PERL

(Peer-led Evaluation, Research, and Leadership)

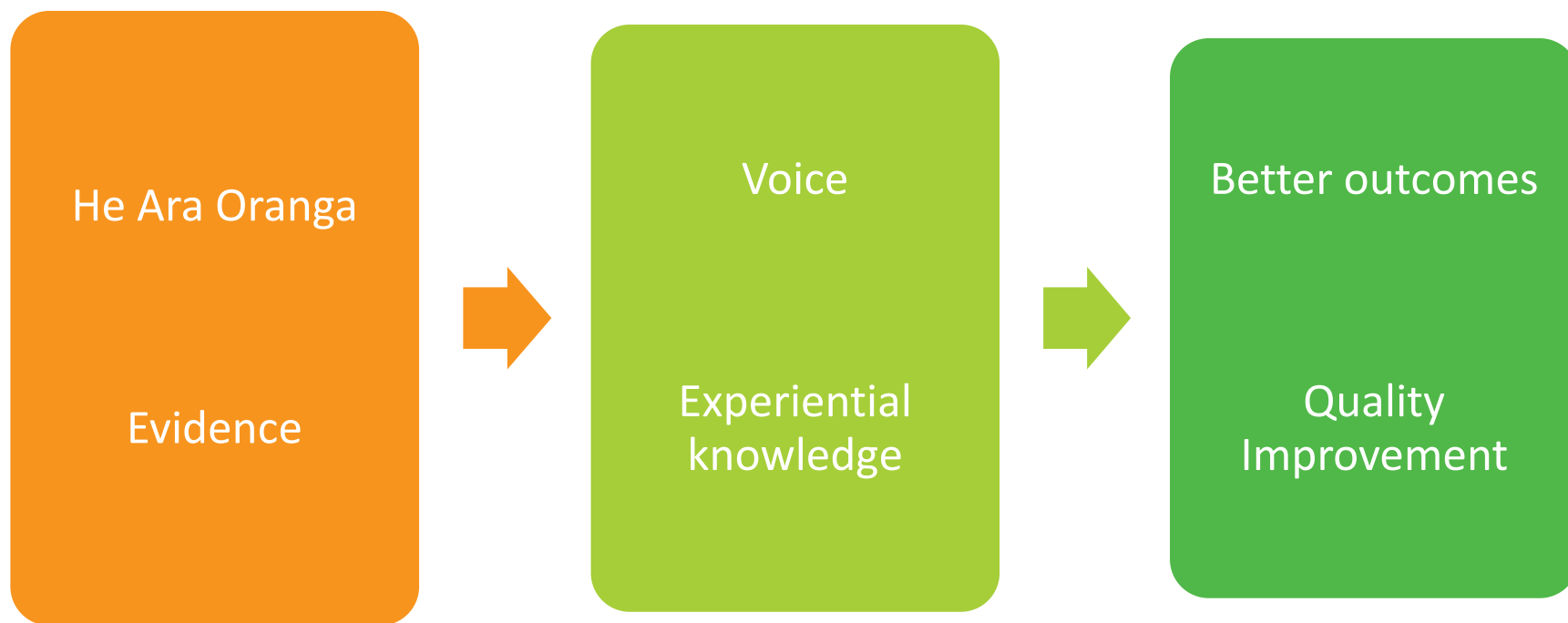# A story so far

(the Case for Mad Studies Academic discipline)
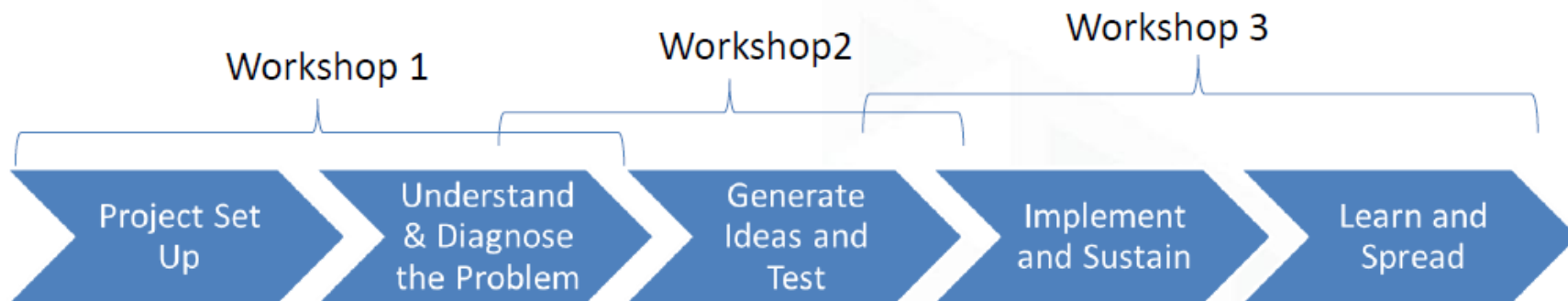
Dr Dean Manley

