

# NSW Health Statewide Biobank

Supporting world-class health and medical research

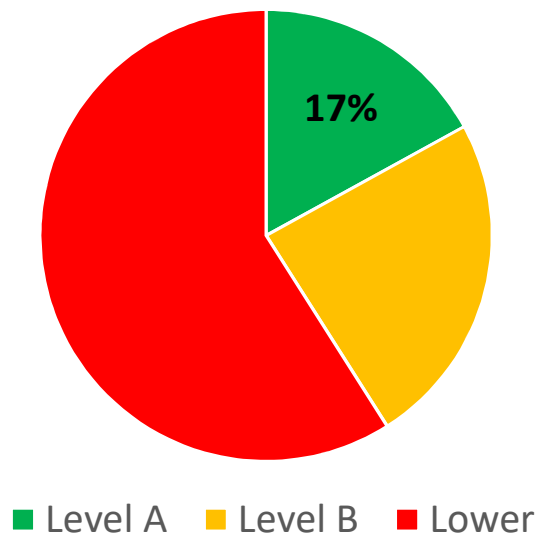


Health  
Statewide Biobank

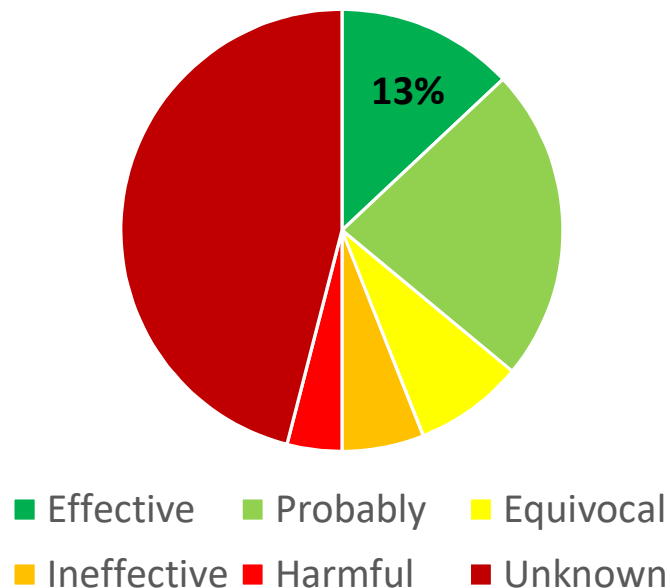
Q. Why do we undertake clinical research?

A. Because most health-care is not evidence-based

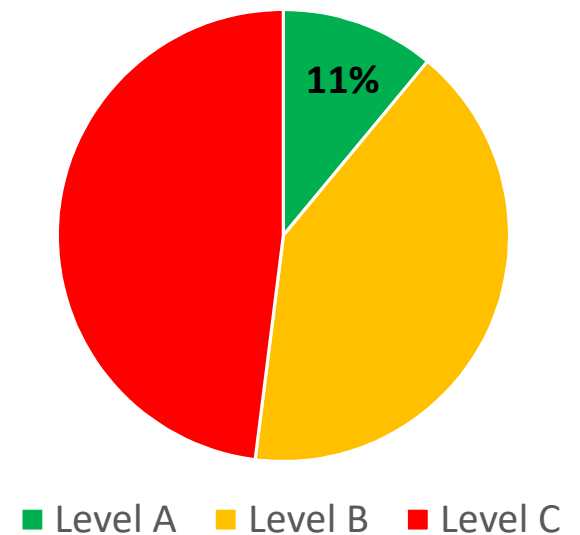
UpToDate Evidence Level for Treatment Recommendations



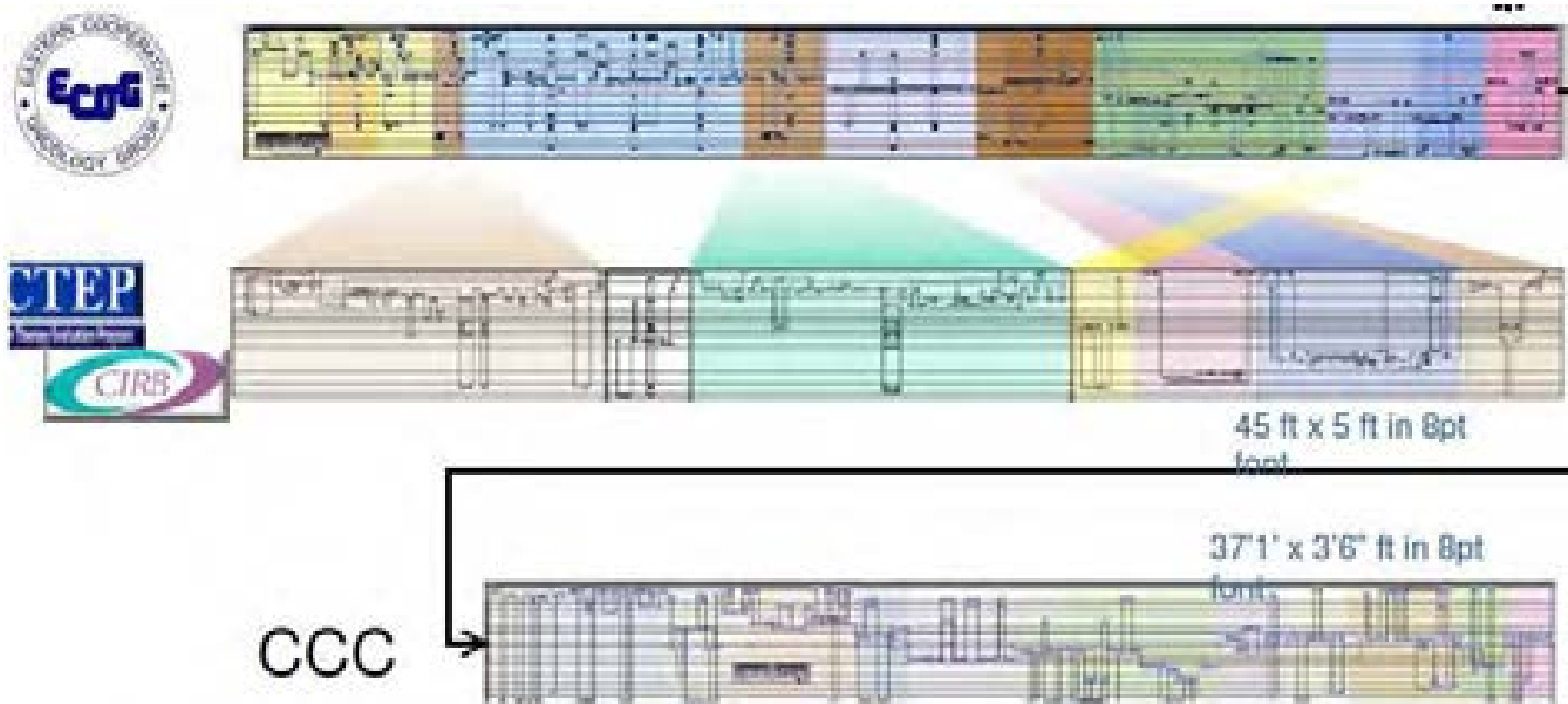
Overview of Knowledge Base of 2500 Medical Treatments



