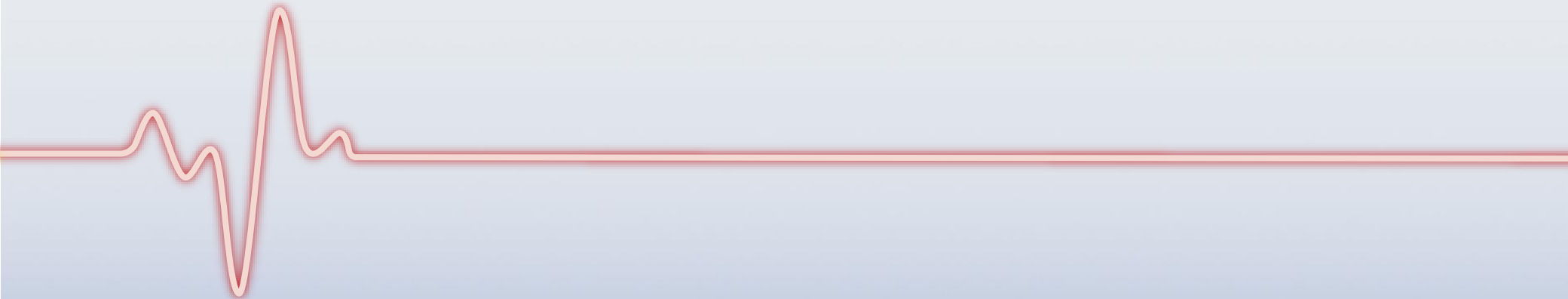


Outcome Registries

Our private sector journey along the registry road...



Karen Patching, National Registry Coordinator. **March 2018**

GenesisCare Outcomes Registries – GCOR

Improving Guideline compliance in Australia with National Outcomes Registries

Status

**UNDERSTAND
CHALLENGES**

COORDINATION

- Limited national coordination of patient outcome data across private sectors

DATA CAPTURE

- Patient follow up is under resourced and lacks centralized guidance systems

RESOURCES

- National resources aren't optimally leveraged to enable efficient and adequately powered data capture
- Fragmented research community, silos working hard, the right intent, and ultimately the same vision, but underpowered as mutually exclusive entities

BENCHMARKING

- Benchmarking of clinical outcomes is ad hoc, site/state-based and highly biased due non-standardized governance and fragmented resource allocation

LOCAL RELEVANCE

- Australia's diversity poses unique challenges in translating global performance indicators reflecting clinical variations and patient outcomes into our own "real world" clinical setting relevant to our population

EVIDENCE-BASED

- Evidence-based medicine is increasingly important – ethically, medicolegally, government health resource allocation and private insurance entities

GOVERNANCE

- Bureaucratic governance can impede efficiency, particularly when poorly coordinated across multiple governance groups involved in a single investigation project

QUALITY

- Ultimately, it's uncertain whether Australians are provided cardiac care that exceeds / meets / or is suboptimal when compared to global standard

GenesisCare Outcomes Registries – GCOR

Improving Guideline compliance in Australia with National Outcomes Registries

Objective

**IMPROVE PATIENT
OUTCOMES**

Status

**UNDERSTAND
CHALLENGES**

COORDINATION

DATA CAPTURE

RESOURCES

BENCHMARKING

LOCAL RELEVANC

EVIDENCE-BASED

GOVERNANCE

QUALITY

COORDINATED

- National outcome data captured to centralized system

100% DATA CAPTURE

- Significantly powered data generation

COLLABORATION

- Optimal resource allocation [human & financial] to maximise benefit across our nation
- Funding allocation targeted to national “greater good” via collaborative approach to improving patient outcomes

BENCHMARKED

- National care and clinical outcomes with quality assurance capabilities

NATIONAL PERFORMANCE INDICATORS

- Reflecting Australia’s unique clinical variations, risk-adjusted, consumer-centric and “real world”

CLINICAL GUIDANCE PRODUCED

- Founded on thorough clinical research integrated with global best practice and understanding of the specific needs of Australian physicians and patients

STREAMLINED GOVERNANCE

- Maximise efficiency without compromising ethical standards and **QUALITY ASSURANCE**

GenesisCare Outcomes Registries – GCOR

Improving Guideline compliance in Australia with National Outcomes Registries

Strategy

**OPTIMISE
EVIDENCE-BASED
HEALTHCARE**

Status

**UNDERSTAND
CHALLENGES**

COORDINATION

DATA CAPTURE

RESOURCES

BENCHMARKING

LOCAL RELEVANC

EVIDENCE-BASED

GOVERNANCE

QUALITY

Objective

**IMPROVE PATIENT
OUTCOMES**

COORDINATED

100% DATA CAPTURE

COLLABORATION

BENCHMARKED

NATIONAL PERFORMANCE

INDICATORS

CLINICAL GUIDANCE PRODUCED

STREAMLINED GOVERNANCE

QUAITY ASSURANCE

NATIONAL CLINICAL GOVERNANCE

- Establish a Centre of Excellence for clinical benchmarking
- Leverage strength of Australia's research network
- Streamlined bureaucratic requirements

ELECTRONIC MEDICAL RECORD linkage to REGISTRY

- Coordinated national patient outcome data captured to central system
- Implement systems to reduce barriers to 100% data capture
- Streamlined database interrogation

NATIONAL RESOURCE ALLOCATION JUSTIFICATION

- Government Health
- Private Health Insurers
- Industry Partnerships
- Charitable donations

