

Opportunities and challenges of linking routinely-collected data to evaluate blood-borne virus management and outcomes in WA

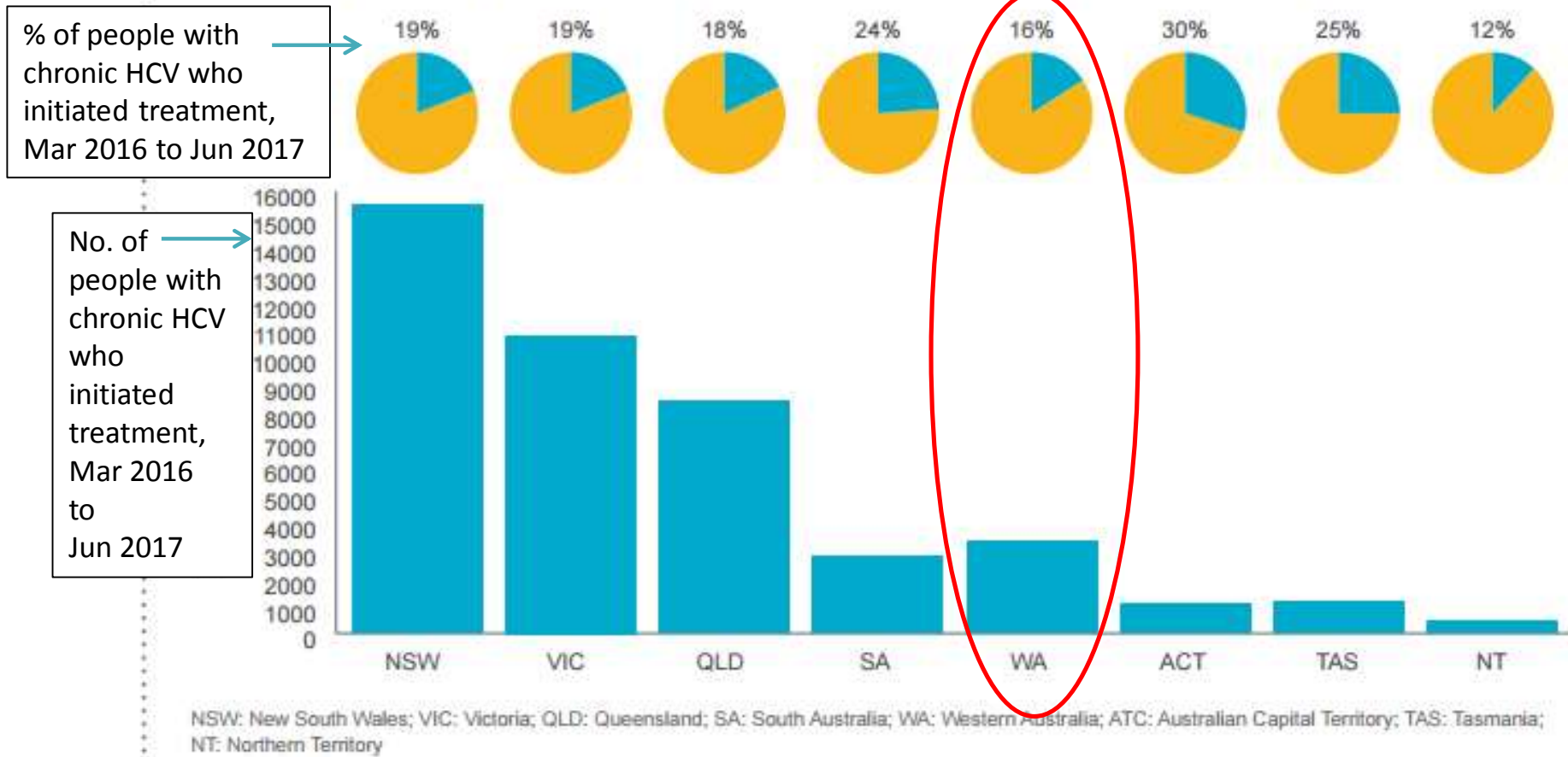
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better health ■ better care ■ better value

Background

- March 2016: PBS listing of oral direct-acting anti-viral curative treatments for hepatitis C.
- Australian government investing A\$1 billion over 5 years to treat 230,000 Australians living with hepatitis C.
- Success depends on a large proportion of infected people being cured in as short a timeframe as possible to reduce infective pool – Treatment as prevention.