Scientific Evidence Underlying ACC/AHA Clinical Guidelines



# Clinical trials are often complicated



<http://www.nationalacademies.org/hmd/~/media/Files/Activity%20Files/Disease/NCPE/Dilts.pdf>

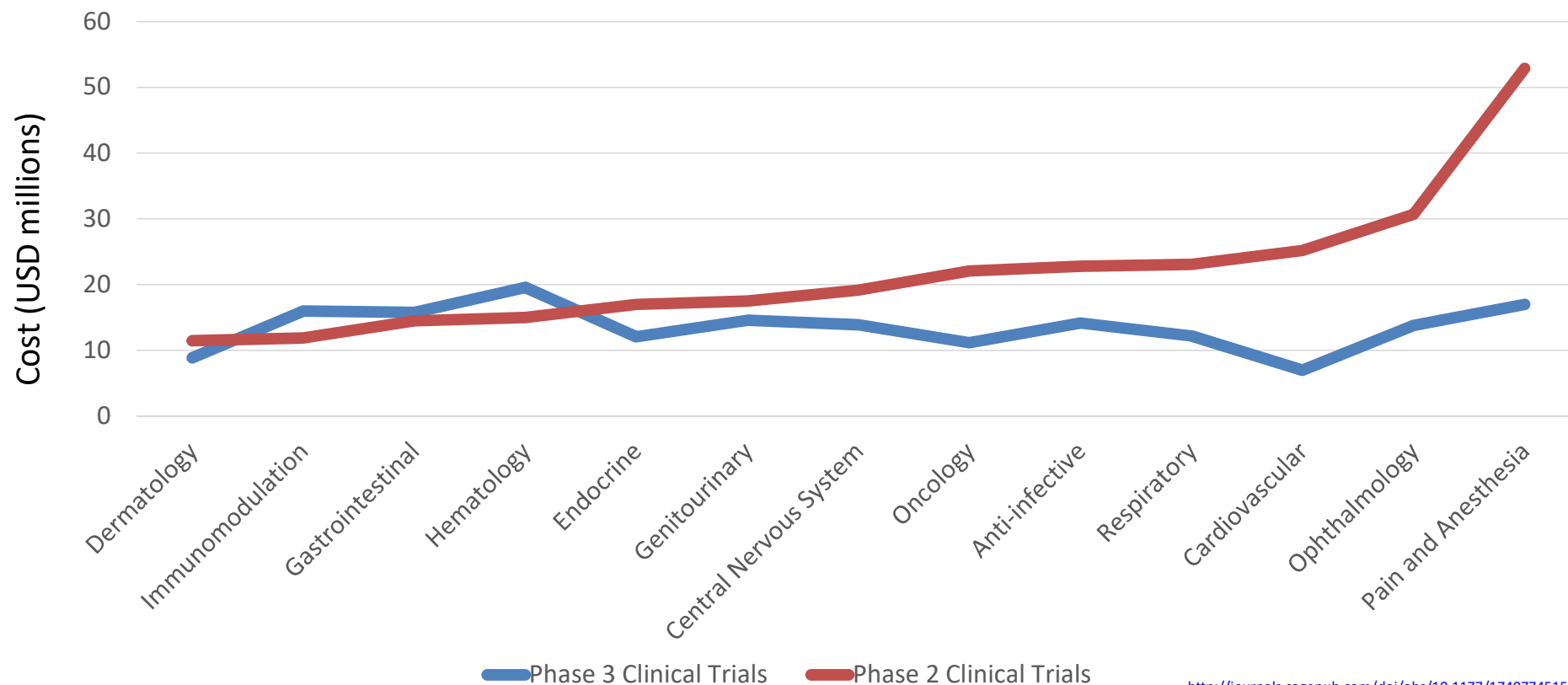
# Clinical trials are inefficient

*“The participation rate of adults in cancer clinical trials is low. Currently in Australia it is about 5% of cancer patients. About 85% of children participate in trials even though there are far fewer children than adults who are diagnosed with cancer...”*

[https://www.cancercouncil.com.au/wp-content/uploads/2012/05/CT+R\\_NSW\\_LR.pdf](https://www.cancercouncil.com.au/wp-content/uploads/2012/05/CT+R_NSW_LR.pdf)



# Clinical trials can be expensive



<http://journals.sagepub.com/doi/abs/10.1177/1740774515625964?journalCode=ctja>

<https://www.centerpointclinicalservices.com/blog-posts/driving-drive-drug-innovation-and-market-access-part-1-clinical-trial-cost-breakdown/>

