Longitudinal Research Challenges: Lessons learned from our study of the impacts of a mass literacy campaign on the social determinants of Health
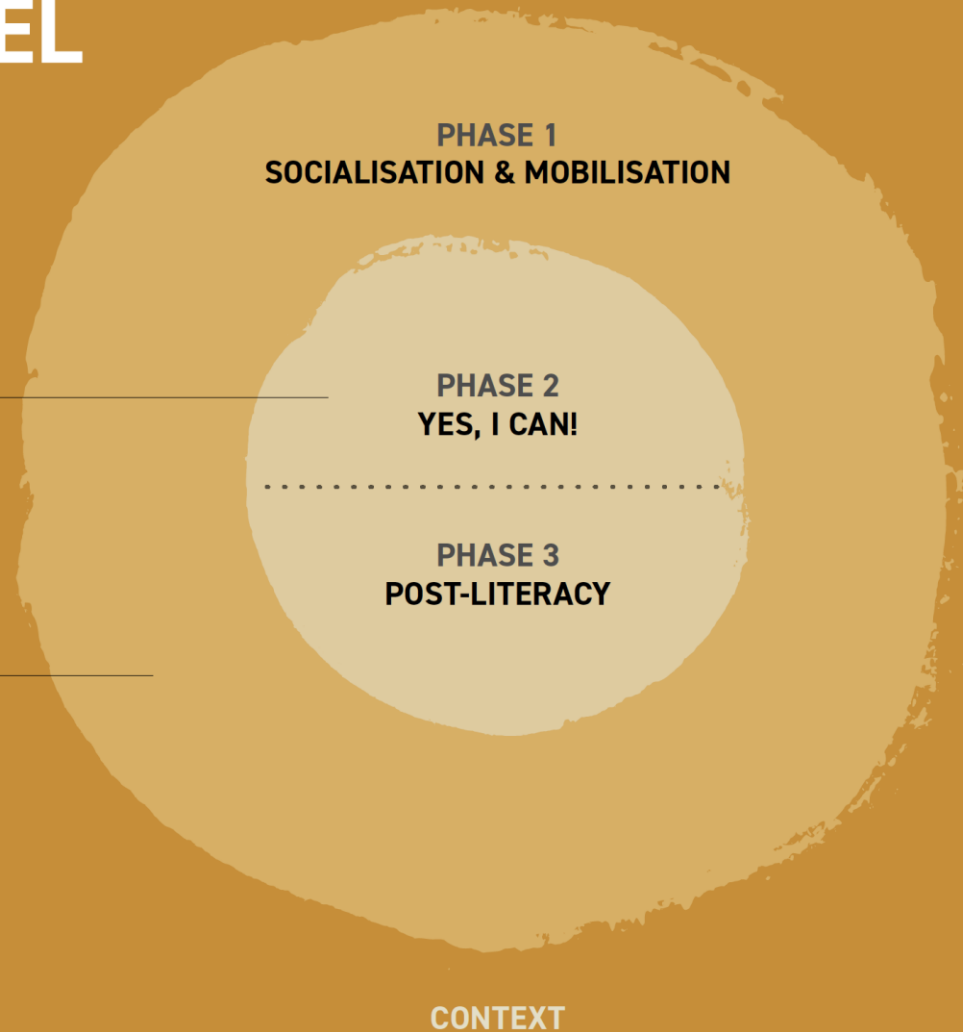
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THE MASS LITERACY CAMPAIGN MODEL

- Mass adult literacy campaigns have been a feature of independence struggles in the Global South
- Yes, I Can! developed in Cuba
- Has been run in 30 countries
- Basic literacy classes taught to 10 million people
- Local community takes control: Literacy is everyone's right, everyones business

PHASE 1
SOCIALISATION & MOBILISATION

PHASE 2
YES, I CAN!