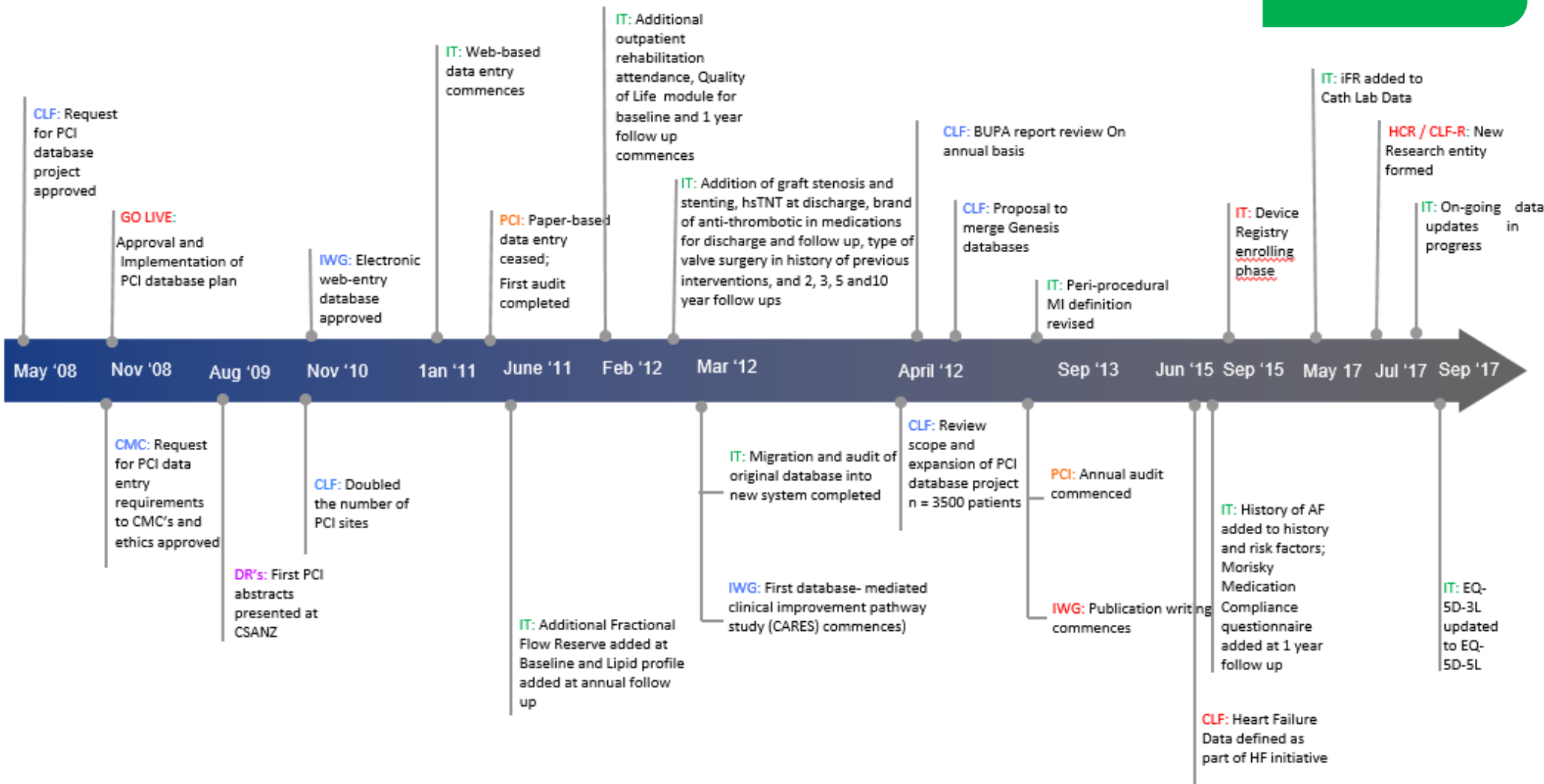
QUALITY ASSURANCE INDICATORS

- Report Guideline Therapy adherence & justification
- Assess & investigate trends deviating from Guideline recommendations

From Humble Beginnings...

GCOR's Project Timeline Overview

Strategy
**NATIONAL
STRUCTURE**



From Humble Beginnings...

GCOR's expansion throughout the subspecialties

Strategy
**NATIONAL
EXPANSION**

PCI Registry:

Creating the BluePrint

- Commenced data collection 1 November 2008
- ~150+ data points
- Publications to date:
 - ~30 national and international papers & presentations
 - Published in Heart Lung and Circulation, 6 January 2017

PCI database provided the blueprint for HC to evaluate & improve patient care.

Now being implemented into other areas of HC cardiology:

