

Ever wondered how a global
registry works?
Come on a journey of discovery,
successes, challenges and lessons
learnt!

Presented by:
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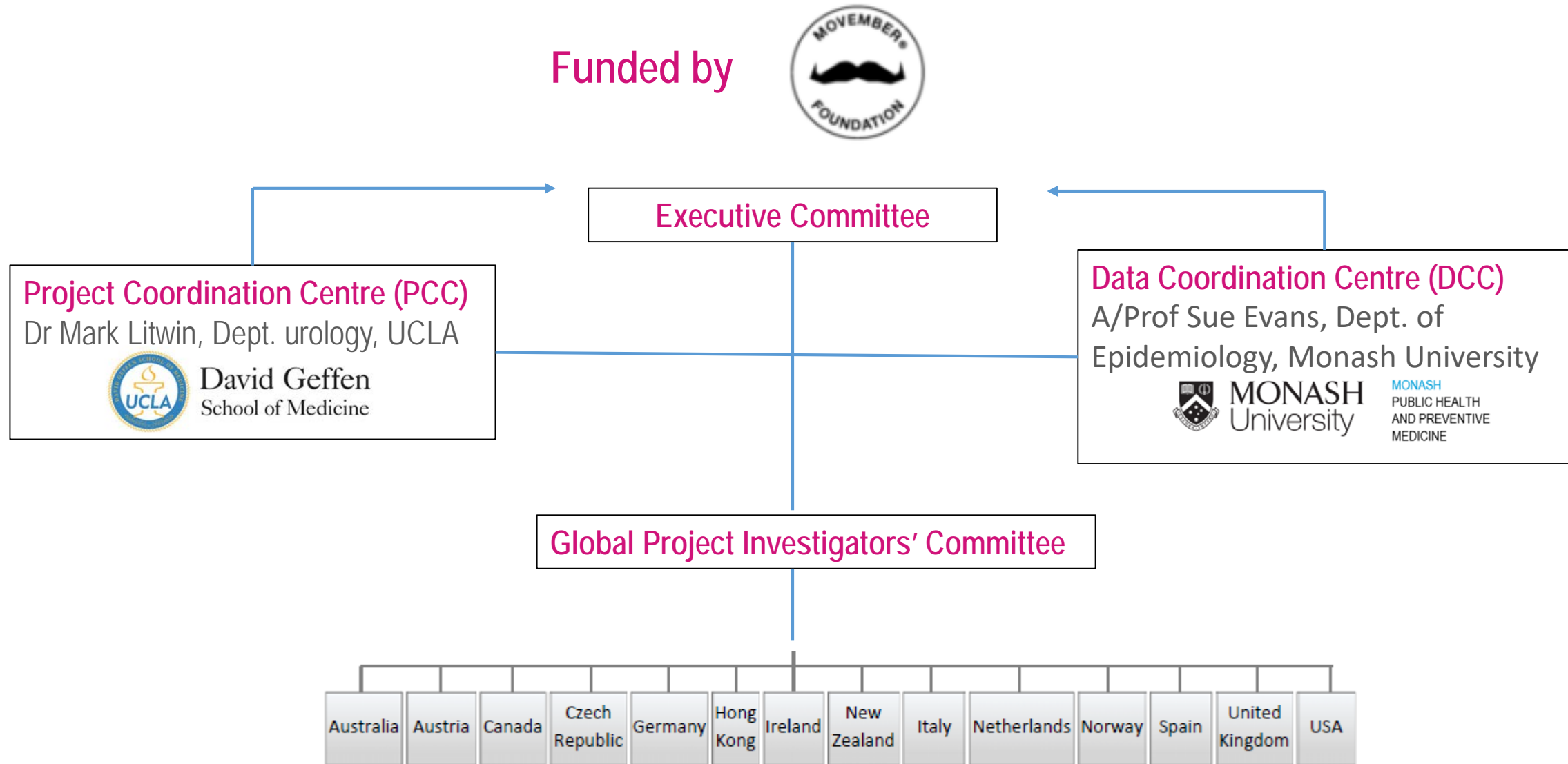
GLOBAL REGISTRY
PROSTATE CANCER OUTCOMES