# Most clinical trials don't improve patient outcomes

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## Pharmaceuticals industry

### Over half of new cancer drugs 'show no benefits' for survival or wellbeing

Of 48 cancer drugs approved between 2009-2013, 57% of uses showed no benefits and some benefits were 'clinically meaningless', says BMJ study

Nicola Davis  
@nicoladavis1000  
Thu 3 Oct 2017 16:04 AEST  
5,730

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*Dylan Curry*

NSW GOVERNMENT

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ESSAY

# Why Most Published Research Findings Are False

John P. A. Ioannidis

Published: August 30, 2005 • <https://doi.org/10.1371/journal.pmed.0020124>

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# Why Most Clinical Research Is Not Useful

John P. A. Ioannidis 

Published: June 21, 2016 • <https://doi.org/10.1371/journal.pmed.1002049>

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# Our first statewide biobank

- State-of-the-art facility for NSW health and medical research
- Supporting world-class population studies, clinical trials and disease-specific research across NSW
- Able to store and process up to 3 million human bio-specimens with large-scale robotic technology



# A partnership philosophy

Flagship facility for NSW Health developed in partnership with:

- NSW Health Pathology
- Office for Health and Medical Research
- Sydney Local Health District
- Health Infrastructure
- \$12 million NSW Government investment
- Bringing together researchers, LHDs, universities, research institutes and industry



Health  
Statewide Biobank

Partnerships with NSW's research community to help provide  
a pathway to better treatment for patients

# Physical efficiencies

- Advanced robotic technology reducing time taken to manually manage and retrieve samples
- Dedicated processing laboratory to deposit and retrieve samples from cold storage facility
- Streamlined workflows to allow for fast, efficient handling of a variety of sample types:
  - Externally processed samples
  - Fresh liquid samples such as blood, urine and saliva
  - Fresh and fixed solid samples such as tissues



# NSW Health OHMR Strategic Collections

- NSW Health is investing in collections aligned to health and medical research priorities
- Dedicated group of senior NSW researchers advising on strategic directions for collections
- NSW Health Statewide Biobank may be custodian and hold appropriate ethics and governance approvals



Health  
Statewide Biobank



Health  
Pathology

# Biobank Certification Program



Developed by:



Office of Biobank  
Education and Research



CANADIAN TISSUE  
REPOSITORY NETWORK  
RESEAU CANADIEN DE  
BANQUES DE TISSUS

Endorsed by:



Partnered with:

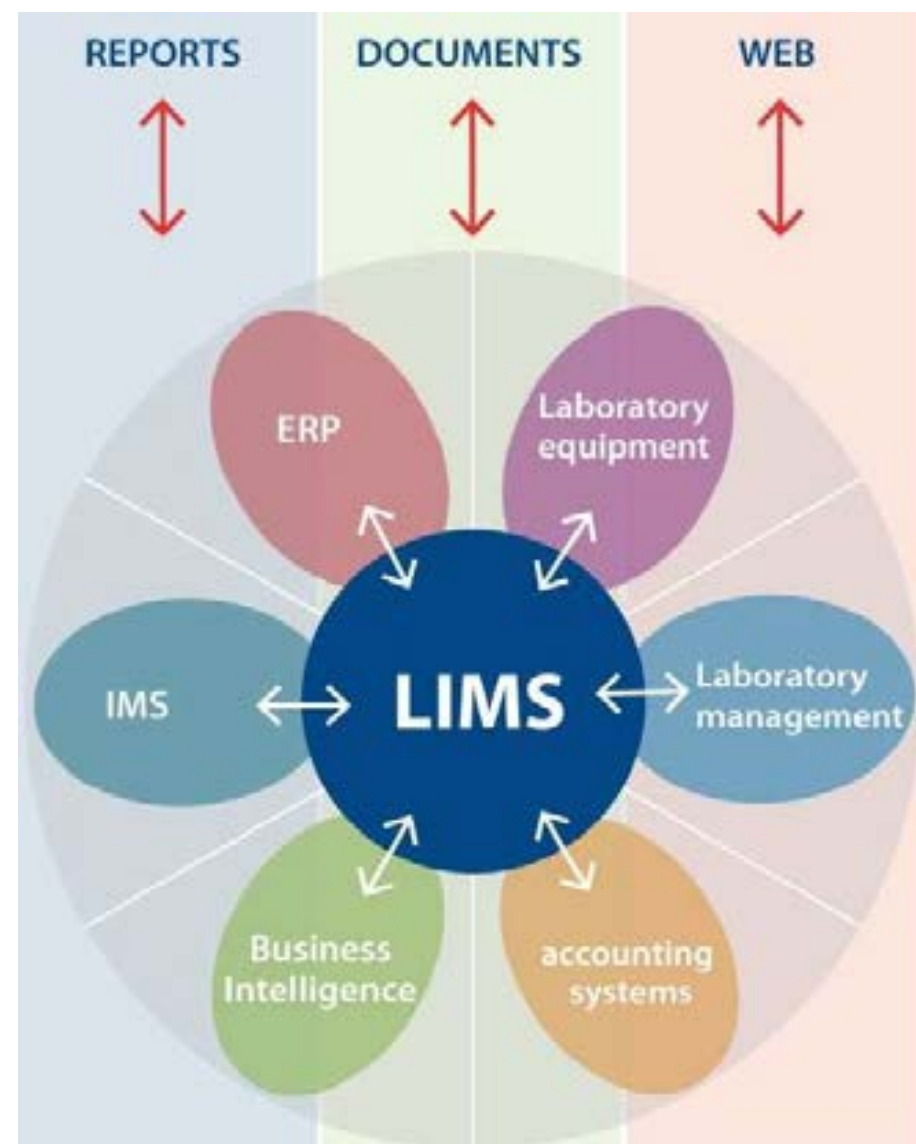


MY HEALTH  
LEARNING





Central specimen locator



# NSW Health Statewide Biobank CONSENT TOOLKIT

Introducing a new standard of biobank consent in NSW



The Consent Toolkit is mandatory for new collections banked in the NSW Health Statewide Biobank. Other biobanks in NSW will be encouraged to use it.