Echocardiography

Commenced ~2013

Device Registry

Commenced 1 September 2015

- ~75 data points
- Publications
 - First national paper and presentation

Heart Failure

In Development

Atrial Fibrillation

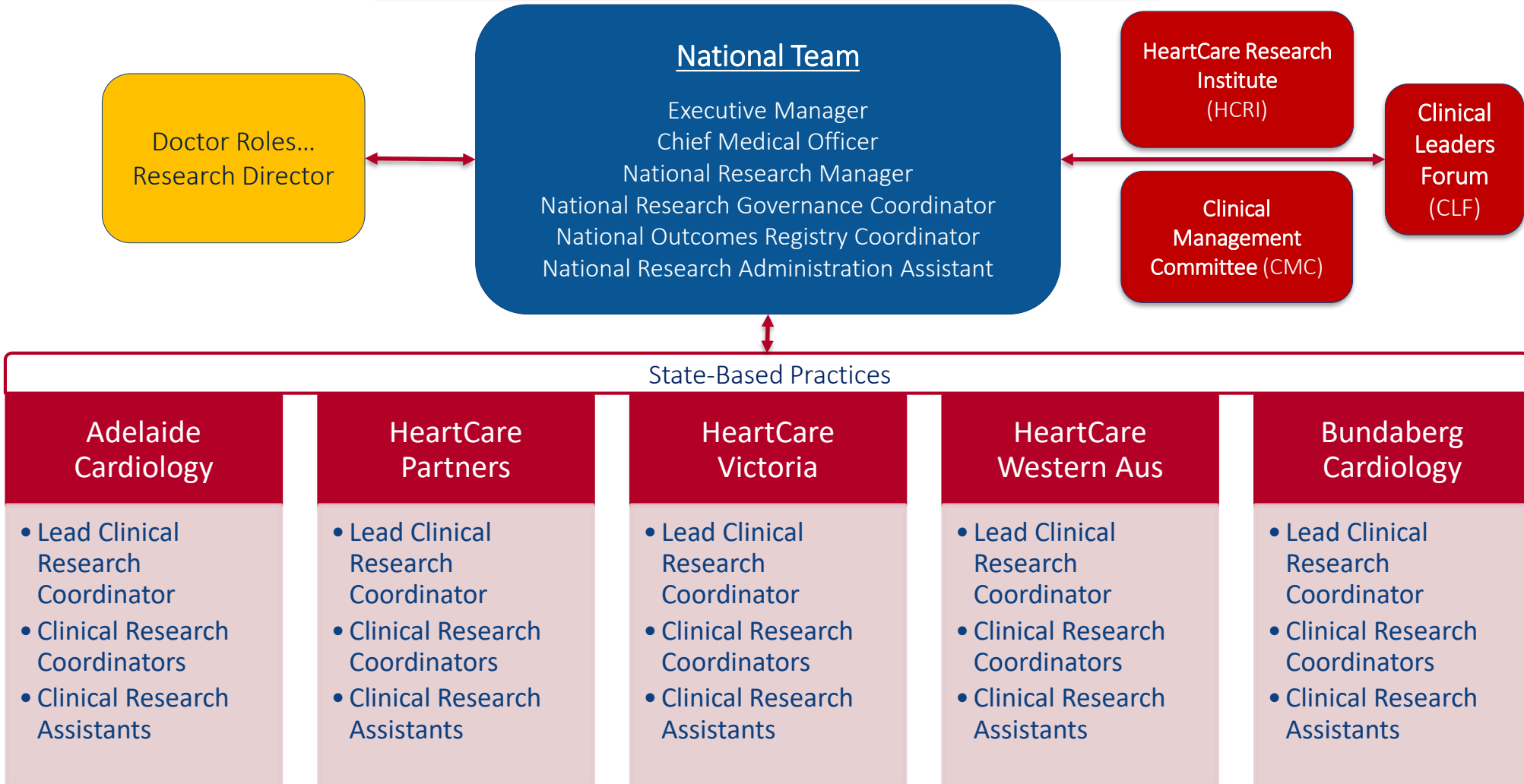
Watch this space!

First things first...

GCOR's National Clinical Governance

Strategy
**NATIONAL
CLINICAL
GOVERNANCE**

HeartCare Research Organisational Chart



GCOR's National Clinical Governance, Guiding Principles & Quality Assurance

- World Medical Association Declaration of Helsinki
- European and American Cardiology Guidelines

- Operating Principles and Technical Standards for Australian Clinical Registries 2010 (Australian Commission on Safety and Quality in Healthcare (ACSQH))
- National Statement on Ethical Conduct in Human Research (2007)
- National Health and Medical Research Council (NHMRC)
- Guidelines Under Section 95 of the Privacy Act 1988

- Human Research Ethics Committee Approval
- Patient Information Sheet – opt-out consent
- Standardized Data Definitions – universal clinical guidelines
- Annual data audit, PCI since 2012 ; Device since 2017
- CLF-R [Clinical Leaders Forum – Research]
 - Industry reports
 - BUPA (PCI, Device)
 - 6 monthly reports
 - Summarizing clinical indicators
 - Providing feedback
- Coordinators Manual
- Annual national research team face-to-face meeting
- Annual face-to-face local team support
- Quarterly research team TELCO's
- Team support available through mixed media 24/7



Leveraging latest technology...

Electronic Medical Record Linkage to Registries

Strategy
Electronic
Medical Record
Linkage

ELECTRONIC MEDICAL RECORD linkage to REGISTRY

- Coordinated national patient outcome data captured to central system
- Implement systems to reduce barriers to 100% data capture
- Streamlined database interrogation

What's been done so far...

- Web-based data entry evolving since Jan-Apr 2011
- Evolving data and definitions review
- Designation of registry roles i.e. data entry, administration, data base servicing
- Data entry support – coordinators manual, induction and regular communication with users
- Baseline data entry & FU's – real-time data collection
 - 30 day
 - 1 year
 - 2 year
 - 3 year
 - 5 year
 - 10 year
- Professional links:
 - Monash Clinical Data Management Services
 - Industry partnerships e.g. BUPA