Evolution of an idea

He Ara Oranga

Evidence

Voice

Experiential knowledge

Better outcomes

Quality Improvement

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Process: The Project Life-Cycle

Workshop 1

Workshop2

Workshop 3

Project Set Up → Understand & Diagnose the Problem → Generate Ideas and Test → Implement and Sustain → Learn and Spread

- The life cycle is how a project is phased
- Using a pathway like this helps teams to be successful by ensuring an improvement project is set-up well, executed effectively, and the results are sustained
- In healthcare, we also want to look for opportunities to share learnings and spread ideas that work to other areas, systems

HEALTH QUALITY & SAFETY COMMISSION NEW ZEALAND
Kupu Taurangi Hauora o Aotearoa

KO AWATEA
HEALTH SYSTEM INNOVATION AND IMPROVEMENT

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The origin - Diagnose the problem

- He Puna Waiora (HPW), a mental health and addictions inpatient unit, has **struggled to meet the needs of tangata whai I Te Ora and Whānau**
- **Serious adverse events** have drawn attention to inadequate responses to people experiencing psychological distress and effects of trauma
- **Two SAC1 events** on 11 May 2019 and 16 May 2019 involved a service user becoming deceased by suspected suicide
- **Problem Analysis**
- **Root cause analysis**
- **Observation and feedback from service users and Whānau**

Define the Problem

- **Relative knowledge and personnel, physical environment, and lack of engagement time** impedes the ability of HPW staff to respond in a way they would expect of themselves and their service

- **The environment** is modelled on bio-medical health delivery systems and are inadequate for mental health and wellbeing services
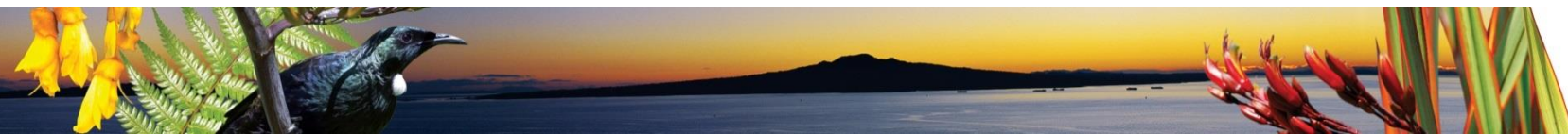
Guiding principles
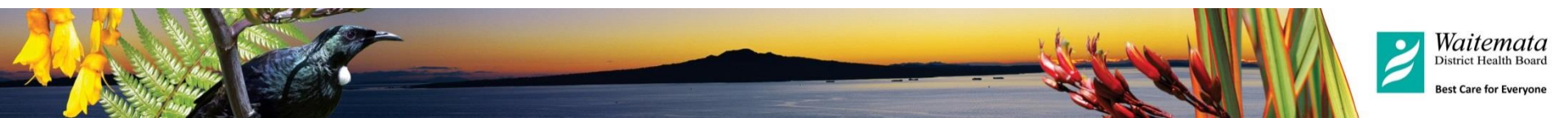
Staff presentation

Incidents in mental health services

- Earlier this year a number of tragic incidents occurred

- A number of serious incident investigations are taking place. It is expected these will be completed in January