Figure 1: The estimated number of individuals initiating DAA treatment (bar charts) and the proportion of individuals living with chronic HCV infection who initiated DAA treatment (pie charts) during March 2016 to June 2017, by jurisdiction.



PBS data cannot provide accurate estimates of treatment uptake by Aboriginality.

Aim

- Monitor HBV- and HCV-related health outcomes and deaths, and evaluate the management, diagnosis, treatment uptake, equity of access to treatment, and treatment outcomes of people with HBV and HCV infections within Western Australia (WA).
- Identify groups at increased risk of HBV- and HCV-related health outcomes and deaths, e.g. people who inject drugs, Aboriginal and Torres Strait Islander peoples, co-infection with HIV, in prison, people on opiate substitution therapy, and by health region.

Opportunity

- Partner with Kirby Institute to adapt NSW study for WA
- Link HBV and HCV notifications with routinely collected health administration datasets to assess morbidity, mortality, diagnosis, treatment uptake and treatment outcomes.
- Linkage will be done in:
 - 2018
 - 2019
 - 2021

using data collected up to 2016, 2018 and 2020, respectively, or most recent available.

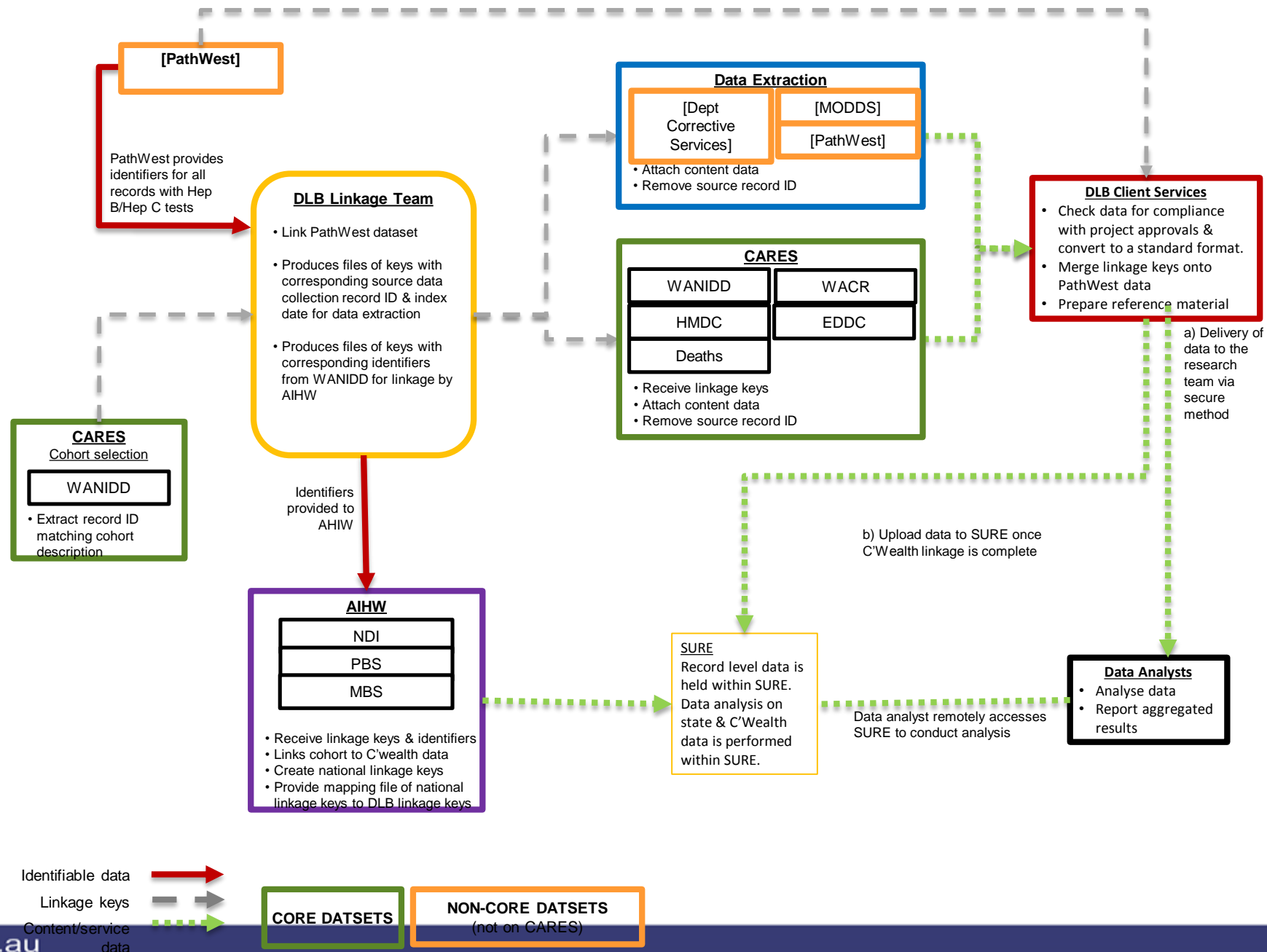
Local stakeholder support: Project Steering Group

