

PRECISION PUBLIC HEALTH

ASiA 2018

18 - 19 October 2018

Esplanade Hotel Fremantle

Western Australia

Professor Hugh Dawkins

Director, Office of Population Health Genomics

Public and Aboriginal Health Division

Department of Health, Western Australia



NEXT 10 MINUTES



- Introducing innovation and technology adoption
- Introducing Rare Disease as a public health exemplar- what we did
 - Identifying that 6-8% of our population was invisible in the health system
 - Rare disease families wanting to be visible, to be able to live the best life possible
 - A speedy accurate diagnosis
 - Equitable place in the health system
 - Assurance of receiving best practice care
 - Gaining visibility and a voice
- A few thoughts about success factors and lessons learned
- Introduction to Keynote speakers and Sania Nishtar

Technology (Steel processing technologies; electricity, oil & gas discoveries; combustion engine; computing; informatics; genomics...)

- Innovation and technology adoption occurs in waves
- Resources and society organise around the technology
 - people; investment; markets, and resources aggregate
- First wave of knowledge translation and benefits accrue in resource rich countries based on conventional investment risk - reward paradigm
- Creates inequities – initially those with the most benefit the most
- Subsequent waves of knowledge translation and benefits are linked to start (entry) point and local resource leverage...equity
- Public health is a person centred, concerned with ensuring benefit ‘to the many’ delivered through policy, resource aggregation and equity-based frameworks

Rare Diseases (RD) – a Public Health exemplar



- People recognised RD as a public health issue; unmet need for RD community and for the health system
 - Orphan drugs policies
 - Convergent Technologies: molecular & computer
 - Inequity
- Organise : People meet and agree to coordinate efforts
- Re-organise around issues - International Rare Diseases Research Consortium (IRDiRC)
 - Agreed to 2 aspirational 10 year goals and ‘simply counting’;
 - Members commit to aligning their resource
 - Agreed a minimal commitment across 10 years; contributing through strengths
 - Patient voice through umbrella organisations
 - grounded on needs of people and families living with RD;
 - Regular reporting and members accountability- not on quantum, but on the true value of effort to meet aspirational goals through aligning systems locally with other members
 - Is resources help aggregate dispersed rare disease efforts
- How could Australia and WA Health participate & meaningfully contribute?

Big Country, Small Population



Unmet needs and issues faced

- At need population within our community
- Rare diseases invisible to the health system
- Dispersed population (urban to remote communities)
- Dispersed resources
- Limited research funds

Outcomes required

- Equitable access
- Optimised outcomes
- Sustainable
- Better use of public health system resources
- Empower rare diseases patients

OUR STARTING POINT



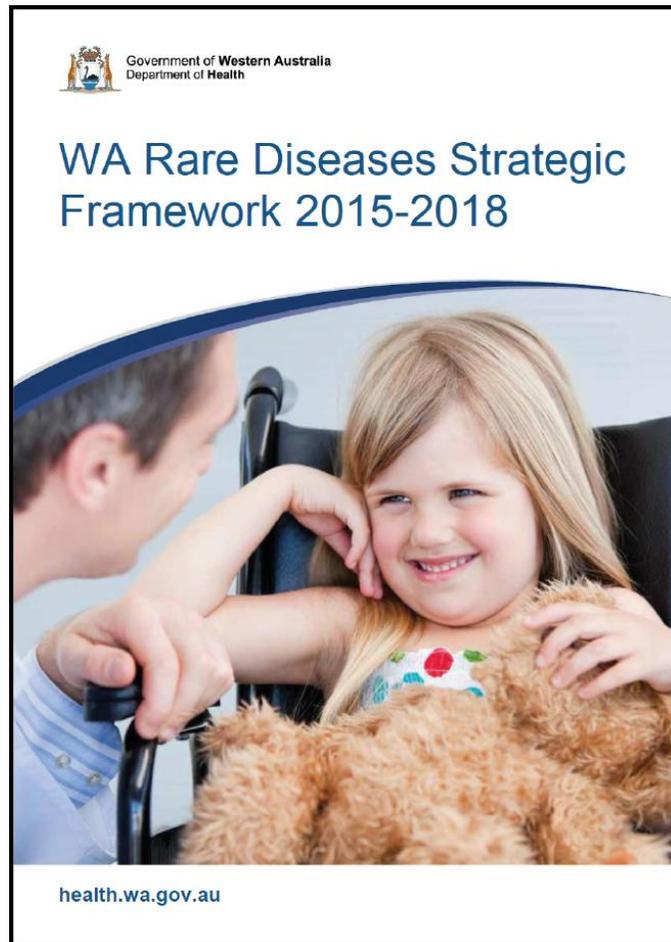
- Be pragmatic: use local strengths & be agile
- Use the public health system, moving towards person-centred care (equity)
- Access clinical records (data)
- Engage health system executives looking for efficiencies and optimised patient outcomes
- Empower patient voices
- Engage clinical champions
- Use policy champions

WHAT DID WE DO?