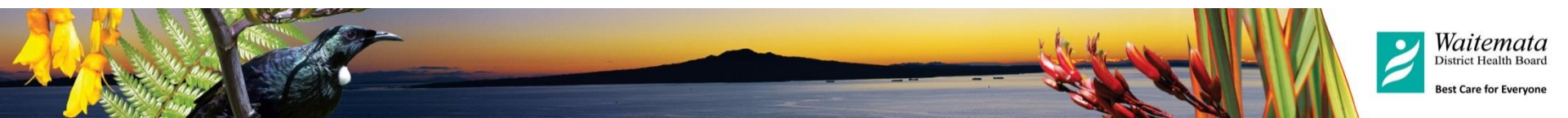- Things we have learned from the reviews will be shared across the services
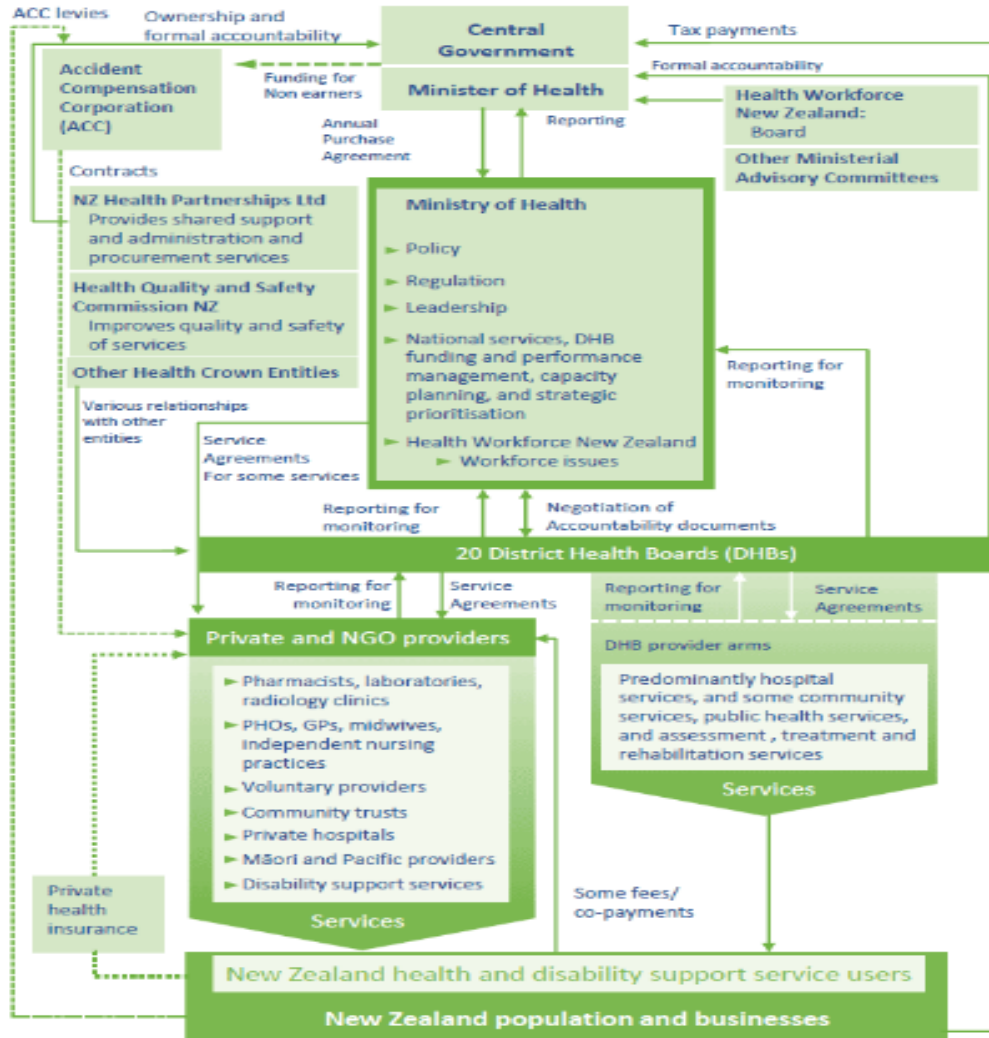
Outcomes data

- Clinical data – HONOS, PRIMHD, etc.