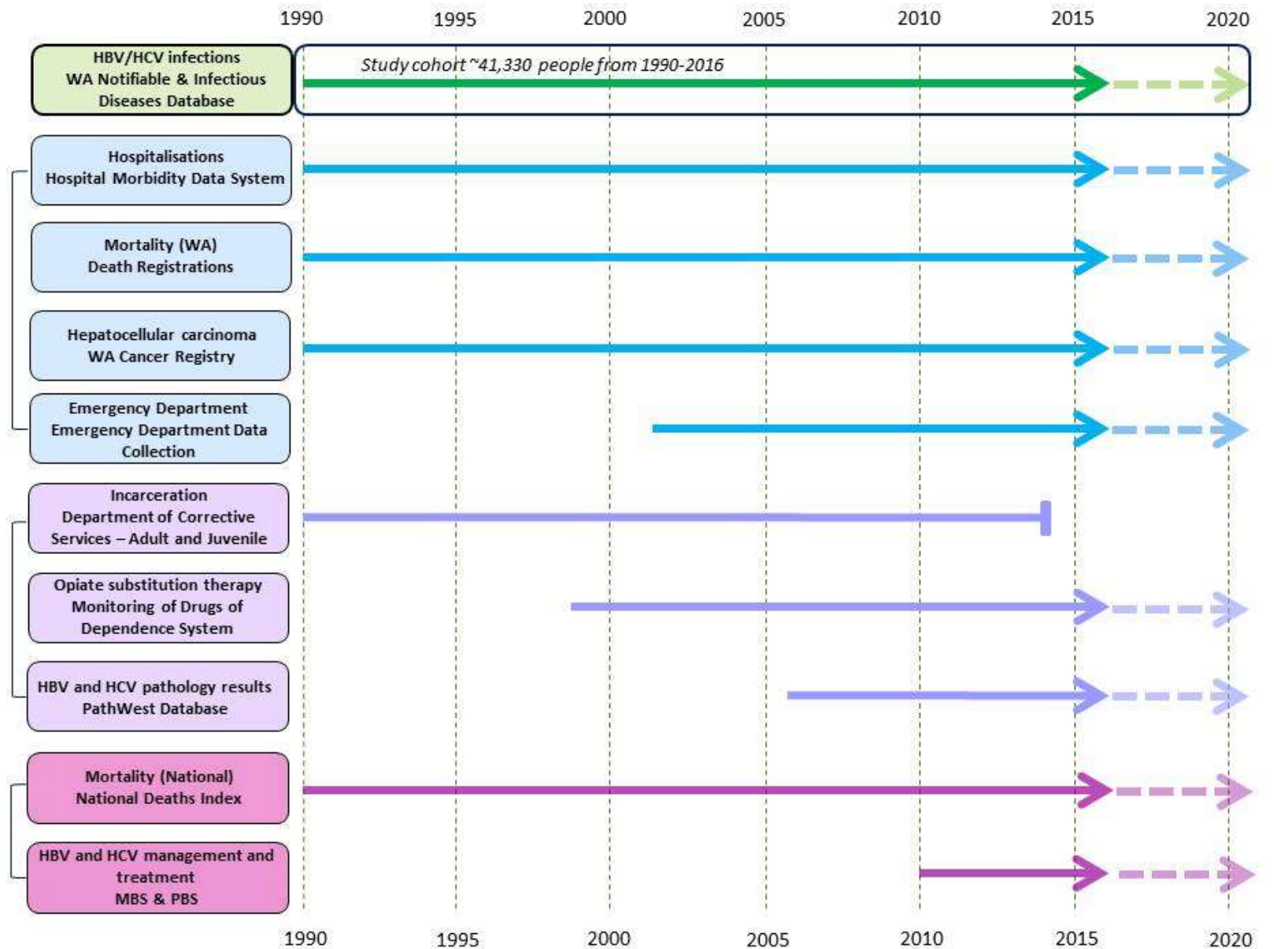
- Hepatitis WA
- Health Services (Royal Perth, Fiona Stanley & Sir Charles Gairdner Hospitals)
- Department of Correct Services
- WA Country Health Service
- Aboriginal Health Council of WA
- Health Consumer Council of WA