PHASE 3
POST-LITERACY

CONTEXT

Campaign outcomes in Australia

- Ten communities have joined campaign
- 8 in NW NSW; 1 in outer Sydney; 1 in Central Australia
- 1300 adults have taken part in household survey/consultation re literacy needs
- Approx 70% have self-identified as having low literacy = Australian Core Skills Framework (ACSF) Level 1 & below)
- 385 people have joined the classes; 206 graduates as at December 2018, with 60 more expected by December 2019
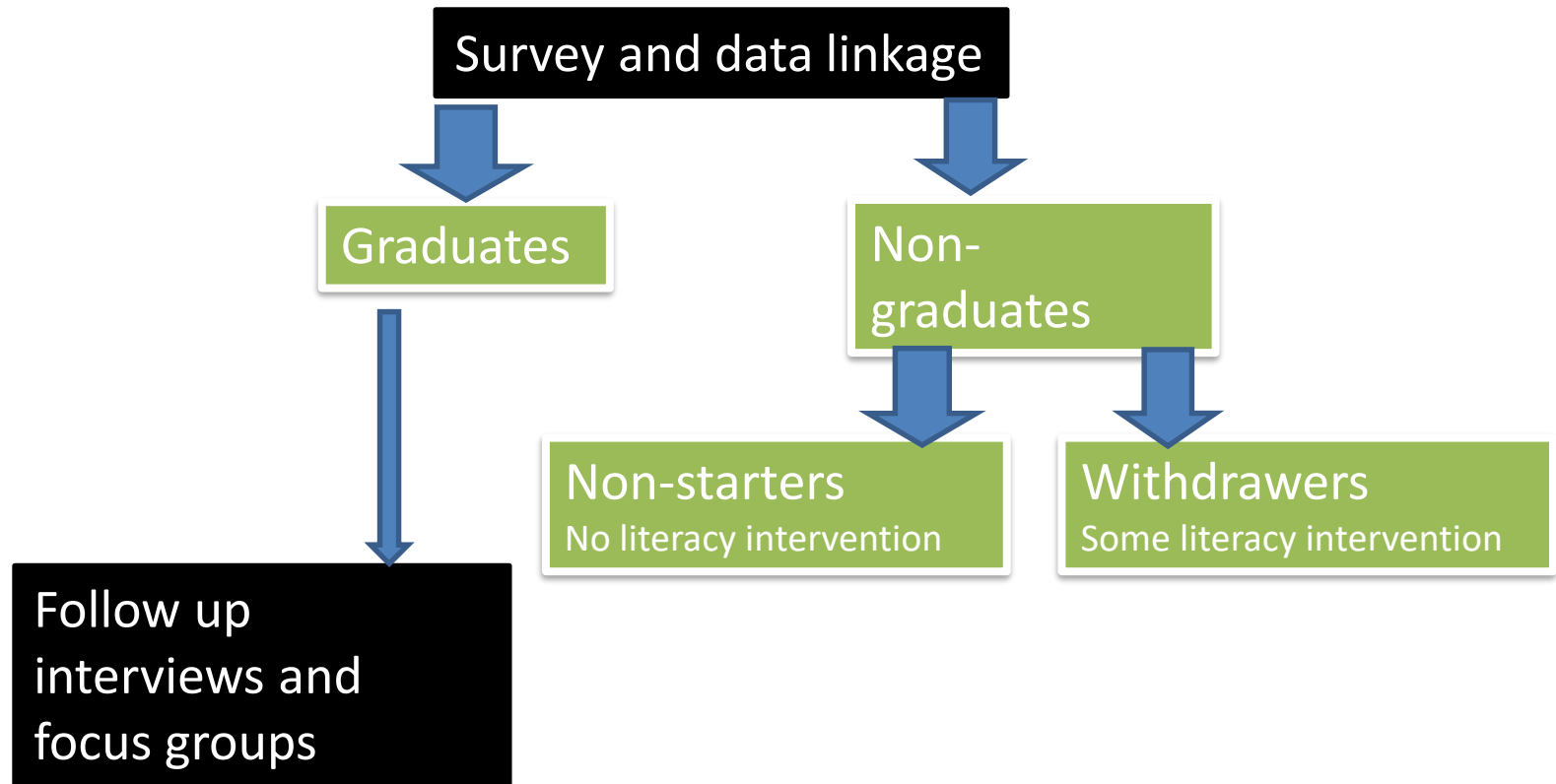- Graduation = L1/L2 on ACSF – still a long way to go