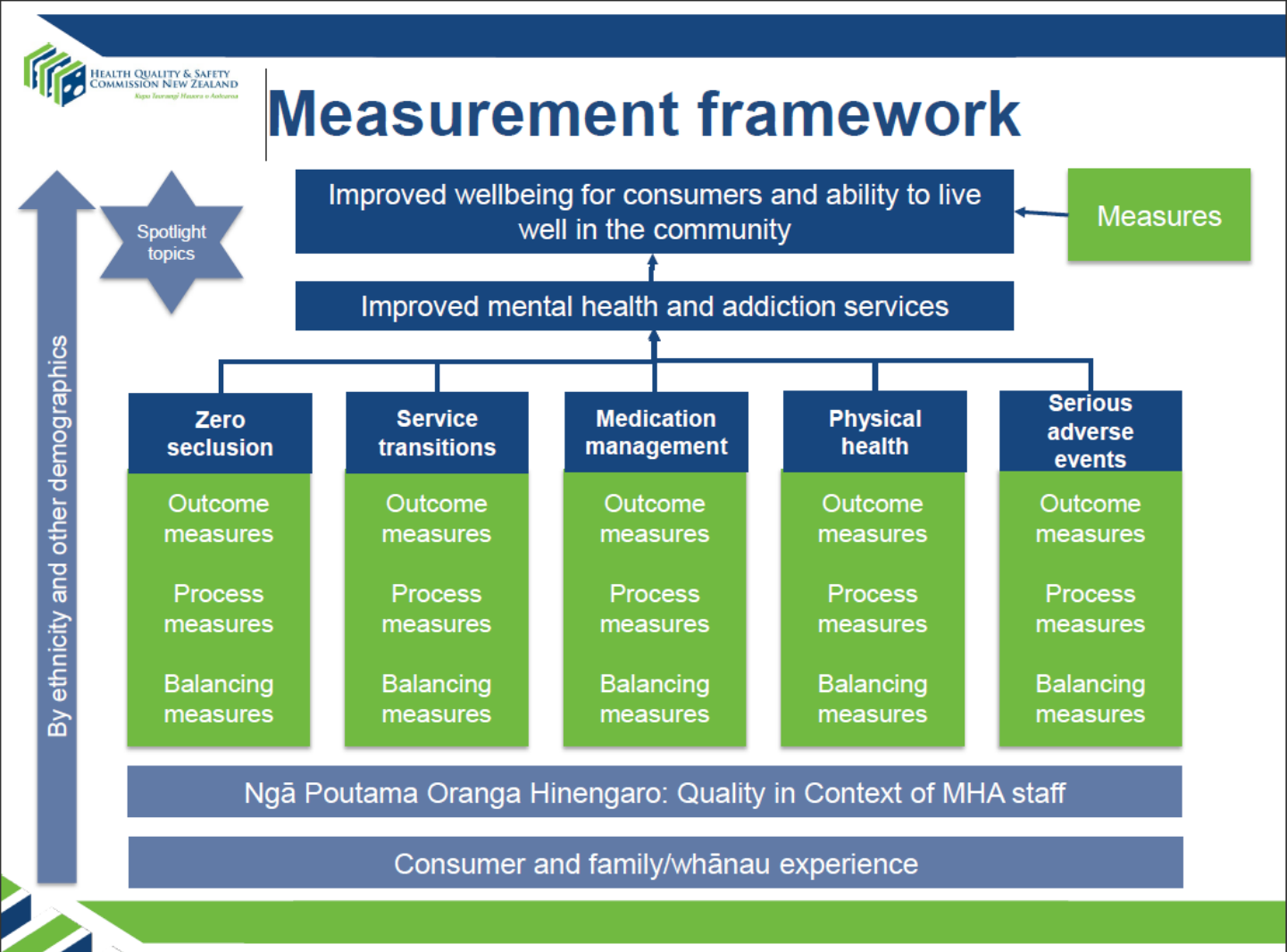- Predictive analysis

- Big Data policy strategy

Structure H&D Sector

The structure of the New Zealand health and disability sector

Measurement Framework

Outcomes data

KPI Definitions
Click on the linked heading text to expand or collapse.

Whānau Engagement ﹀

Description   Technical Notes

Whānau engagement following first face-to-face contact is important. Early initial contact should be established regardless of service/team types.

Measurement Dimensions

- Number of eligible episodes with Whānau engagement
- Percentage of eligible episodes with Whānau engagement
- Percentage of eligible episodes with Whānau engagement where first activity is Community Non-Crisis
- Percentage of eligible episodes with Whānau engagement within 2 days for all activity types
- Percentage of eligible episodes with Whānau engagement within 2 days where first activity is Community Non-Crisis
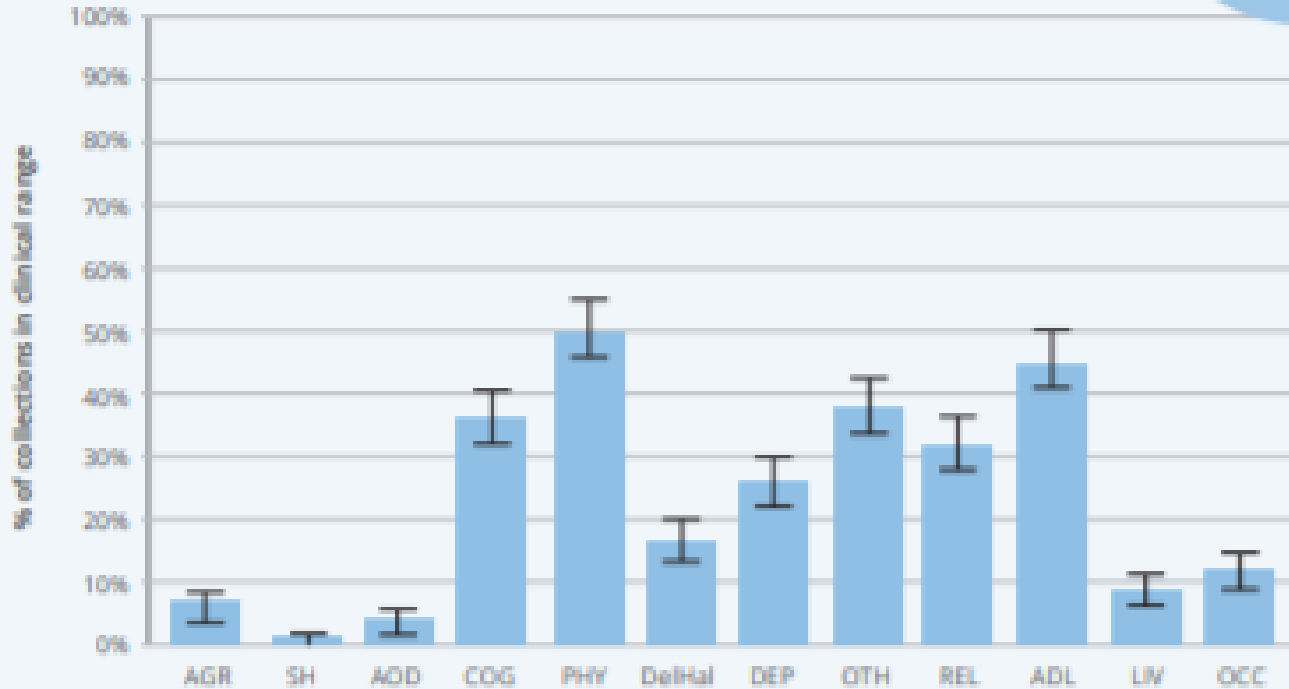
Seclusion Hours ›

