THE GEORGE INSTITUTE

Unlocking the power of linked data to improve patient journeys across the health system

David Peiris

Chief Scientist, The George Institute

Professor, Faculty of Medicine & Health, UNSW Sydney

UNSW SYDNEY

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Prof David Peiris
Prof Stephen Jan
Dr Anna Campain
Dr Gill Schierhout
Dr Tristan Bouckley
Dr Viola Korczak
Dr Shangzhi Xiong
Dr Katie Harris
John Mulley
Rimma Myton

International Centre for Future Health Systems

Prof Michael Kidd

NSW Lumos

Ms Patricia Correll
Dr Damien Cordery
Dr Anne-Marie Feyer
(Consultant)

HEALTH CONSUMERS NSW

Dr Anthony Brown
Bella Spongberg-Ross

Centre for Big Data Research in Health

Prof Louisa Jorm
Dr Heidi Welberry
Dr Sanja Lujic
Dr Nick Kuo

Australian National University

Dr Rosemary Wyber

NSW GOVERNMENT South Western Sydney Local Health District

Dr Andrew Knight

Research overview

Partnership between NSW Health, Health Consumers NSW, and an academic consortia

Workstream 1

Risk prediction & decision aids for multidisciplinary care

Workstream 2

Integrated care delivery at the primary/acute junction

Workstream 3

Scale-up regional multidisciplinary care programs

Cross-cutting theme 1: Citizen assemblies and consumer reference groups to strengthen participatory decision making in policy

Cross-cutting theme 2: Symposia to inform national primary and acute care data linkage

Workstream 1: Risk prediction and decision aids to support multidisciplinary care

Using Lumos to develop novel predictive models to underpin practical tools and resources to support care for people at high risk of chronic and complex conditions.

(1) Dynamic cardiovascular risk prediction: extending previous work

- Previous approach has been static, requiring fixed look-back & follow-up periods
- Aim is to develop and validate a dynamic on-the-fly approach based on whatever data is available at patient consult
- More realistic of GP-patient interactions to facilitate wider application

(2) Cognitive decline/dementia risk assessment

- Risk reduction and growing recognition of benefits of early diagnosis
- Existing tools are mostly questionnaire based and validated in cohort studies
- Can we accurately predict 10-year risk of cognitive decline and dementia using routinely collected data in primary care?

(3) Supporting end-of-life care using predictive modelling

- Early initiation of palliative care is associated with improved quality of life & reduced hospital use
- Predicting end-of-life is challenging in non-cancer conditions
- Can primary care records be used to predict when a person is entering the last 3-6 months of life in non-cancer conditions?

Workstream 2: Supporting integrated care delivery at the primary/acute care interface

What are the associations between primary care utilisation, hospital admissions, and emergency department attendances?

Three proposed areas of focus:

1

Do patients attending 'high connectivity' general practices have lower emergency department attendances?

2

Do patients with early post-discharge attendance at primary care have reduced unplanned hospital readmissions?

3

How do multiple long-term conditions impact acute care use & can measures of multimorbidity be incorporated into risk of hospitalisation calculators to facilitate multidisciplinary care planning?

‘High connectivity’ general practices

- There is a need for more robust and contemporary evidence on how primary care continuity influences health and health care outcomes
- This study will generate new evidence on how general practice attendance patterns influence acute care use

Early post-discharge attendance in primary care

- The transition between hospital and home is a vulnerable time for patients
- Multi-disciplinary care coordination required between patients/carers and hospital, general practice, and community care providers
- Some evidence that discharge planning and post-discharge interventions reduce readmissions but studies are of variable quality and small sample sizes

Impact of multiple long-term conditions (MLTCs) on acute care use

- Prevalence of MLTCs is rapidly growing
- Health systems that are specialised and disease-centric need to respond to changing demographic needs
- The addition of primary care data to hospital data could greatly improve our understanding of disease clusters & impact on care quality and utilisation

Do patients attending ‘high connectivity’ general practices have lower emergency department attendances?

1. Lumos used to identify a threshold for frequent attenders to general practice in NSW

- 12+ encounters was observed as the threshold for a frequent attender
- Which equates to 13.7% of the whole Lumos population

2. Data driven thresholds for defining “low-”, “medium-” and “high-” density frequent attender practices have been calculated

For the practices with data in LUMOS:

- 29% have a low % of frequent attenders (<9%)
- 37% have a medium % of frequent attenders (9-15%)
- 34% have a high % of frequent attenders (>15%)

3. Evaluate the impact of attending “low-”, “medium-” and “high-” density practices on health service utilisation patterns

Protocol in development (circulation October 2026)

Workstream 3: Scale-up regional multidisciplinary care programs

Aim: To understand the potential to spread and scale interventions and programs that have demonstrated value at local or regional levels.

One initial area of focus with others in development

Identify local diabetes and pre-diabetes programs designed to enhance multi-disciplinary, integrated care and prevention

Conduct analyses to determine if these programs are associated with with reduced acute care utilisation at the LHD/PHN level

What NSW Health already knows

Preliminary Lumos analyses already point to a substantial T2DM burden and strong variation by age, disadvantage and geography.

9.37%
Adult T2DM prevalence in FY23/24

26.5%
Prevalence in adults aged 80+

6.8–12.7%
Range across Local Health Districts

~2M
Adults in the Lumos denominator cohort

Age gradient

A steep increase with age: around 7.7% in adults aged 45–54 years versus 26.5% in those aged 80+.

Our proposal

To understand whether existing programs have been implemented in the right places, at sufficient intensity, and with measurable impact on care and outcomes

Diabetes programs

The project moves from program mapping to linked-data analysis to scale-up advice.

Phase 1 · Review

Identify recent diabetes programs (type 2, gestational, pre-diabetes) across NSW and build the implementation dataset needed for evaluation.