Building a research program

- Evaluation PAR integral to Cuban campaign model
  - Community household surveys, designed in consultation with community
  - Enrolment, attendance and outcomes data recorded by local staff
  - Interview with staff, participants, community leaders
  - Evaluation reportbacks to Community Working Group
  - LFLF data now covers period 2012-2019:
    - 10 communities;24 intakes; approx. 250 graduates; 1300 household survey participants including self-assessed literacy
- Evaluation research the base on which to build the longitudinal impact study

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ARC-funded Longitudinal Study

- Funded on 2nd attempt, for 3 years only 2016-2019
- Two indigenous partner organisations
  - LFLF & Lowitja Institute
  - 3 PIs, 2 Aboriginal, 1 non-Aboriginal
- Multi-disciplinary multi-institution academic team
  - UNE – 2 CIs, 1 Snr Research Associate , 1 Admin Offr
  - UNSW – 1 CI, 1 Research Associate
- Multi methods
  - Survey – n =200
  - Qualitative interviews & focus groups
  - Data linkage
- Five communities only
- Retrospective and prospective of participants; & a governance & organization study
- Budget ARC $440k; LFLF $44k

Longitudinal impact study

Impact survey

Category	Topics covered
Demographics	Gender, age, highest schooling level, highest post school qualification
Involvement in LFLF literacy campaign	YIC attendance, evaluation participation, experience
Further education and training	Current involvement in further education & training, now & in last 3 years; Further study plans
Employment	Current work status, including CDP; work aspirations; Financial stress
Children and schools	Children at home, reading habits with children , engagement in school activities
Housing	Housing tenure; housing conditions; housing management capacity
Community and governance	Membership & participation in local land council another community organisations and unions; confidence in speaking up; Voter enrolment & participation, State, Federal, Local; Political participation understanding and confidence
Connection with country and culture	Tribal/language affiliation; Aboriginal language knowledge & use; Participation on cultural activities
Health	Self-assessed physical health; Self assessed social & emotional wellbeing
Health care	Aboriginal Primary health care service utilisation; Other health service utilisation ; Experiences/ Attitudes regarding h health services; Barriers to health service utilisation
Drug and alcohol use	Use of drugs & alcohol – self and in community
Community safety	Perceptions regarding community safety; Experience of violence – self & community; Experiences with law and justice system; driving offences and other police charges, including offences
Self Efficacy	Sense of control; ability to solve problems; confidence
Literacy	Literacy practices including reading, writing and use of internet; Self-assessed literacy; Basic literacy task test – reading, writing & comprehension

Survey issues

- Questions had to align with other work, including ABS NATSIS for validity & comparability

- Wording of some questions too complex for some participants – "Break it down!"

- Intimidation because of history of "interrogation" by police, Centrelink, Jobnetwork etc

- Individualised method contradicted community ways of discussing – had to have other people around – a clash of 'logics' – social science logic versus community 'logic'/theory about how knowledge is created and communicated
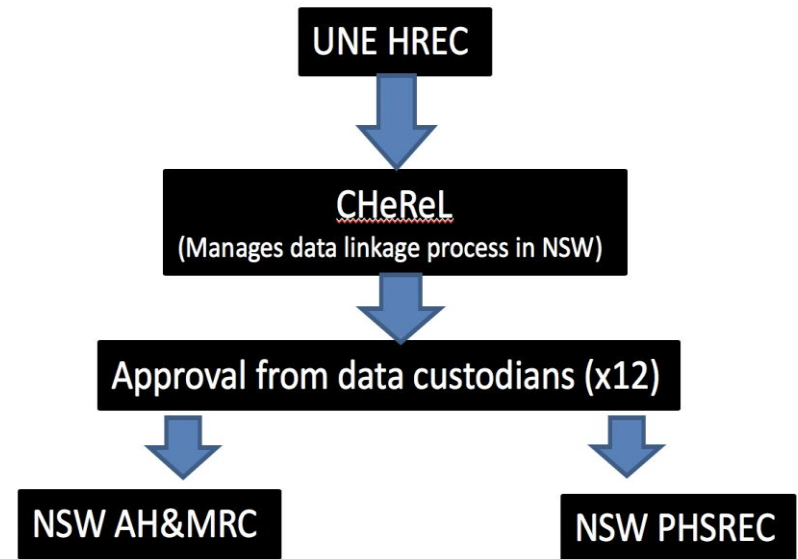

LFLF Community research assistant, Tannia Edwards from Enngonia, "breaking it down".