Seclusion Events ›

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Report one – Tāngata whai ora needs

What are the characteristics of people that attend our service? What are their needs?

Graph 1: Percentage of community service collections in the clinical range on each HoNOS65+ Item (review collections) for one DHB. April 2013 - March 2014.

KEY

AGR = Aggression/Agitation
SH = Self-harm
AOD = Alcohol and Other Drugs
COG = Cognitive problems

PHY = Physical illness/Disability
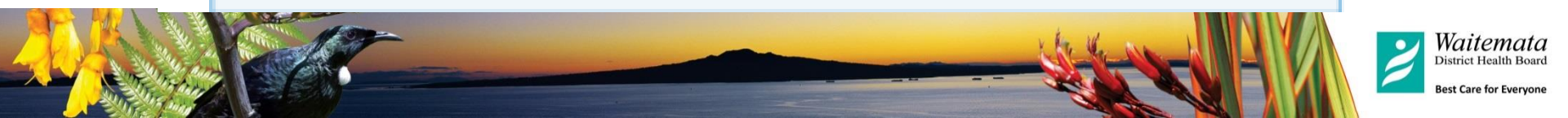DelHal = Delusions and Hallucinations
DEP = Depression
OTH = Other mental/behavioural problems

REL = Relationship
ADL = Activities of Daily Living
LIV = Living Conditions
OCC = Occupation Activities

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PRIMHD usage

Observation Classifiers e.g.

Ward	Type	Obs Date	Obs Time	Behaviour
High Care Area	15/60	-	2:45:20 PM	Agitated/restless
High Care Area	15/60	-	4:02:17 PM	Agitated/restless
High Care Area	15/60	-	4:07:22 PM	Agitated/restless
High Care Area	15/60	-	10:41:53 AM	Agitated/restless
High Care Area	15/60	-	3:01:34 PM	Agitated/restless
High Care Area	15/60	-	10:07:56 AM	Agitated/restless
High Care Area	15/60	-	10:41:36 AM	Agitated/restless
Rongoa	1:1	-	4:36:43 PM	Agitated/restless
High Care Area	15/60	-	8:29:04 AM	Agitated/restless
High Care Area	15/60	-	11:30:41 AM	Agitated/restless
Waiatarau WTH	15/60	-	2:31:56 PM	Agitated/restless
High Care Area	15/60	-	8:34:53 AM	Agitated/restless
High Care Area	15/60	-	9:37:39 AM	Agitated/restless
High Care Area	15/60	-	10:42:16 AM	Agitated/restless
Waiatarau WTH	15/60	-	2:31:34 PM	Agitated/restless
High Care Area	15/60	-	10:33:00 AM	Agitated/restless
High Care Area	15/60	-	3:59:45 PM	Agitated/restless
Waiatarau WTH	60	-	1:14:01 PM	Angry/irritated
High Care Area	15/60	-	3:48:25 PM	Angry/irritated
High Care Area	15/60	-	3:52:30 PM	Angry/irritated
Kereru	15/60	-	4:00:20 PM	Angry/irritated
High Care Area	15/60	-	10:07:45 AM	Anxious/confused
High Care Area	15/60	-	2:44:40 PM	Anxious/confused
High Care Area	On Leave	-	9:05:30 AM	Anxious/confused
High Care Area	15/60	-	10:07:48 AM	Anxious/confused
Rongoa	60	-	10:31:45 AM	Anxious/confused
High Care Area	15/60	-	11:43:25 AM	Anxious/confused
High Care Area	15/60	-	3:52:24 PM	Anxious/confused
High Care Area	15/60	-	3:34:25 PM	Anxious/confused