A robust consent process will support ethical human research and a sustainable approach to managing human biobanks.



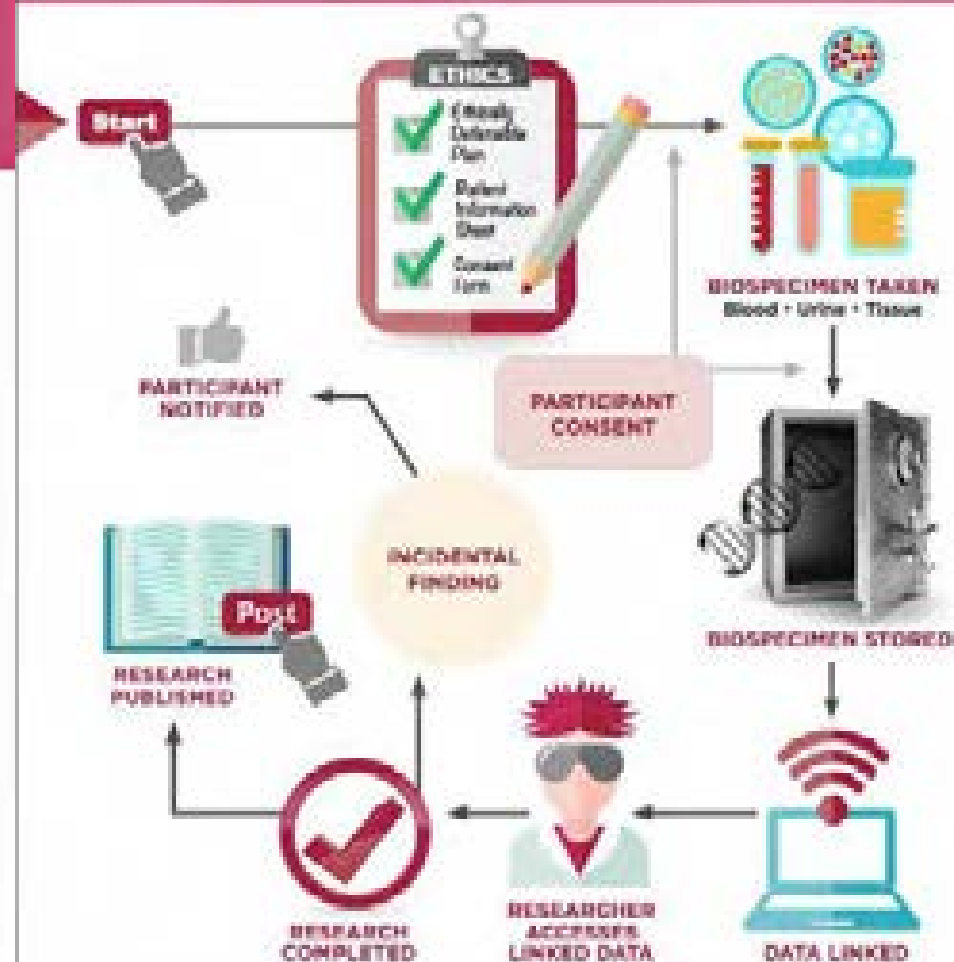
The goal of consent is to ensure participants are aware of the potential risks and benefits and can make an informed, voluntary decision about participating in the research.



It includes principles and protocol, a participant information sheet, consent form for adults and children, ethically defensible plan guidelines and compliance checklist.

Download a copy at [www.biobank.health.nsw.gov.au](http://www.biobank.health.nsw.gov.au)

## NSW Health Statewide Biobank CONSENT PROCESS



Download a copy at [www.biobank.health.nsw.gov.au](http://www.biobank.health.nsw.gov.au)



# The NSW Health Centre for Health Record Linkage

## The CHeReL



### Linking Data for more than 10 years

Established in 2006, the CHeReL provides data linkage services to researchers, clinicians and government. As part of NSW Health, the SWB and CHeReL will ensure secure and high quality linkage of biospecimen data to other data collections



### Large data linkage infrastructure

The CHeReL holds over 170 million records from 27 datasets in its Master Linkage Key. Datasets include public and private hospital, ambulance, Cancer register, Emergency department and mental health. The data is routinely updated and new datasets are regularly added