Background

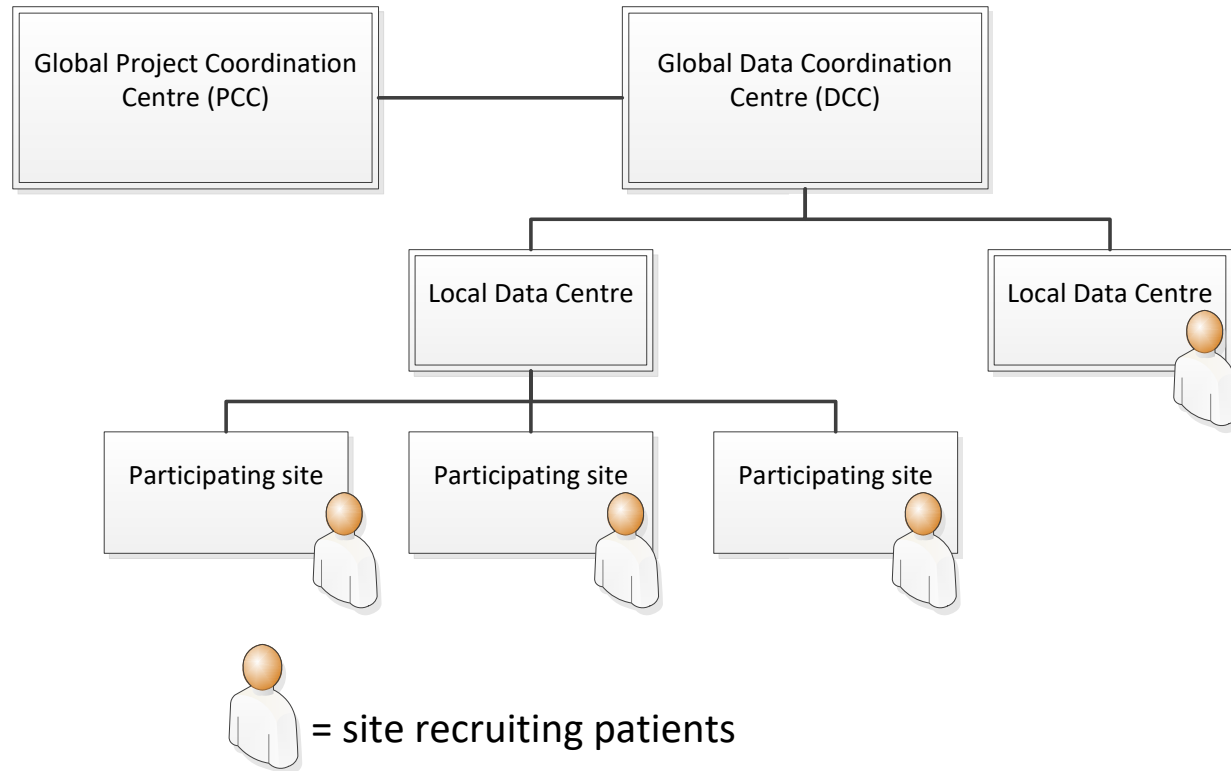
- TrueNTH Global Registry is an international project that aims to improve the physical and mental health of men with prostate cancer.
- **22** Local Data Centre's, operating in **15** countries:



Governance



Data Linkage



A network of 22 global Local Data Centres and their Participating Sites provide de-identified patient clinical data to the DCC bi-annually.

ICHOM – Consistency is key

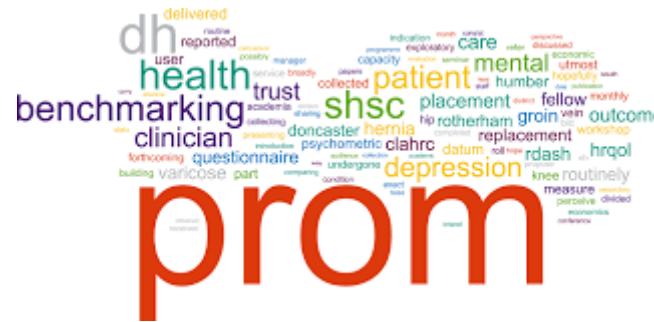


- T1 clinical data is collected as per ICHOM standard for localised prostate cancer.
- PROMs are collected at baseline and 12 months post active treatment.