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Streetlight effect
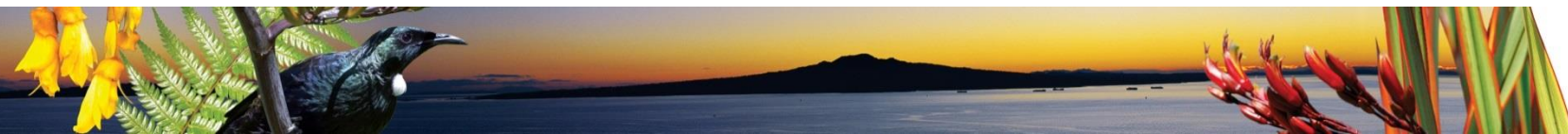
Information asymmetry

" … clinicians are experts in medicine, but patients are experts in their experiences, preferences, and values, and both clinicians and patients can participate more effectively in care if these imbalances are reduced … "

Jayakumar, p. MBBS, Dphil; Bozic, K. J. MD, MBA; Lee, T. H. MD, MSc.
Dell Medical School, University of Texas at Austin

October 15, 2019

Streetlight effect
Information asymmetry

HoNOS summary scores

The individual HoNOS scales (items) constituting both variants (HoNOS and HoNOS65+) of the measure and the summary scores.

Data element	HoNOS item number and description	Item score	Summary score
HoNOS behavioural problems summary score		2 items	0 -8
HoNOS item 01	1. Overactive, aggressive, disruptive or agitated behaviour	0 – 4	
HoNOS item 03	3. Problem drinking or drug–taking	0 – 4	
HoNOS impairment summary score		2 items	0 – 8
HoNOS item 04	4. Cognitive problems	0 – 4	
HoNOS item 05	5. Physical illness or disability problems	0 – 4	
HoNOS delusions/hallucinations problems summary score		1 item	0 – 4
HoNOS item 06	6. Problems associated with hallucinations and delusions	0 – 4	
HoNOS depression problems summary score		4 items	0 – 16
HoNOS item 02	2. Non–accidental self–injury	0 – 4	
HoNOS item 07	7. Problems with depressed mood	0 – 4	
HoNOS item 08	8. Other mental and behavioural problems	0 – 4	
HoNOS item 09	9. Problems with relationships	0 – 4	
HoNOS social problems summary score		4 items	0 – 16
HoNOS item 09	9. Problems with relationships	0 – 4	
HoNOS item 10	10. Problems with activities of daily living	0 – 4	
HoNOS item 11	11. Problems with living conditions	0 – 4	
HoNOS item 12	12. Problems with occupation and activities	0 – 4	
HoNOS total (12–item) score		12 items	0 – 48

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Streetlight effect
Addressing Information asymmetry

Peer-led data:

- Classifiers
- Indicators
- Descriptors
- Rating scales
- Outcomes quality
- Efficacy
- Contribution
- Attribution

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Background of the PERL project

Low profile in peer-led, applied research and evaluation

- little peer-led, applied research, evaluation, training/education, policy formulation and/or leadership activity.

- a lack of quantifiable and qualifiable evidence of successful non-clinical, recovery-based interventions by peers for peers;

- a gap in theoretical understanding around how 'lived experience', and 'experiential knowledge' can inform and be used in research, and policy formulation activities.

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Local, national and international policy and strategic contexts

International policy and strategy

- Mental health action plan 2013-2020 (World Health Organisation, 2013),

- UN Conventions on the rights of Persons with Disabilities (UN, 2006)

- Mental health and human rights: Report of the United Nations high commissioner for human rights (Human Rights Council, 2017)

Local, national and international policy and strategic contexts

National policy and strategy

- The New Zealand Health Research Strategy 2017-2027 (MBIE & MoH, 2017),

- New Zealand Health Strategy 2016: Future directions (Ministry of Health, 2016)

- Like Minds, Like Mine National Plan 2014-2019 (Ministry of Health & Health Promotion Agency, 2014),

- Rising to the Challenge (Ministry of Health, 2012),

- He Ara Oranga (Mental health and addiction inquiry, 2018).