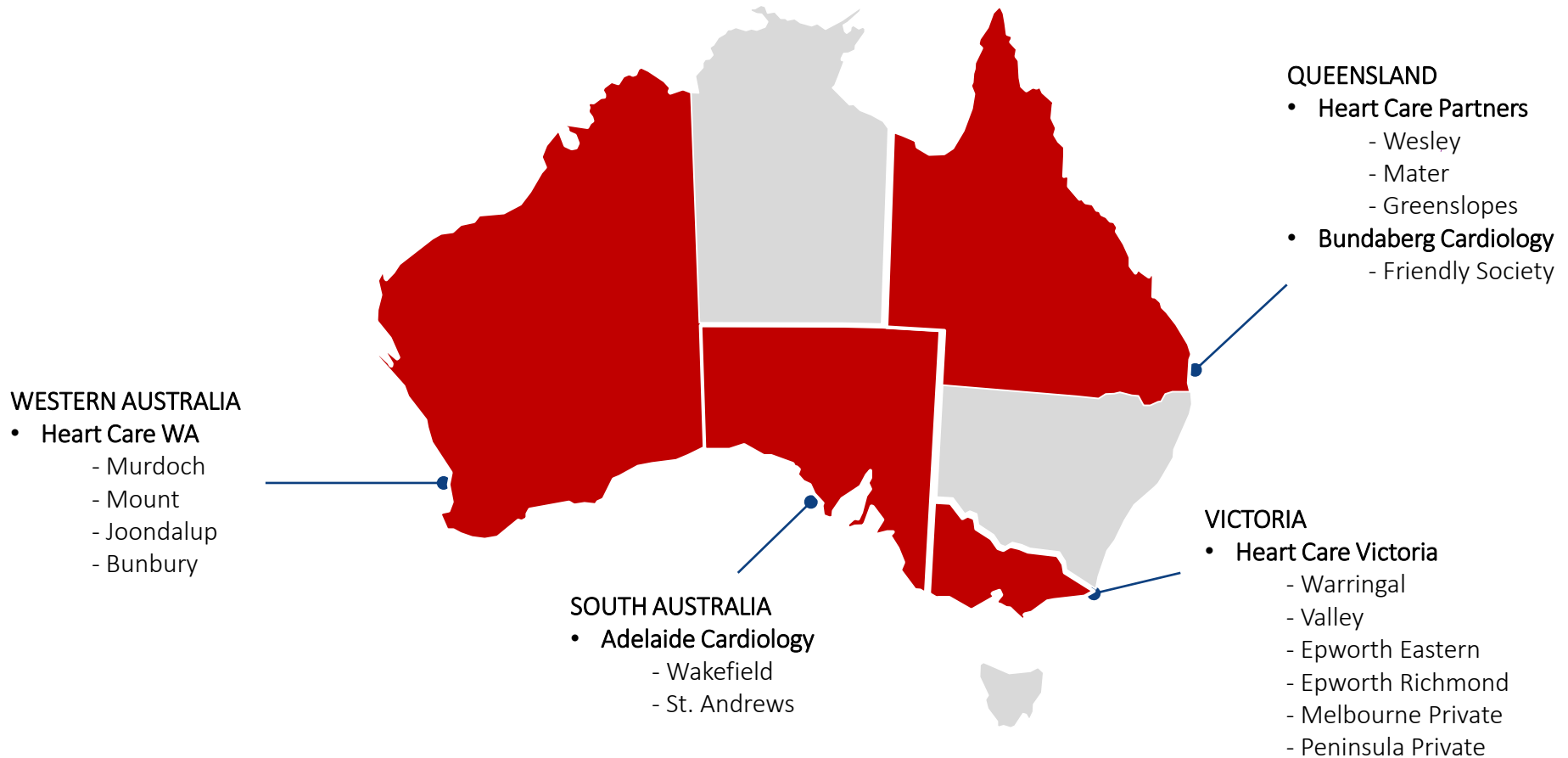
The image shows a tablet displaying a medical data entry interface. The screen is divided into a sidebar menu on the left and a main content area. The sidebar menu includes options like 'Data', 'Medical History', 'Assessment', 'Management', 'Non-Pharma', 'Pharma', 'Devices', 'Summary', 'Letter Options', 'Notifications', 'Clinical Notes', and 'Search Patient'. The main content area displays a form for 'CRT Pacemaker' and 'ICD' with various checkboxes and input fields. Red arrows point to the 'CRT Pacemaker' and 'ICD' sections. The form includes sections for 'Status of treatment' and 'Consider for advanced therapy (VAD, transplant)'.

Leveraging National Strengths...

Leveraging national research network across 16 Cath Lab Sites

Genesis Heart Private Hospital Partnerships

Strategy
**Leverage
National
Strength**



Leveraging National Strengths...

Leveraging national research network across Consulting Suite Locations

Strategy
**Leverage
National
Strength**

- Genesis Heart Care Practices

WESTERN AUSTRALIA

- Heart Care WA
 - Perth
 - Cockburn
 - Duncraig
 - Joondalup
 - Kalamunda
 - Midland
 - Murdoch
 - Nedlands
 - Rockingham
 - Yokine
 - + 12 Country Clinics

SOUTH AUSTRALIA

- Adelaide Cardiology
 - Adelaide
 - Leabrook
 - Modbury
 - Malvern
 - Gawler
 - Murray Bridge
 - Mount Barker
 - + 7 Country Clinics

QUEENSLAND

- Heart Care Partners
 - Clayfield
 - Greenslopes
 - Hervey Bay
 - Woolloongabba
 - Mount Ommaney
 - Sunshine Coast
 - Auchenflower
 - + 14 Visiting Clinics