Ex-officio

- Department of Health WA, Sexual Health & Blood-borne Virus Program and Aboriginal Health Directorate
- Kirby Institute

Data flow - 201706.03: Surveillance of disease outcomes and management of people diagnosed with hepatitis B or hepatitis C virus infection in Western Australia: A population-based linkage study





↑ 2017
 ↑ 2019
 ↑ 2021

Proposed analyses

- Demographics
- Hospitalisations
- Mortality
- Treatment uptake
- Time from notification to antiviral therapy commencement

Demographics

The demographics of people with Hepatitis B or C will be reported by:

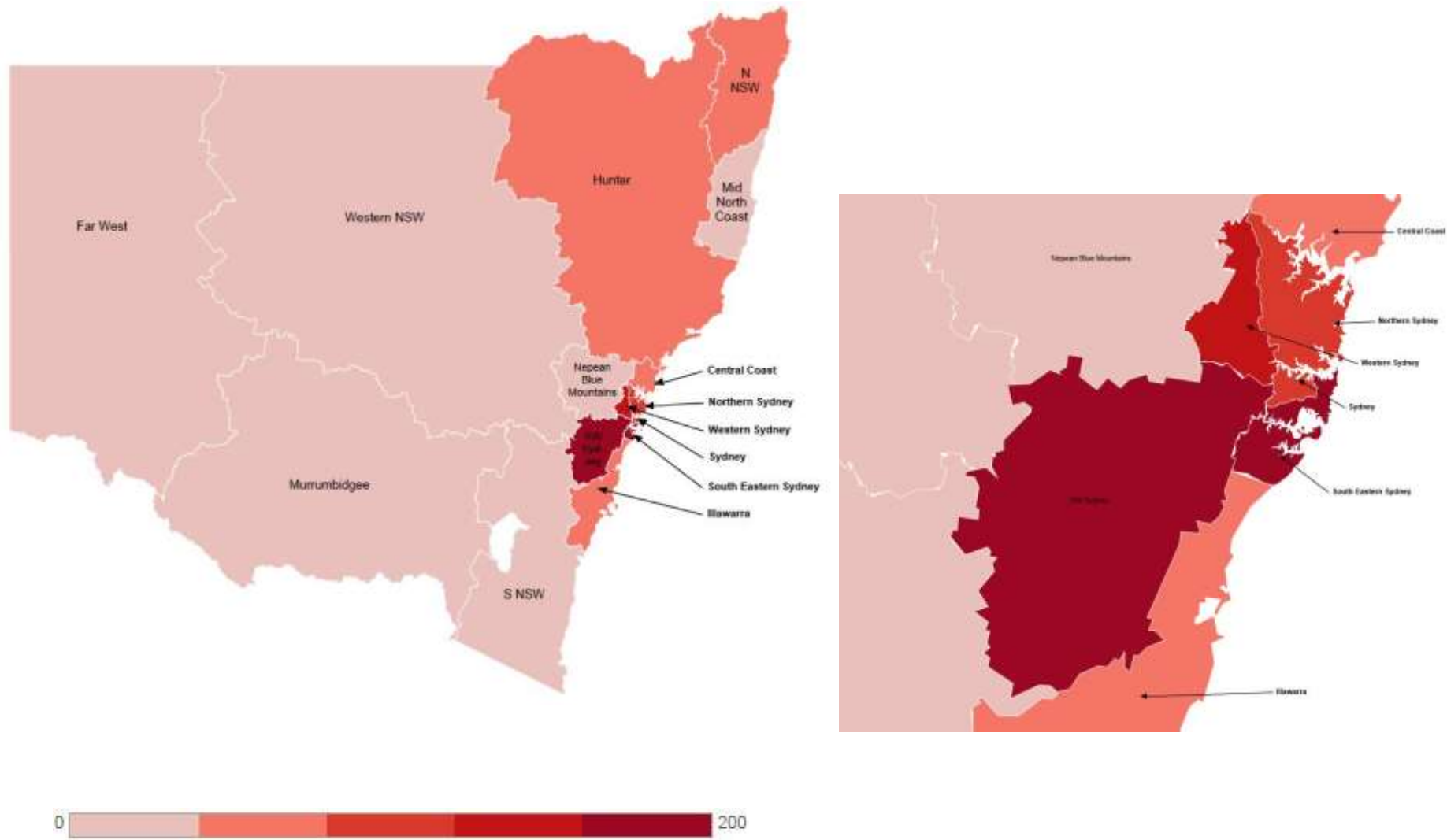
- Age
- Sex
- Aboriginal or Torres Strait Islander
- Country of birth
- Year of notification
- HIV co-infection
- History of opiate substitution therapy
- History of incarceration
- Area and Health Region of residence at time of notification

Hospitalisations

- Trends of hospitalisations will be reported from 1990 – 2016.
- For disease-specific hospitalisations, as well as by demographic factors.
- These trends will assist in assessing the burden of illness associated with hepatitis B and C.
- It is expected that hospitalisations will decrease with improved treatment.

