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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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, everyone's business.
Campaign outcomes in Australia

- Ten communities have joined the campaign
- 8 in NW NSW; 1 in outer Sydney; 1 in Central Australia
- 1300 adults have taken part in a household survey/consultation regarding literacy needs
- Approximately 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
ARC-funded Longitudinal Study

- Funded on 2\textsuperscript{nd} 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

Survey and data linkage

Graduates

Non-graduates

Follow up interviews and focus groups

Non-starters
No literacy intervention

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

Data Sovereignty?

“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
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!