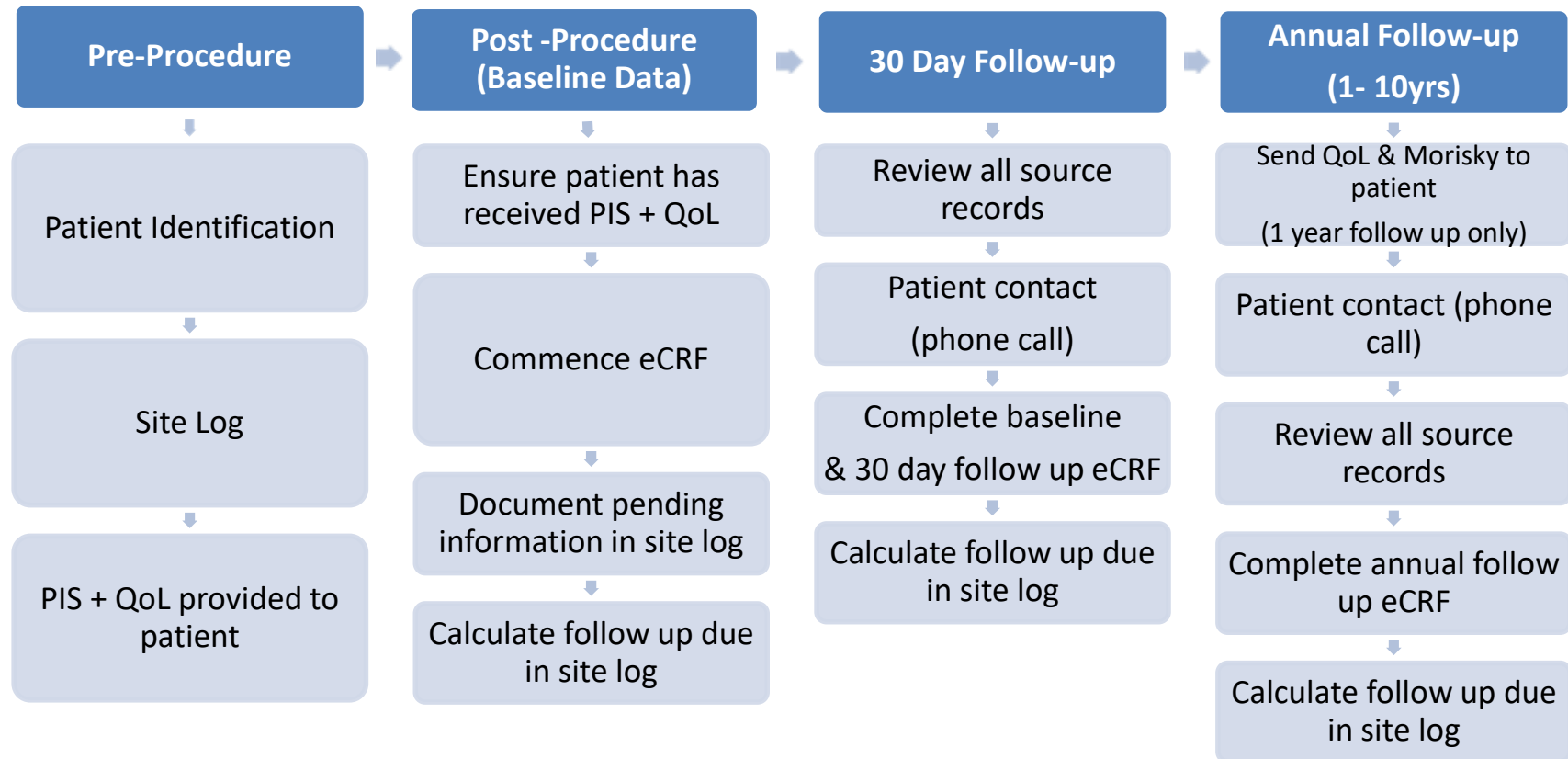
VICTORIA

- Heart Care Victoria
 - Balwyn
 - Berwick
 - Bundoora
 - Doncaster East
 - East Melbourne
 - Heidelberg
 - Lilydale
 - Langwarrin
 - Mulgrave
 - Pakenham
 - Parkville
 - Whittlesea

Streamlining Data Collection...

On-Site Research Nurses



Strategy
Streamlined
Systems
Reducing Barriers



Streamlining Data Collection...


eCRF – Electronic Case Report Form

Strategy
Streamlined
Systems
Reducing Barriers

**MONASH University**
Medicine, Nursing and Health Sciences

Genesis HeartCare Cardiovascular Outcomes Registry

Log In



User ID

Password

[Forgot your password?](#)

Contact us

Mail:
Genesis HeartCare Cardiovascular Outcomes Registry
GenesisCare Pty Ltd
Level 5, 126 Wellington Parade
East Melbourne VICTORIA 3002
Australia
Phone: +61 3 9418 2290

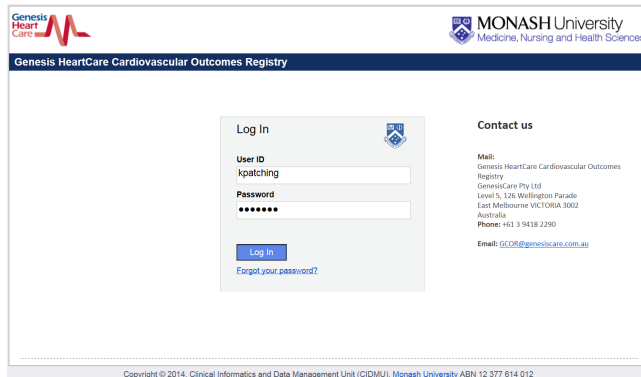
Email: GCOR@genesiscare.com.au

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Streamlining Data Collection...