Example of mapping of hepatitis related disease, by region, in NSW

HCC by LHD in individuals with HCV, 2001-2012, NSW



Deaths

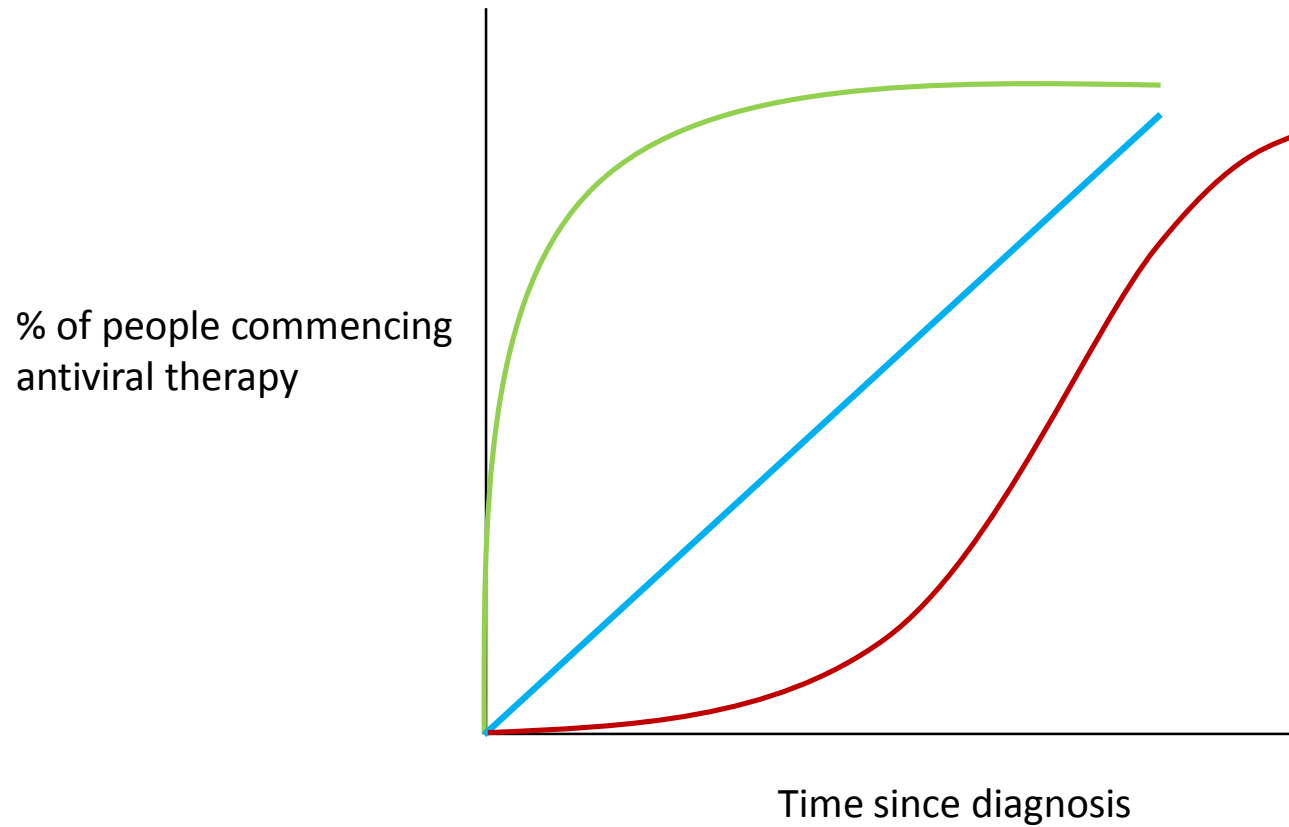
- Trends of mortality will be reported from 1990 – 2016.
- Disease-specific causes of deaths will be reported, as well as by demographic factors.
- These trends will assist in assessing mortality associated with hepatitis B and C.
- It is expected that mortality will decrease with improved treatment.

Antiviral treatment

- Trends of treatment uptake will be reported from 2010 – 2016.
- By health region, as well as by demographic factors.
- These trends will assist in assessing treatment access and uptake.
- It is expected that treatment uptake will improve with time. Areas where treatment uptake is slow will assist in guiding the need for improved service delivery in that area.

Results: Time to antiviral therapy

Kaplan-Meier survival curve of time from notification of hepatitis C to commencement of antiviral therapy



Challenges: time & human resources

Project started March 2017

| Application | Submitted | Approved |
|---|----------------|---------------|
| WA Dept of Health (DoH) data linkage | June 2017 | October 2017 |
| Australian Institute of Health & Welfare (AIHW) data linkage | June 2017 | Pending |
| Research Applications and Advisory Committee, Dept of Justice to access data pre-2014 | September 2017 | January 2018 |
| Developmental Pathways Project through Telethon Kids Institute to access more recent Dept of Justice data | September 2017 | January 2018 |
| WA DoH Health Research Ethics Committee | October 2017 | November 2017 |
| WA DoH Research Governance | October 2017 | Pending |
| WA Aboriginal Health Ethics Committee | November 2017 | February 2018 |
| AIHW Ethics | March 2018 | Pending |

Challenges: time & human resources

- 1-2 year lag time between data reporting, data availability and data analysis
- Policy decisions may need to be made in absence of recent data

Opportunities & benefits

- Use existing data and research protocols – minimise inconvenience to patients and cost
- Support from data custodians & stakeholders
- Build relationships between researchers, policy makers, service providers
- Improved capacity for policy & practice based on LOCAL evidence