Phase 2 · Analyse

Use Lumos to profile people with type 2, gestational & pre-diabetes and assess outcomes in regions with different levels of program exposure.

Phase 3 · Translate

Turn the evidence into design guidance, cost insights and a practical case for scale-up.

Key question 1

Which program models are most scalable?

Key question 2

Do better-implemented regions achieve better outcomes?

Key question 3

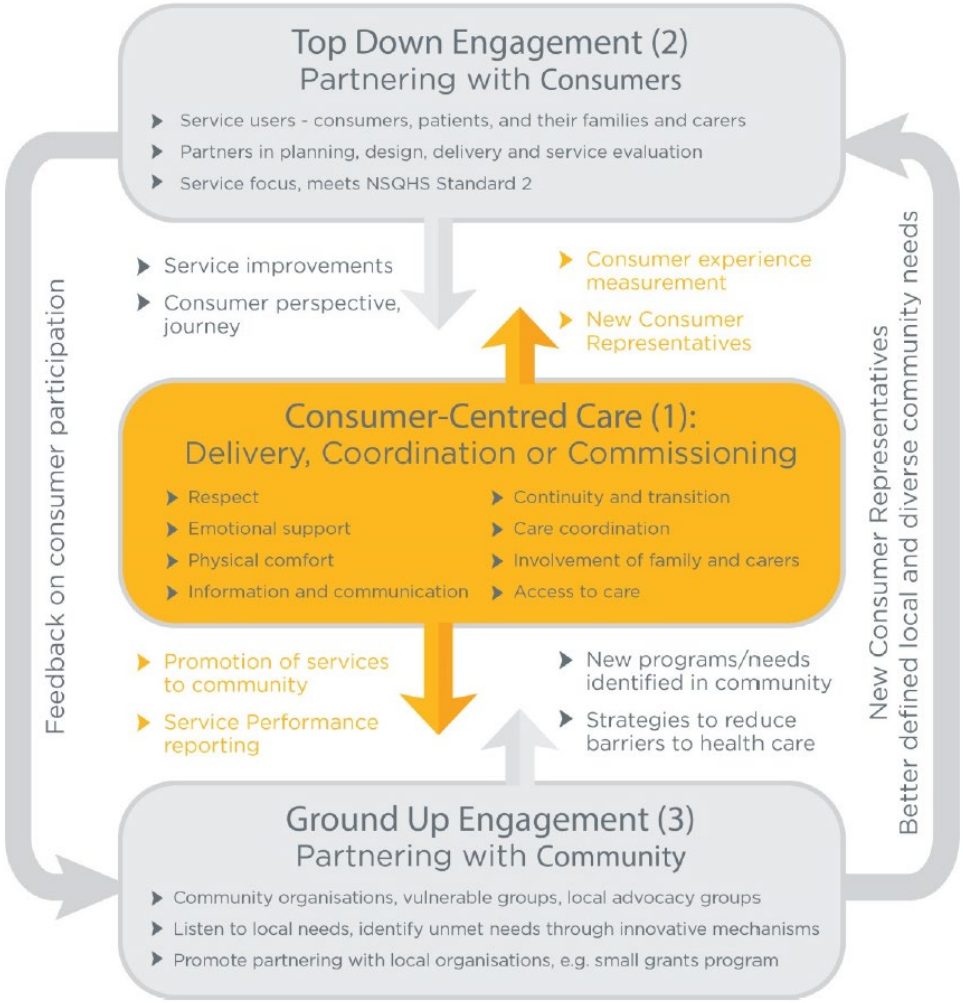
Where should NSW invest next?

Cross-cutting theme 1: Consumer reference groups and citizen assemblies to support participatory decision making in policy

Normative standards - The use of consumer and community involvement as a deliberative process for public decision making as recommended by the Organisation for Economic Co-operation and Development

Project governance - Consumer reference groups will critically appraise the 3 workstreams across the research lifecycle & make recommendations on study implications

Shaping public discourse - Citizen assemblies with diverse representation convened annually to contribute to national policy on linked data and inform the agenda for national symposia



Work to Date

First CRG Meeting (online) → Training Workshop → Report of Workshop outcomes → July CRG Meeting

Upcoming...

August CRG Meeting → October CRG Meeting → 1st Citizens' Assembly

Project Hub

- Glossary
- About the Project
- About data
- About Lumos
- Resource Library
- CRG resources

Glossary of terms

- Data terms
- Consumer & community involvement terms

Resource library

- Fact sheets
- FAQs
- Journal articles
- Glossary & Handbook

Will continue to evolve and grow

What is a Citizens' Assembly?

"A Citizens' Assembly is a group of people, selected by a lottery-type system, who are broadly representative of a community.

They spend time (often days or weeks) learning and collaborating through facilitated deliberation to find common ground and form collective recommendations for policy makers, decision makers, and the community.

These Assemblies are sometimes called Citizens' Juries, Panels, or Councils depending on their size, their role, and where they are taking place.

Project Context

NSW population	**~30 people**
2 days	**Annual (for life of project)**

Consumer Reference Group
=
Consumer views & insight

Citizens' Assemblies
=
Broader public views & insight

CRG involved in shaping Citizen Assembly topics

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Cross-cutting theme 2: National symposia to support integrated health care enabled by linked data assets

National Primary and Acute Care Data Linkage project is underway

We aim to conduct national symposia to support progress for national linkage with 4 focus areas:

1. Showcase insights gained from the three workstreams
2. Highlight similar work in other jurisdictions
3. Facilitate consumer and GP led deliberations
4. Invite international speakers to share their experiences of using national linked data assets

Thank you

More information:

John Mulley

Senior Project Manager, The George Institute

jmulley@georgeinstitute.org.au