EMR – Electronic Medical Records

Strategy
Streamlined
Systems
Reducing Barriers



Genesis HeartCare Cardiovascular Outcomes Registry

MONASH University
Medicine, Nursing and Health Sciences

Log In

User ID
kpatching

Password

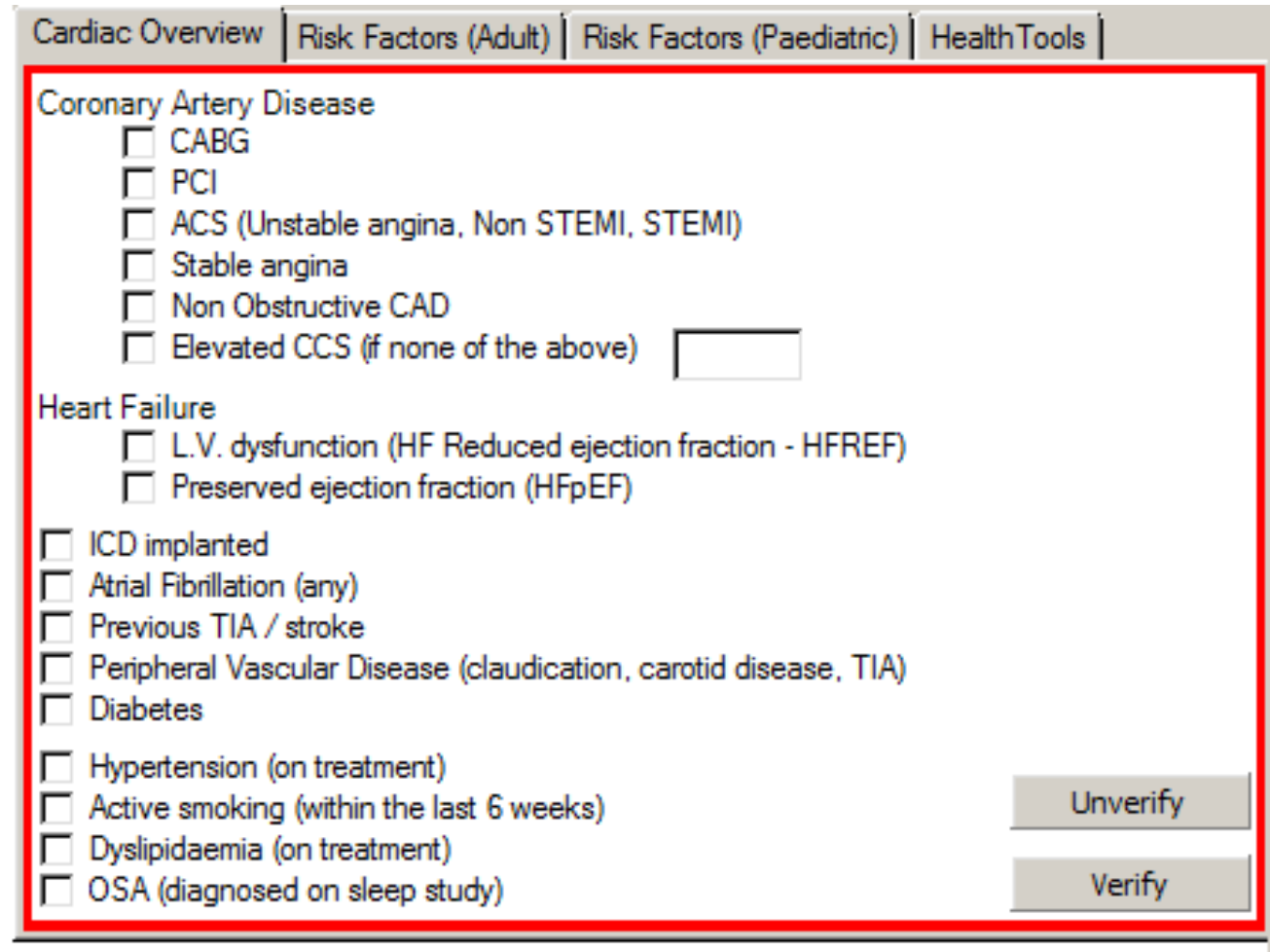
Log In

Forgot your password?

Contact us

Email: Genesis HeartCare Cardiovascular Outcomes Registry
GenesisCare Pty Ltd
Level 5, 126 Wellington Parade
East Melbourne VICTORIA 3002
Australia
Phone: +61 3 9418 2290
Email: OCCOR@genesiscare.com.au

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Cardiac Overview | Risk Factors (Adult) | Risk Factors (Paediatric) | HealthTools

Coronary Artery Disease

- ☐ CABG
- ☐ PCI
- ☐ ACS (Unstable angina, Non STEMI, STEMI)
- ☐ Stable angina
- ☐ Non Obstructive CAD
- ☐ Elevated CCS (if none of the above)

Heart Failure

- ☐ L.V. dysfunction (HF Reduced ejection fraction - HFREF)
- ☐ Preserved ejection fraction (HFpEF)

- ☐ ICD implanted
- ☐ Atrial Fibrillation (any)
- ☐ Previous TIA / stroke
- ☐ Peripheral Vascular Disease (claudication, carotid disease, TIA)
- ☐ Diabetes
- ☐ Hypertension (on treatment)
- ☐ Active smoking (within the last 6 weeks)
- ☐ Dyslipidaemia (on treatment)
- ☐ OSA (diagnosed on sleep study)

Unverify

Verify

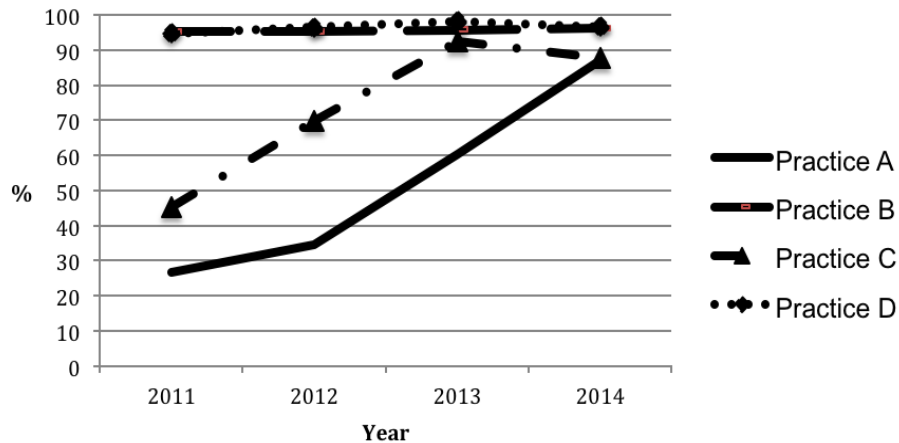
Are we achieving our objectives?