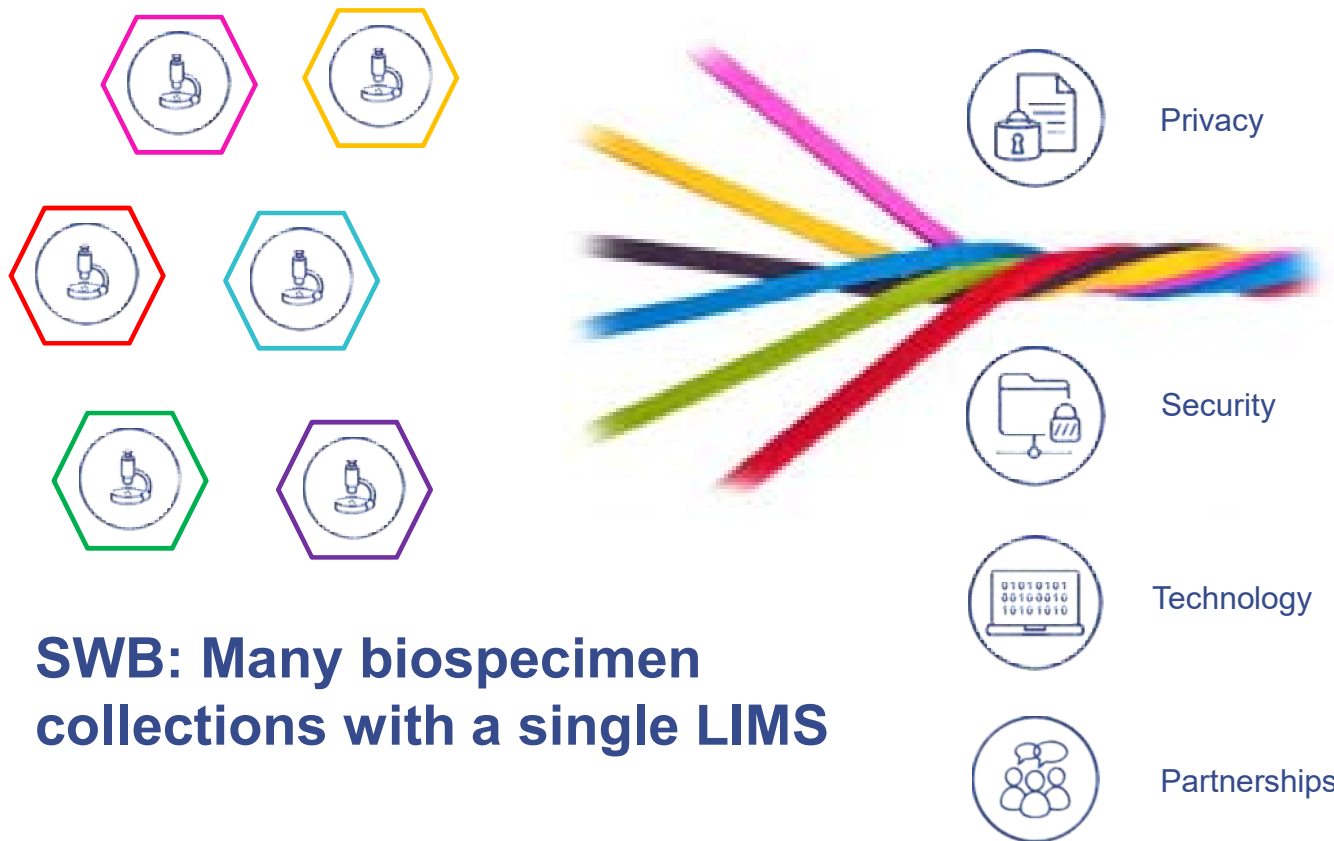


### Bespoke linkage options

The CHeReL is able to link biobank specimen collections to datasets outside of the MLK, for example disease registries, screening data and toxicology data. More than 900 million records are released for research and policy annually



# Data Linkage for SWB



**CHeReL: Many data collections with a single Person Number**



Centre for  
Health Record  
Linkage

## CHReL Master Linkage Key



**147** million records  
**12** million people

### NSW

Admitted Patient Data Collection	Emergency Department Data Collection
Perinatal Data Collection	45 and up study
Central Cancer Registry	RBDM death registrations
RBDM Birth Registrations	Notifiable Conditions Information Management system
Perinatal Death Review Database	Cause of Death Unit Record File
Mental Health Ambulatory Data collection	Pop Test Registry
BreastScreen	Ambulance (CAD, PHCR, EMR)
Australian Early Development Census	