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If you think that was challenging, try doing data linkage!!!!

- Initial plan to compare our results with local area data from comparable communities and national data sets
- Not possible because small area data not released by ABS
- Decision to 'link' with data in NSW government agencies – health, justice education
- Requires new set of approvals from NSW Centre for Health Research Linkages, from data custodians and from 2 more Ethics Commitees

UNE HREC

↓

CHeReL
(Manages data linkage process in NSW)

↓

Approval from data custodians (x12)

↓   ↓

NSW AH&MRC   NSW PHSREC
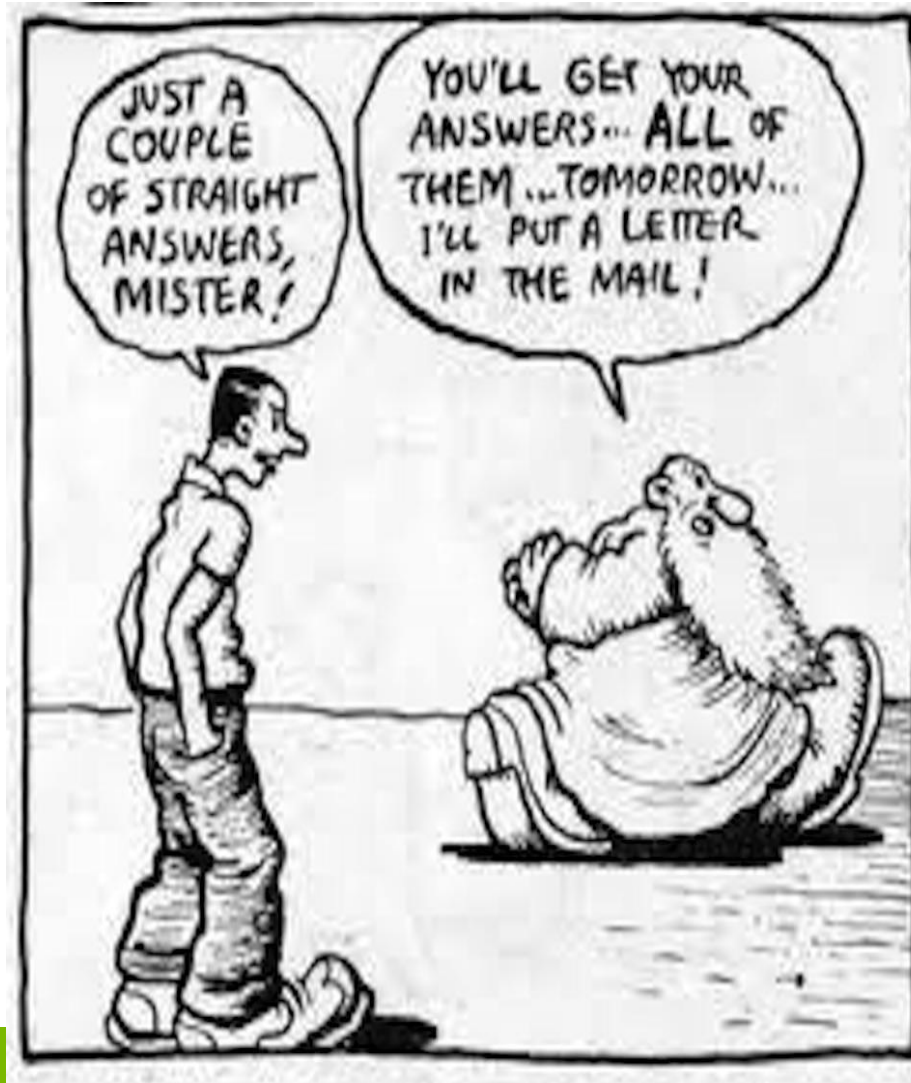
Data linkage datasets