A snapshot of GCOR outcomes so far...

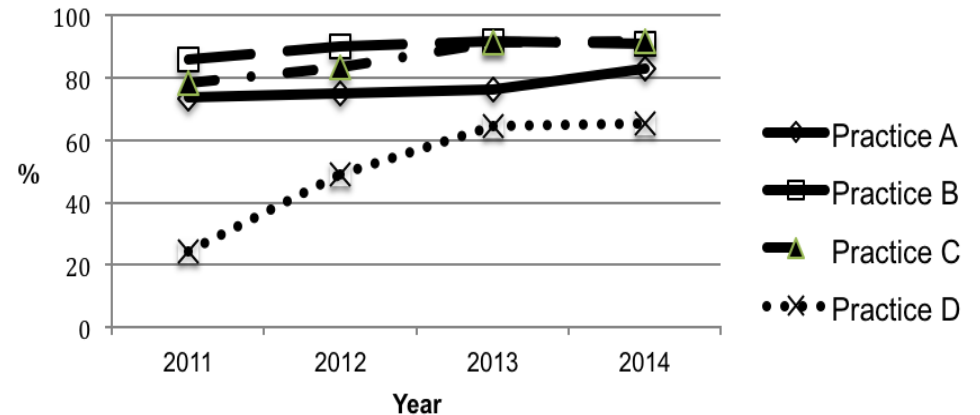
Objective
**IMPROVE
PATIENT
OUTCOMES**

Outcomes - Echocardiography Data Base

EF Measurement Compliance By Practice and Year



E:E' Measurement Compliance by Practice and Year



Are we achieving our objectives?

A snapshot of GCOR outcomes so far...

Outcomes - PCI Data Base

Objective
**IMPROVE
PATIENT
OUTCOMES**

Information for Medical Practitioners

The Genesis HeartCare Clinical Leaders Forum (CLF) is a national committee that acts as an advisory group to approve the network's clinical standards, quality and safety. As part of their commitment to evidence-based clinical practice they have implemented the Genesis Care Percutaneous Coronary Interventional (PCI) database.

The PCI database captures details of PCI procedures to enable a better understanding of patient conditions, care choices and expected treatment results. Bupa has been a partner in the development and maintenance of Genesis HeartCare's PCI database that has over 7,000 patients enrolled and 5,394 patients who have completed a 12-month follow up.



Health outcomes post PCI are extremely good, with low rates of bleeding, stroke, peri-procedural myocardial infarction and mortality.

PCI Database Outcome Results

Genesis HeartCare has recently finalised the evaluation & analysis of the December 2014 data. Highlights include:

- ★ **Improved health outcomes**

Health outcomes post PCI are extremely good, with low rates of bleeding, stroke, peri-procedural myocardial infarction and mortality. Survival post-discharge remains excellent overall and mortality in the 12 months post discharge is low at 0.29%.

- ★ **In-hospital mortality rates are lower**

The rate of in-hospital mortality was 0.27% in December 2014 compared with 0.31% in December 2012. This rate has fallen slightly and continues to compare favourably with the largest international database, the US National Cardiovascular Data Registry (NCDR)'s in-hospital mortality rate of 4.83%.

- ★ **Decreased unplanned cardiac re-admissions**

The number of unplanned or emergency re-admissions due to a cardiac cause continues to fall steadily. The incidence at 30 days was 2.66% in December 2014 compared to 3.21% in December 2012. The incidence at 12 months has also fallen to 8.76% in December 2014 from 9.99% in December 2012.

- ★ **Continued adherence to evidence-based treatment**

Statin use has increased slightly at discharge — 93.82% in December 2014 compared with 93.75% in December 2013. The proportion of patients not receiving any cholesterol lowering medication has also reduced from 4.36% in December 2012 to 3.67% in December 2014. Compliance with guideline-based therapies remains high at baseline and at 12 months.

Anti-platelet therapy rates remains high at 99.04% and 94.25% at baseline and 12 months respectively.

Genesis HeartCare's PCI database has over 7,000 patients enrolled and 5,394 patients who have completed a 12-month follow up.



Improved health outcomes

Lower in-hospital mortality rates

Decreased un-planned cardiac readmissions

Evidence-based treatment adherence

Are we achieving our objectives?

A snapshot of GCOR outcomes so far...

Outcomes - PCI Data Base

Objective
**IMPROVE
PATIENT
OUTCOMES**

The Prevalence of Risk Factors

Known risk factors that Genesis HeartCare's patients undergoing treatment with PCI procedures were collected

LIFESTYLE	Patients at baseline BMI above 40
	Patients at baseline BMI above 30
BIOMEDICAL	LDL-C <2.0mmol/L
	Blood Pressure <130/80 at baseline
	Patients with diabetes
	Patients with diabetes and lifestyle measures
	Patients with diabetes predominantly with type 2
	Patients with insulin dependent diabetes

Please note the fall in smoking rates over the period

CATEGORY	HEALTH PARAMETER	Baseline
LIFESTYLE	Male smokers at baseline	9%
	Female smokers at baseline	7%

Is GCOR meeting objectives to date?