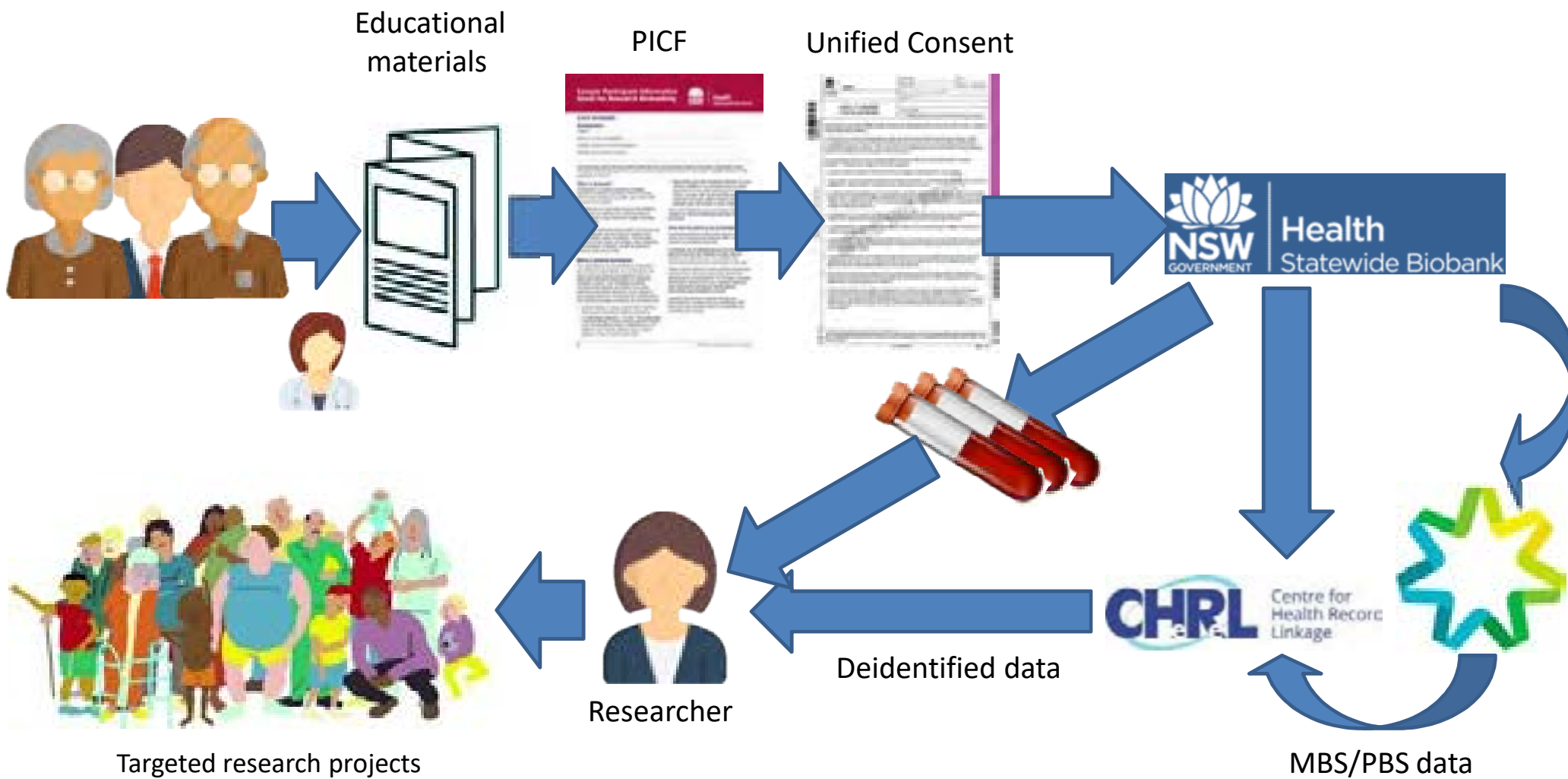
### ACT

Admitted Patient Collection
Cancer Registry
Emergency Department Data Collection
ACT Perinatal Data Collection
ACT BDM deaths
Notifiable Conditions Information Management System
ACT BDM Births
Australian early Development census

<http://www.cherel.org.au/master-linkage-key>

# Recognizable structures from a few components







## The hidden human toll of lax controls on the booming medical device industry

A world-first investigation uncovers a trove of information from regulators and manufacturers to create a global picture of the harm caused by faulty medical devices.

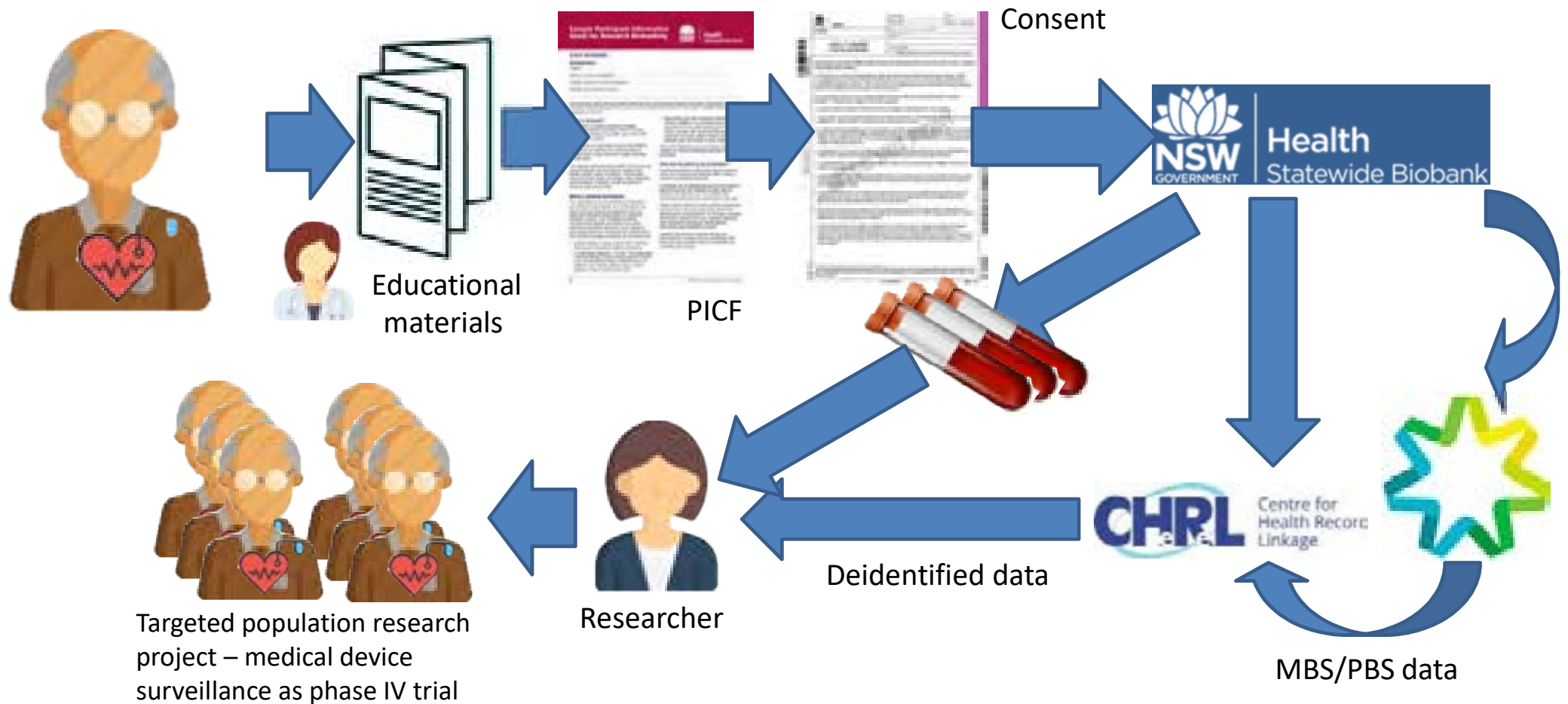
<https://www.abc.net.au/news/2018-11-26/implant-files-shine-light-on-medical-device-industry/10521480>

*“In October, the Government said it supported, in principle the vast majority of Senate recommendations...*

*The report’s recommendations included:*

- Mandatory reporting of adverse events by medical practitioners*
- Establishment of a more comprehensive post-market monitoring scheme*
- A registry for all high-risk implantable devices”*