- Patient organisations & community groups - who are our stakeholders and local champions; what can be done?
- Clinical and public health services – what is in place, identified champions in the system; what can be done?
- Local information – what data are collected, identified champions; what can be done?
- Developed a plan – appreciative approach; empowered by stakeholders; what can be done?
- Needed to be sustainable – we took a public health system and clinical service start point
- Used genomics policy makers

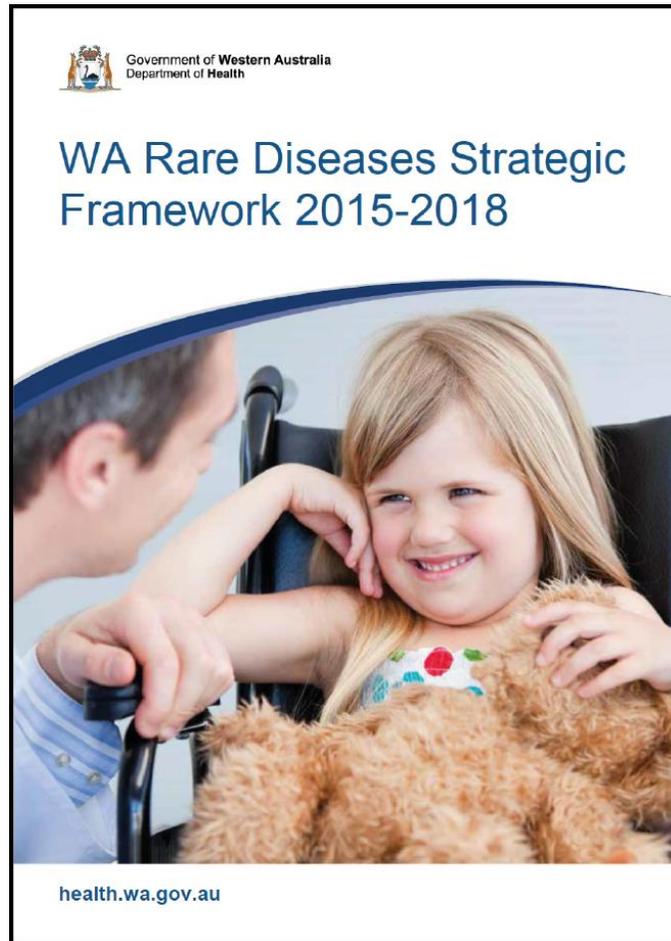
POLICY DEVELOPMENT: what can be done?



The best possible health and wellbeing for Western Australians living with rare diseases

- 12 objectives
 - Facilitate access to support networks and information
 - Build on existing services for screening and diagnosis
 - Promote care coordination
 - Champion integration and partnerships in the delivery of healthcare
 - Facilitate health professionals' access to information
 - Build epidemiology and health system evidence
- Foundation: more local evidence required!

POLICY DEVELOPMENT: what can we all do?



- Build on available evidence
- Do not need to change the whole system – build on strengths and opportunities
- Political support and champions
 - Link up policy-makers and stakeholders, including patients and patient organisations who have the personal stories
- Recognise more evidence of impact is always required

Introducing Sania Nishtar and key note speakers



It is now my very great pleasure to introduce all the keynote speakers over the next two days.

A message stick has been given to all the key note speakers – could all those with a message stick please stand up and remain standing

As a key note speaker and participant of this meeting the question is what are we going to do with it this message stick

certainly a reminder of meeting these two days

might it also represent a commitment and shared obligation to ensure equity of access to the new global public health we are envisioning here

A message from the MOODITJ MOB (pronounced 'moorditch')



Over tens of thousands of years, message sticks were commonly used by our ancestors as one means of communicating between different Aboriginal tribes/nations. Messages were painted and inscribed on a stick, which was then transported by hand. One who carried the message stick was traditionally granted safe and protected entry to other nation's territory - a sort of visa or passport.

Those who found the messenger on their land had an **(shared) obligation to safely deliver the messenger to the elders of their people. The messenger would then convey the message to the elders.** These elders then had an obligation to ensure the messenger was granted safe passage across their land - either returning to his own people or moving on to another Aboriginal nation to spread the message further.

In giving this message stick as our gift we wish you safe passage while you visit Whadjuk Nyoongar Boodja, we hope you enjoy our beautiful country. We have kept the language, stories and culture of this place for thousands of generations and share it with you today.