- Taking mental health seriously - Wellbeing budget – Budget 2019 (Budget 2019, 2019)

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Local, national and international policy and strategic contexts

Local policy and strategy

- Waitemata District Health Board's Research Strategy 2020 (WDHB, 2016)

- Engagement strategy action plan 2016 – 2019 (WDHB, 2016),

- Annual Plan: Incorporating the Statement of Intent and the Statement of Performance Expectations (WDHB, 2017)

- Our Health in Mind: Growing wellbeing for our community A Five-Year Strategic Action Plan 2016-2021 (WDHB, 2016).

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PERL: Aims

To establish four fundamental resources to address information asymmetry:

- Independent peer-led leadership research, evaluation and education/training unit

- Recovery college

- Mad Studies Academic Disciple

- A community of co-operative amongst researchers, evaluators, advisors, academia, students and/or activists with lived experience of / consumers of mental health and/or addiction services.

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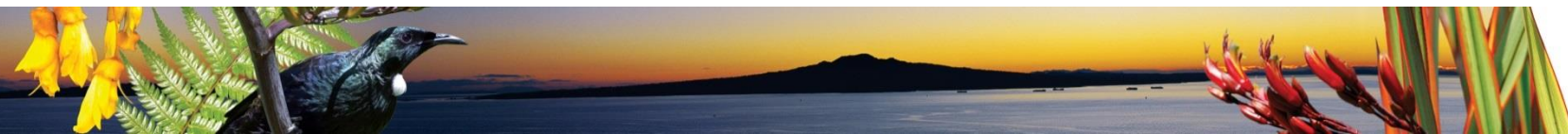
PERL: An infographic

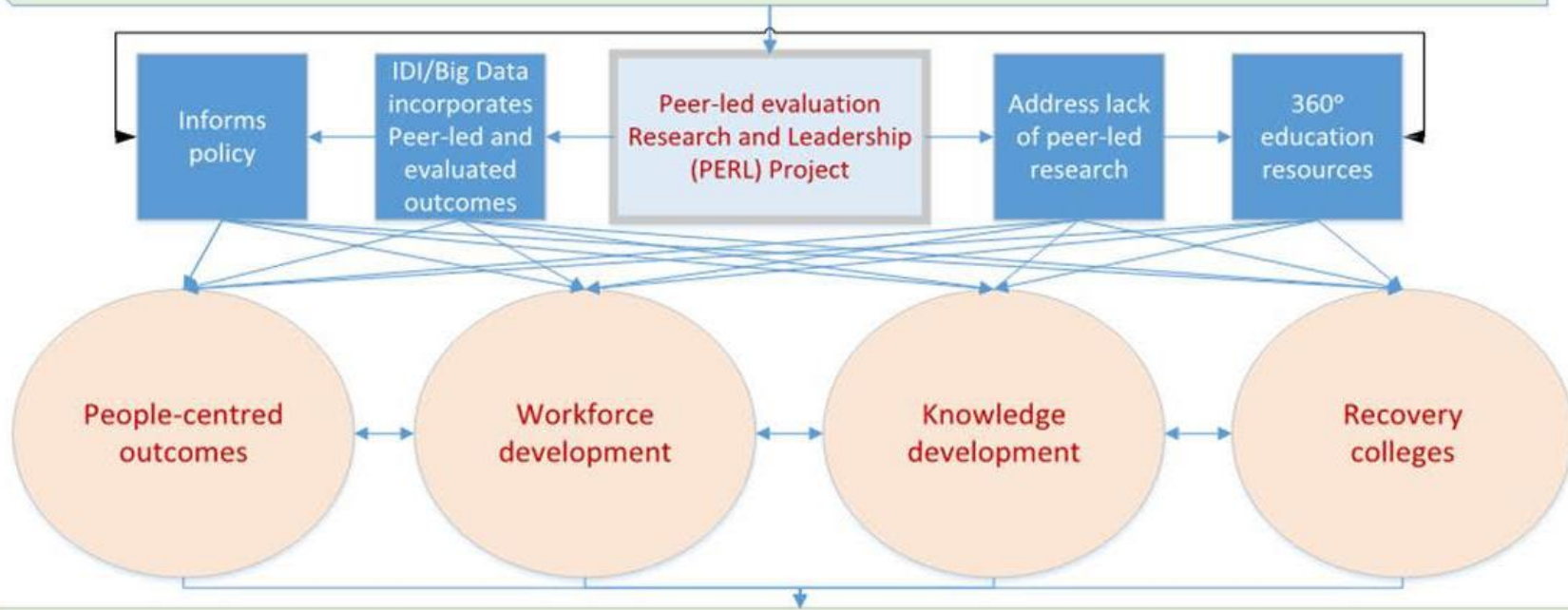PEER-LED EVALUATION, RESEARCH, AND LEADERSHIP PROJECT (PERL)

AIMS

Co-design, develop, implement, and evaluate peer-initiated research and evaluation projects
Develop capability amongst peer-academia researchers and evaluators
Lead peer-research, co-design, evaluation and/or training initiatives; facilitate an innovation in health, mental health, and addiction sectors in Aotearoa New Zealand
Examine evidence in peer-intervention efficacy, and continuous quality learning and improvement
Lead Peer Workforce Development, advocacy, policy and/or organisational development
Develop a national-based, co-designed consumer-assessed based outcome measurement in mental health and addiction.