- NSW Admitted Patient Data Collection;
- NSW Death Registrations;
- Cause of Death Unit Record File;
- NSW Perinatal Data Collection;
- NSW Emergency Department Data Collection;
- NSW Central Cancer Registry;
- NSW Notifiable Conditions Information Management System;
- NSW Mental Health Ambulatory Data Collection;
- NSW Pap Test Register;
- NSW Ambulance;
- BreastScreen NSW;
- and NSW Bureau of Crime Statistics and Research (BOCSAR).

But….(there's always a but!)

- Each body whose approval is required can direct the research team to make changes to the research protocols

AND

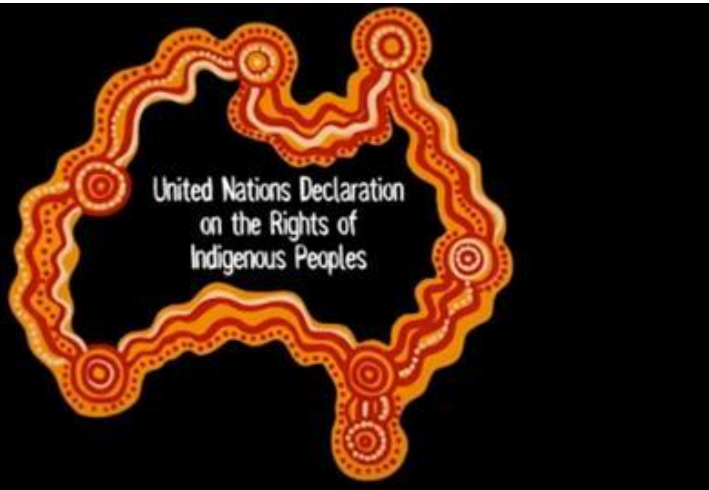- Each time this happens, UNE HREC has to re-consider this as a variation

The story so far

- 200 participants in the study have completed surveys & provided consent for their data to be linked
- Those process has final approval from the NSW Centre for Health Record Linkage (CHeReL), NSW AH&MRC & NSW Health Commission Ethics (& UNE HREC)
- Approvals have been gained from 8 data custodians to access these data sets:
  - NSW Admitted Patient Data Collection;
  - NSW Emergency Department Data Collection;
  - NSW Notifiable Conditions Information Management System;
  - NSW Pap Test Register;
  - NSW Ambulance;
  - BreastScreen NSW;
  - NSW Bureau of Crime Statistics and Research (BOCSAR); and
  - NSW Registry of Births, Deaths and Marriages.

BUT

- ARC Funding runs out in October, & CHeReL has now said there is a several month waiting list

DATA SOVEREIGNTY?

United Nations Declaration on the Rights of Indigenous Peoples

"And the right to:
- participate in decision-making affecting them (article 18)
- determine and develop priorities and strategies to exercise their right to development and be actively involved in developing, determining and administering programs (article 23)
- promote, develop and maintain institutional structures (article 34) for their own development and decision-making (articles 18 and 20)"

Source: Productivity Commission Evaluation Issues Paper June 2019, p.3

"Six foundational rights:
1. Individual and collective access to human rights;
2. Equality and freedom from discrimination;
3. Self-determination;
4. Self-governance;
5. Participation in the life of the State; and
6. Nationality."

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Conclusions

1. After more than thirty years of discussion and debate, non-Indigenous research institutions continue to be largely unaccountable to Aboriginal community-controlled organisations for the ways in which they supervise, regulate and direct research in Aboriginal communities.

2. This paper is not suggesting there is a simple solution. We are saying that no solutions will be found until the research community, seeking to improve programs and policy in the fields of Aboriginal development, acknowledges that there is a political problem at the heart of the ethical governance of research.

3. While the formal education system continues to fail to build the literacy of the majority of Indigenous students, none of these problems will be solved without a mass adult literacy campaign – as Cuba learned in 1961!