# Solution: medical device surveillance as phase IV trial

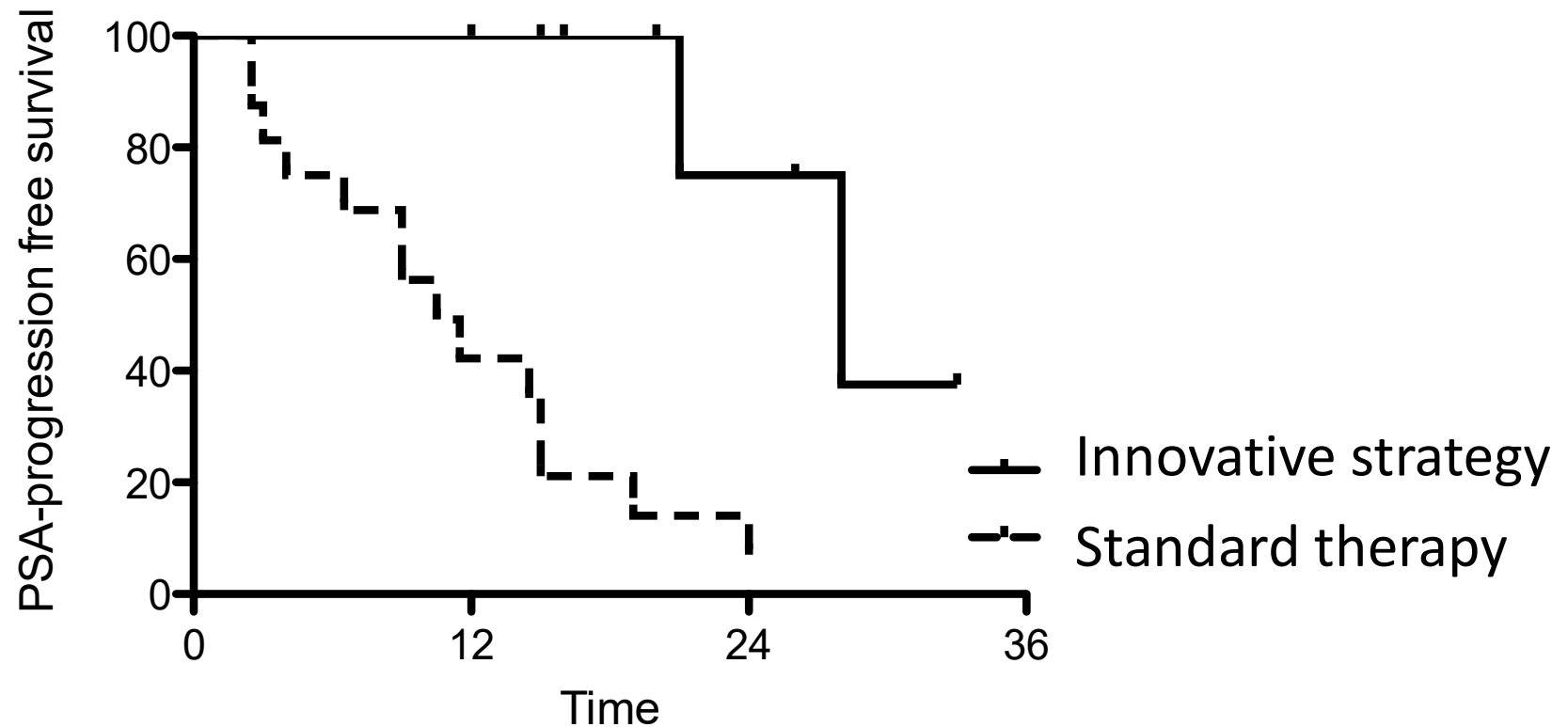


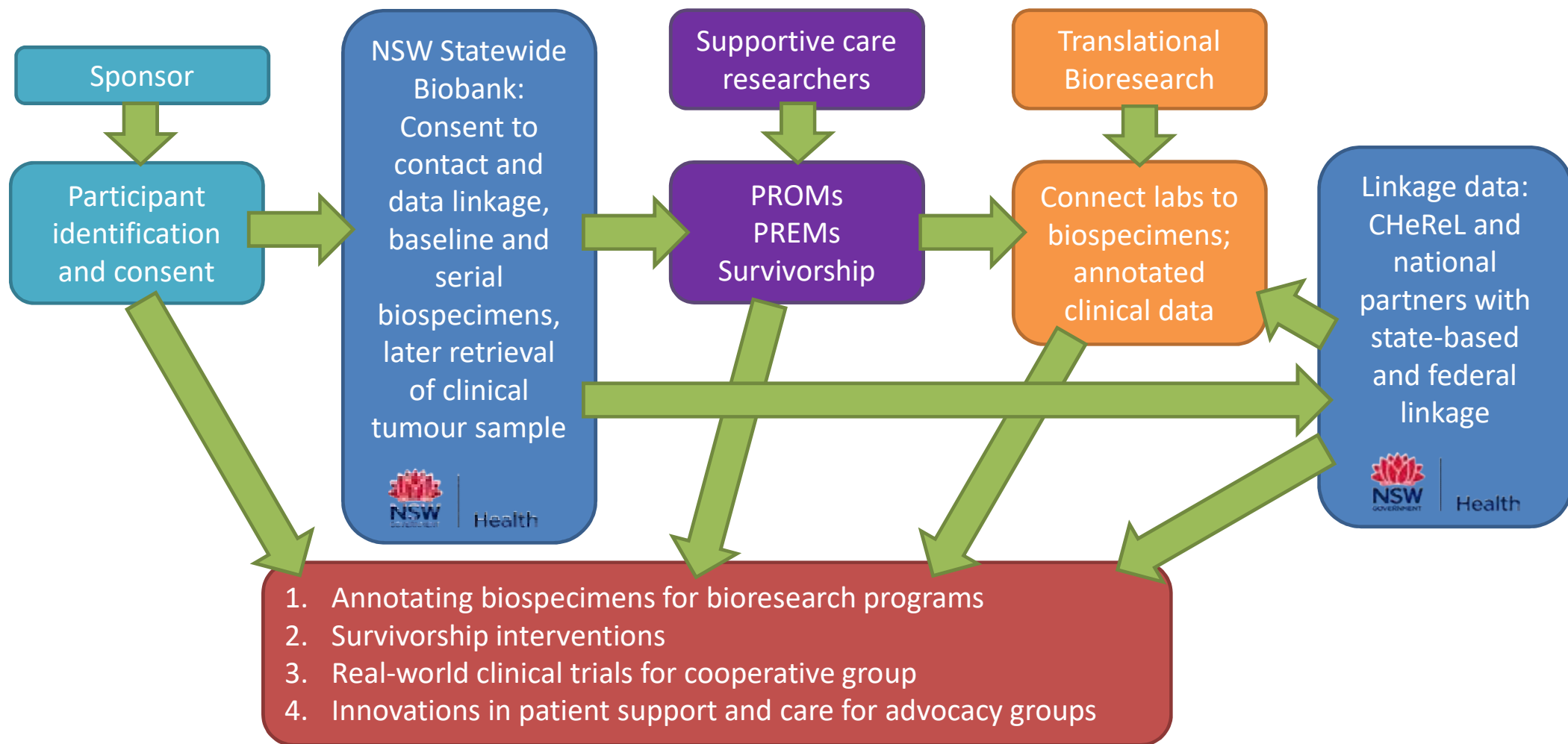
Anti-hormone tablets help men with advanced prostate cancer, on average about 10 months