Informs policy

IDI/Big Data incorporates Peer-led and evaluated outcomes

Peer-led evaluation Research and Leadership (PERL) Project

Address lack of peer-led research

360° education resources

People-centred outcomes

Workforce development

Knowledge development

Recovery colleges

OUTCOMES

Provide scientifically robust, validated data through peer-led applied research and evaluation (interdisciplinary and/or co-design)
Recruit members and an association of established stakeholders' network of peer-researchers
Develop a peer-led advisory group and interdisciplinary/interprofessional, peer-led academic discipline
Provide recommendations and/or innovation in health, mental health and/or addiction service delivery, system, policy and/or organisational development via research and consultation
Establish formal register of peer support workers, complete with required training, peer-based Key Performance indicators (KPI) / outcome measurements, evaluation frameworks, and career pathways
Establish a peer supervisor association that is tasked with developing national standards, updated competency framework, registration and/or terms of reference (ToR).

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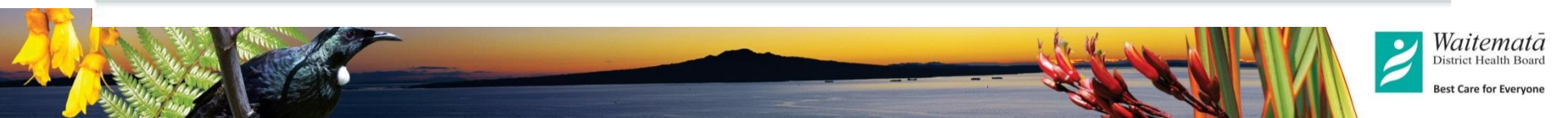
PERL: Phase one

- Grow Waitaha approach (Jansen & Wall, 2018)

- Ethics - from the Massey University Human Ethics Committee (MUHEC) or Health and Disability Ethics Committees (HDEC).

- Community advisory groups - Wellbeing Coalition Aotearoa and Shared Vision North Harbour & West Steering Groups

- One-year pilot project – test trial and market validation

- Funding - A consortium funding approach (Lunt, et al., 2008)

- Organise a conference / Symposium in Auckland.

PERL: Precedents

The overarching outcomes of phase one are:

- to create a PERL governance/advisory board and project team;

- to facilitate the development of capacity and capability of peer-led and/or lived experience-based research, evaluation and leadership in the MH/A sector.

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SERVICE USER RESEARCH ENTERPRISE (SURE)

Projects

Staff

Research tools

CLAHRC South London

BRC Service User Advisory Group

Contact us

Service User Groups in South London

Service User Research Enterprise (SURE)

RESEARCH TOOLS

SURE PROJECTS

BRC SERVICE USER ADVISORY GROUP

The Service User Research Enterprise (SURE) undertakes research that examines mental health services from the perspectives of those that use them, explores empirically and conceptually the impact of service user involvement in research (in terms of both process and outcomes), and critically interrogates how service users have changed knowledge production globally.

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Mad Studies

Search this Guide

SEARCH

WELCOME

Keywords for Mad Studies

Mad Studies Blogs and Websites

Creative Commons License

HOW TO FIND ARTICLES (AND NEWSPAPERS)

HOW TO FIND BOOKS

GREY LITERATURE

HOW TO CITE YOUR SOURCES

Keywords for Mad Studies

Try these search terms when seeking information about Mad Studies.

Ableism

Anti-Oppressive Practice

Antipsychiatry

Consumer

Survivor

Mad identity/pride/community etc……

Madness

Identity Politics

Trauma / Trauma informed

Social constructionism

Sanism

Consumer/survivor

Psychiatric Survivor

Ex-patient

Service user (common term in the UK)

Recovery discourse

Mentalism

Critical mental health

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PERL: Outcomes of Phase one

The overarching outcomes of phase one are:

- to create a PERL governance/advisory board and project team;

- to facilitate the development of capacity and capability of peer-led and/or lived experience-based research, evaluation and leadership in the MH/A sector.

Thanks for your time

Any questions?

If you are interested in the full references, or in learning more about this project please see us right after this session.