayani then presented an overview of responses from the pre-event questionnaire including how different jurisdictions define 'health equity in cancer' and current cancer inequality priorities across jurisdictions. It was noted that in Australia, New Zealand, and Canada, there was a strong focus on improving outcomes for indigenous populations and, across all other countries, socioeconomic status, age, and geography (remote/rural) were considered as priorities for cancer inequality.

Dr Sayani facilitated a discussion using a virtual collaborative tool to collect attendee's reflections on the following themes:

- Language and definitions
- Data collection challenges
- Local, regional, and national strategies and programmes

Dr Pilleron presented ICBP research about age-related disparities, highlighting our findings, gaps in the research, and future research/collaboration considerations. Some key themes raised during the discussion related to:

- The importance of aligning definitions and sharing frameworks
- Acknowledging the intersection between health equity indicators
- Older age groups being missed in the definition of "vulnerable populations"
- Lack of consistency in the capture of ethnicity data within and between jurisdictions
- Parallel public vs private health systems

Further detail on these themes and a full summary of the event can be found here.

Inequalities Network Data Landscape Survey

In early 2023, the Inequalities Network Data Landscape Survey was sent to network members. This survey aimed to gain an understanding of what data were available against the PROGRESS-Plus framework (an acronym used to identify characteristics that stratify health opportunities and

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[1] Australia (New South Wales, Victoria), Canada (Ontario, pan-Canada), Denmark, Ireland, New Zealand, and the UK (England, Scotland, and Wales).

outcomes) across ICBP jurisdictions. Categories include place of residence, race, ethnicity, culture and language, and socioeconomic status amongst others. The survey asked representatives from ICBP jurisdictions what definitions were used for these characteristics, data availability (e.g. national or regional level), data sources, and strategies in place to address inequalities in cancer care. Responses were received from Canada (pan-Canada), Denmark, Australia (NSW, Victoria, Western Australia), New Zealand, and the UK (overall and England, Wales, Scotland, Northern Ireland).

In November 2023, this survey was followed up by an additional data collection activity to fill in gaps in responses and improve coverage across jurisdictions. This consisted of five questions on definitions of demographic data, the potential for data linkage, and jurisdictions' strategies and approaches to addressing inequalities in cancer care. This was completed through a mix of written responses and interviews. Written responses were received from Canada, England, Northern Ireland, New Zealand, and Denmark. Meetings were held with representatives from Wales and Denmark.

Full information on these data collection activities and a summary of the key findings can be found in the Data Landscape Survey summary here.

Lessons Learned

The work of the Inequalities Network has provided insight into what ICBP jurisdictions collect in relation to demographic data needed to examine inequalities, how data practices and definitions vary across jurisdictions, and helped build understanding of how jurisdictions approach tackling inequalities in cancer care.

Information was collected on the following themes:

- **Data definitions:** To understand inequalities in cancer on an international scale, information on how data variables are defined was required to ensure valid comparisons. There was significant variation in definitions across jurisdictions e.g. socioeconomic status was defined by national deprivation indices in some jurisdictions, whereas others used occupation or home size/ownership as a proxy.
- **Data sources:** All ICBP jurisdictions surveyed collect demographic data from a range of sources including population datasets (e.g. census), healthcare data (e.g. cancer registry, primary care data, hospital data) and surveys.
- **Data linkage:** Western Australia, New Zealand, Canada, Denmark, Ireland, Northern Ireland, England, Scotland, and Wales reported the capability to link healthcare data with population datasets (e.g. census data) or surveys to enable better measurement of wider determinants of health.
- **Data access:** New Zealand, Denmark, and New South Wales (NSW) stated that specific conditions need to be met to gain access to demographic data for research.
- **Strategies:** All jurisdictions surveyed have referenced characteristics related to inequalities in their cancer plans, and Scotland has a specific framework to address health inequalities. The approach to addressing inequalities varied, with the majority of jurisdictions aiming to reduce inequalities in a target population or equalise health chances across all groups (England, New Zealand, Denmark, and Canada). In Ireland, the focus was on interventions to improve the health of the least healthy groups to match that of the healthiest groups.

Next Steps for ICBP Phase 3

Addressing Inequalities is one of the core priorities for Phase 3 of the ICBP and to support our vision to improve equity in cancer control and outcomes. However, data availability and consistency has been a key barrier to achieving this ambition. The Inequalities Network has helped build understanding of considerations around demographics data access, how variables are defined, and the impact this could have on international comparisons. These learnings will support advocacy for better data practices (including better collection, access, and linkage of data) as Phase 3 progresses.

The Inequalities Network will come to a close in Phase 3, however, the ICBP will maintain connections between researchers and the Inequalities Network Leadership to share expertise and ensure Network insights are embedded into research. ICBP researchers aim to expand on this work and fill existing gaps during their scoping work.

The Phase 3 research portfolio will seek to address inequalities in the following ways:

- Benchmark study: Aims to build on our previous analysis on sex and age and create a framework to enable international comparisons using sociodemographic data to understand how different characteristics can impact on cancer outcomes, including incidence, survival, and mortality (subject to data availability).
- Exploratory Research studies:
  - Cancer Patient Pathways: Explores the patient journey from diagnosis to treatment, examining referral pathways, access to diagnostics, and timeliness along the pathway. This research aims to catalyse further work within jurisdictions to identify barriers in the pathway for specific patient groups and how these can be mitigated.
  - Treatment: Explores use of treatments and aims to investigate barriers and enablers to receiving optimal treatment and how that might vary for specific patient groups.
  - Models of Care: Explores how and why cancer services are structured and how the variation may reduce/address inequalities.
  - Cancer Workforce: Explores variation in multidisciplinary team (MDT) meetings, explore workforce challenges, and aims to understand the impact of these on inequalities of access.

To allow the network findings to be shared with a wider audience, Dr Sayani’s research group (in collaboration with the Network Leadership and ICBP Programme Management Team) are collating the findings into an academic paper. This will aim to stimulate further discussion on international inequalities data practices to promote improvements in this area.

Acknowledgements and Thanks

Since the formation of the Inequalities Network, the ICBP has achieved its aim of bringing together experts to understand cancer inequalities priorities, the data landscape across jurisdictions, and what jurisdictions are doing to address inequalities in cancer care. The network is now being brought to a close with learnings from the network to be embedded and built on in Phase 3.

We would like to thank the Inequalities Network Leadership for all their support in engaging the network and delivering the activities. Their expertise was invaluable, and we are looking forward to bringing this insight into Phase 3.

We would like to thank all members of the Inequalities Network who helped to inform and direct this work and provided us with key contacts in their jurisdictions. We are incredibly grateful for your time and support.