- ✓ COORDINATED
- ✓ 100% DATA CAPTURE
- ✓ COLLABORATION
- ✓ STREAMLINED GOVERNANCE
- ✓ QUALITY ASSURANCE
- ☐ BENCHMARKED
- ☐ NATIONAL PERFORMANCE INDICATORS
- ☐ CLINICAL GUIDANCE PRODUCED



The road ahead

A snapshot of challenges on the horizon...

Resourcing appropriately and balancing with busy private practices

Team structure

- Job descriptions & CPD (multi task roles with various backgrounds)
- Levels of supervision (across states)

Data consistency

- Changes to definitions & additional data requests
 - Real-time
 - Retrospective
- Source documentation
 - Inconsistency in location of data (hospital MR, HeartCare electronic records or verbal from patient)
 - Site log inconsistency across states
 - Double entry of data as our EMR and Registry are separate platforms
- Differences in site data collection method
 - Direct eCRF entry is preferred
 - Paper based data collection with secondary eCRF data entry (double handling)
- Follow up challenges
 - Patient contact once beyond year 1

Ethics

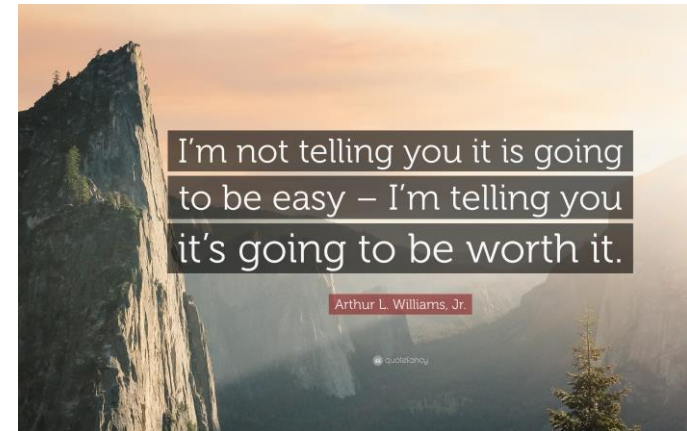
- What is appropriate for registries as opposed to clinical trials
 - Data evolution
 - Extensions & Progress reports

From the nursing/research team perspective

- Maximising the information contained in the registry
- CPD and balancing this given role diversity
- Keeping the team inspired

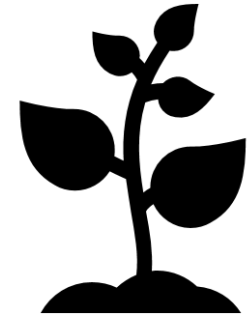
How to best develop ways of using the data that is meaningful

Objective
**IMPROVE
PATIENT
OUTCOMES**



GenesisCare Outcomes Registries – GCOR

Improving Guideline compliance in Australia with National Outcomes Registries



Status

**UNDERSTAND OUR
CLINICAL
LANDSCAPE**

Objective

**IMPROVE PATIENT
OUTCOMES**

Strategy

**OPTIMISE
EVIDENCE-BASED
HEALTHCARE**

COORDINATION

DATA CAPTURE

RESOURCES

BENCHMARKING

LOCAL RELEVANCE

EVIDENCE-BASED

GOVERNANCE

QUALITY

COORDINATED

100% DATA CAPTURE

COLLABORATION

BENCHMARKED

NATIONAL PERFORMANCE

INDICATORS

CLINICAL GUIDANCE PRODUCED

STREAMLINED GOVERNANCE

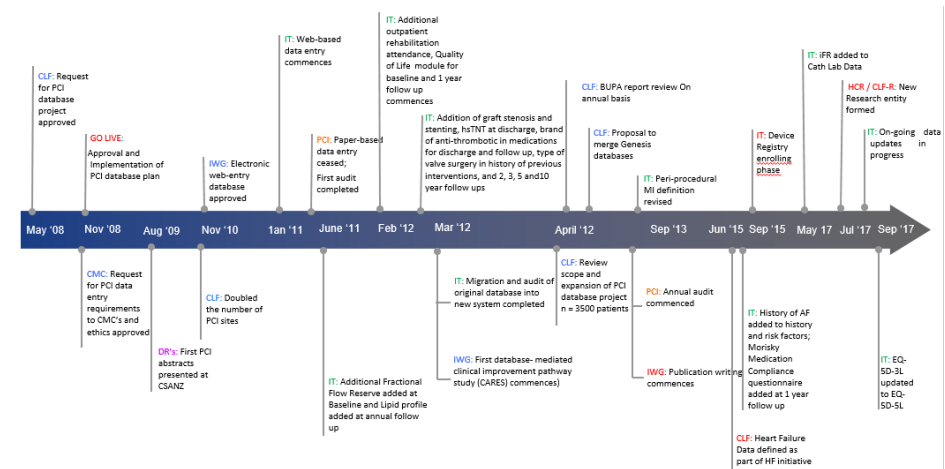
QUALITY ASSURANCE

NATIONAL CLINICAL GOVERNANCE

ELECTRONIC MEDICAL RECORD linkage to REGISTRY

NATIONAL RESOURCE ALLOCATION JUSTIFICATION

QUALITY ASSURANCE INDICATORS



GenesisCare Outcomes Registries – GCOR 2018

Improving Guideline compliance in Australia with National Outcomes Registries

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Abbreviations

- CLF: Clinical Lead Forum
- CLF-R: Clinical Lead Forum-Research
- CMC: Clinical Management Committee
- Dr: Doctor
- eCRF: electronic Case Report Form
- FU: Follow up
- GC: GenesisCare
- HC: HeartCare
- HCRI: HeartCare Research Institute
- IWG: Interventional Working Group (prior HC governance group)
- PIS: Patient Information Sheet
- QoL: Quality of Life (questionnaire)
- WA: Western Australia