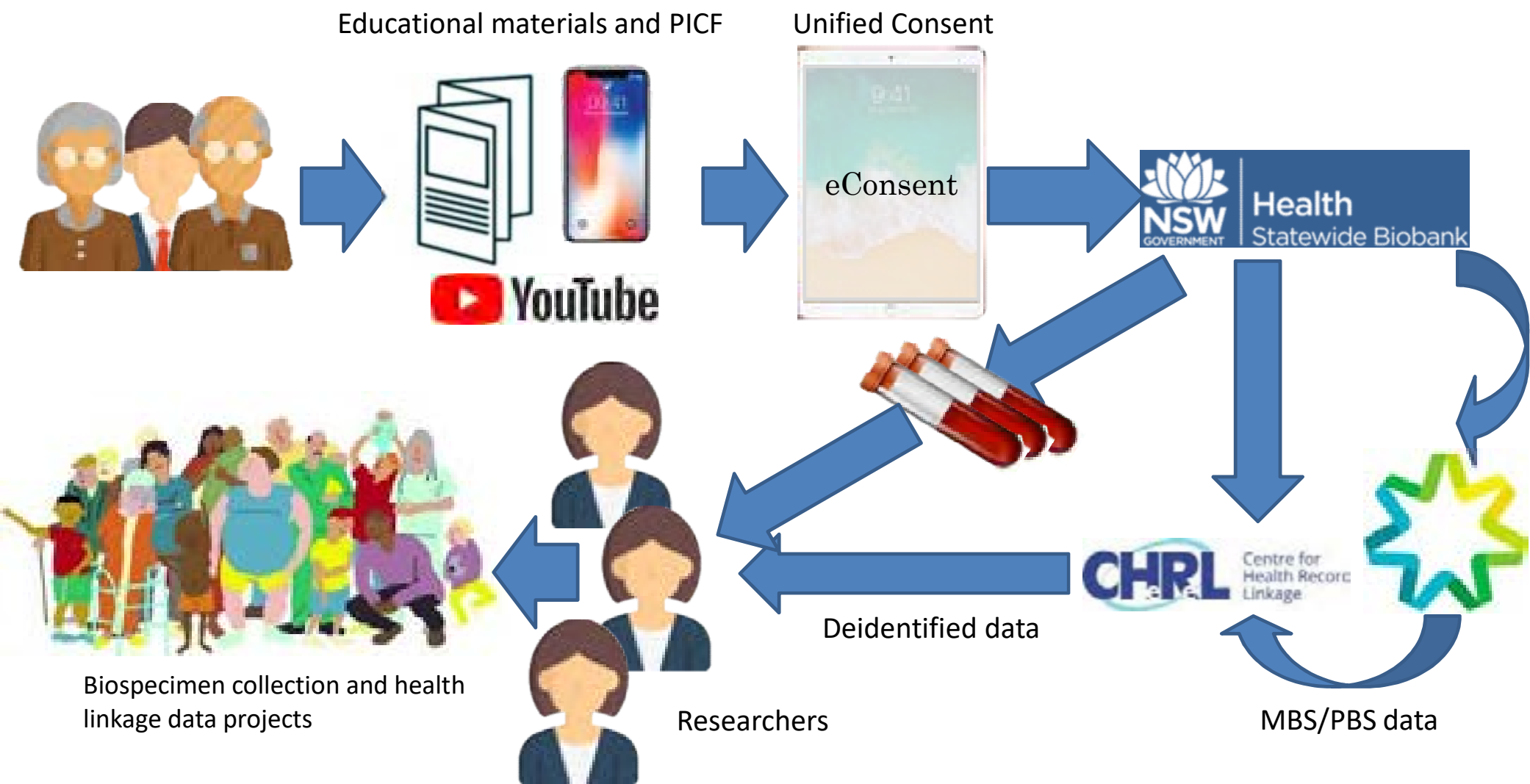




# An innovative strategy can DOUBLE the benefit







# Questions

## Want to know more?

- FAQs and supporting materials are now available:

Visit: [www.biobank.health.nsw.gov.au](http://www.biobank.health.nsw.gov.au)

For any further information, contact:

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T: (02) 4920 4138

E: [NSWPATH-Biobanking@health.nsw.gov.au](mailto:NSWPATH-Biobanking@health.nsw.gov.au)