First Data Upload February 2018

4731

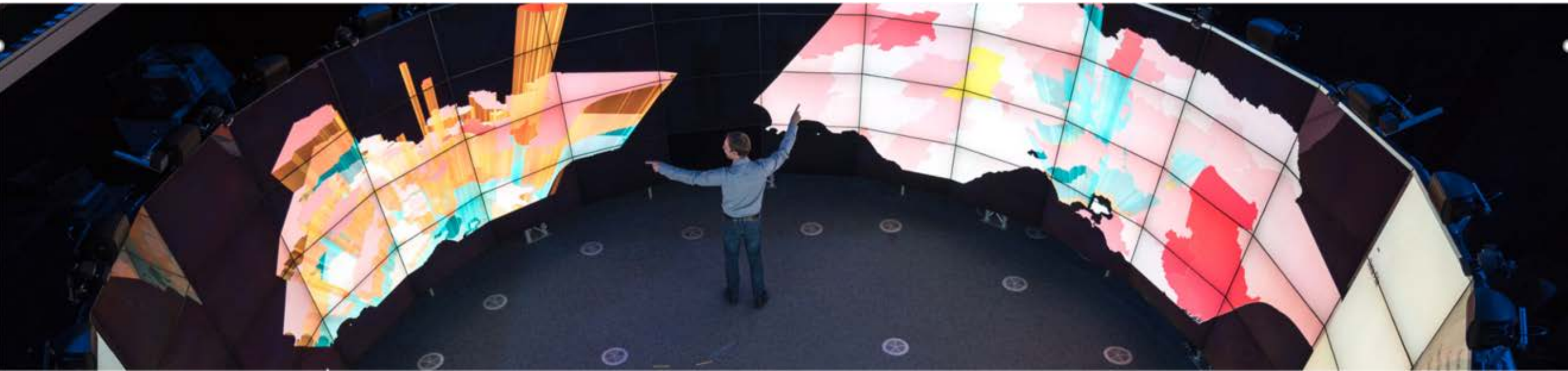
Baseline PROMS



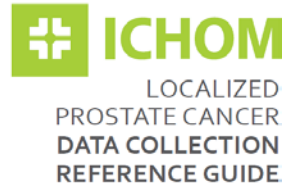
Multiple consent methods

22% Other

Let the Journey begin.....



The build...



- Data harmonisation using
- Implementation
 - ☐ Naming convention
 - ☐ Data dictionary
- System design
 - ☐ Secure transfer and storage
 - ☐ Database structure
 - ☐ Error handling
- File submission process
 - ☐ Data submission portal
 - ☐ 2-steps validation

CENTRALISED
REGISTRY

Demo



Not all smooth sailing...

Challenges

- The roll out of 'opt-out' consent for registry participation
- Introduction of GDPR (affirmative consent; de-identified data)
- Time difference – most meetings are held outside working hours
- Staff skill level – pioneering work never been done before
- Availability of local IT support to assist LDC data manager to transform their data into the import file format
- Keeping sites engaged
- Quality Indicator report development
- What do we do with the data collected?



What did we learn...

Lessons learnt

- Ethics boards had different interpretation on the appropriateness of an opt-out consent.
- Transfer of personal data prohibited
- Custom builds can take a long time...exceeding project timeframes
- Data format needs to be clearly specified in the data dictionary. E.g. DOB, decimal value.

Next Steps

- Recruitment of more local data centre
- Establishing Quality Indicator reports
- Research publications
- Reporting on outcomes and patterns of care that matter!



THANK YOU

Collecting a common data set of clinical measures across the globe enables reporting to clinicians and hospitals on outcomes and patterns of care that matter!



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