Sharing Data When You Are Malcolm in the Middle

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The Logan Beaudesert area has the highest rate of risk factors of chronic diseases in Australia

1 in 4 people smoke

13% consume alcohol at a high risk level

60% are overweight

Planning problem

Volume of datasets

Disintegration of data sets (silos)

Lack of spatial context

Lack of collaboration in decision-making

Not using evidence in decision-making

Solution: Integrated datasets around location, pre-processed data and spatial analytical tools. Research: what are the right tools, right presentation and the right data
Health Profile Assessment framework

I. FUNDAMENTAL
(Macro level)
- Natural environment
  (topography, climate, water supply)
- Macro social factors
  - Historical conditions
  - Political orders
  - Economic order
  - Legal codes
  - Human rights doctrines
  - Social and cultural institutions
  - Ideologies (racism, social justice, democracy)
- Inequalities
  - Distribution of material wealth
  - Distribution of employment opportunities
  - Distribution of educational opportunities
  - Distribution of political influence

II. INTERMEDIATE
(Meso/community level)
- Built environment
  - Land use (industrial, residential, mixed use or single use)
  - Transportation systems
  - Services (shopping, banking, health care facilities, waste transfer stations)
  - Public resources (parks, museums, libraries)
  - Zoning regulations
  - Buildings (housing, schools, workplaces)
- Social context
  - Community investment (economic development, maintenance, police services)
  - Policies (public, fiscal, environmental, workplace)
  - Enforcement of ordinances (public, environmental, workplace)
  - Community capacity
  - Civic participation and political influence
  - Quality of education
- Stressors
  - Environmental, neighbourhood, workplace and housing conditions
  - Violent crime and safety
  - Police response
  - Financial insecurity
  - Environmental toxins (lead, particulates)
  - Unfair treatment
- Health behaviours
  - Dietary practices
  - Physical activity
  - Health screening
- Social integration and social support
  - Social participation and integration
  - Shape of social networks and resources available within networks
  - Social support

III. PROXIMATE
(Micro/interpersonal level)
- Stressors
- Health behaviours
- Social integration and social support

IV. HEALTH & WELL-BEING
(Individual or population levels)
- Health outcomes
  - Infant and child health (low birth weight, lead poisoning)
  - Obesity
  - Cardiovascular diseases
  - Diabetes
  - Cancers
  - Injuries and violence
  - Infectious diseases
  - Respiratory health (asthma)
  - Mental health
  - All-cause mortality
- Well-being
  - Hope/despair
  - Life satisfaction
  - Psychosocial distress
  - Happiness
  - Disability
  - Body size and body image
Example data use

Admissions to hospitals for depression vs mental health facilities – hot spot analysis
Example data use

Patients’ Behaviour – service utilisation

Legend
- Major CHC
10 minutes travel time (by car) from the CHC
- Beenleigh - 10 min catchment area
- Inala - 10 min catchment area
- Logan Central - 10 min catchment area
- QEII - 10 min catchment area

Travel of Patients to Community Health Centres

Author: Ori Gudes
Date: 18/07/2012

1 centimeter = 2,000 meters
1. Moral Rights Consent / IP Licence
2. Contributor’s Agreement
3. Subscription Agreement
4. Terms of Use
They must have clear IP
They must not breach laws by giving to us
Our use doesn’t breach moral or other rights of third parties from whom they collected data
There are no other restrictions on the use by us
They warrant that data it is accurate, complete and suitable for our purpose
Integrity of any 3rd party data collected by them
Comply with human ethics (NMHRC) and Australian Code of Responsible Conduct of Research
any personal information within
State or Cwlth retention restrictions
< 18 years suitability
Any other rules/regulations
Any IP or fees involved
Who is able to view data
Contributor’s Agreements
Checklist – Host’s Position

- Our rights to annotate/enhance
- Contributor to obtain moral rights clearance
- Our rights on how it will be used (if at all)
- Our obligations to maintain integrity of data and use as per our licence
- We are indemnified if a third party makes a claim against us in relation to data provided
- We are not liable for how data is used
Both parties have rights to remove
Outline termination terms
Definitions/Glossary
Schedule - describe the data in question
Attach moral rights consents, etc
End User’s Agreement

Checklist – Usage

☐ User to acknowledge the rights of the data “owner”
☐ Specify users variable rights e.g. to copy/reproduce, adapt, display etc
☐ Specify exclusions e.g. commercial use or sub-license
☐ Individuals must be > 18 years
☐ Our right to suspend/deny access
☐ Any fees involved
☐ Our right to update any material without notice
Use of the service/repository is “as is” e.g. we make no representation/warranty about accuracy, legality, content, quality of data

Exclude any implied terms, representations and warranties (to extent law permits us to)

User will indemnify us in relation to:
- Claims against us about user’s use
- Any claims by other persons as a result of their use
End User’s Agreement
Checklist for an Institutional Subscription

- Ensure only authorized users access data
- Only use data consistent with the access agreement
- Can’t use data for unethical, unlawful, illegal etc
- Proper acknowledgement when using data
- Sensitive material to be kept confidential
- Reasonable data security
- No hacking or disruptive activities
- Adherence to national privacy laws
- Users behavior governed by employee/agency laws
- You tell us who will be using and level of access
- Any Fees
- Defined Service Levels
Written Agreements

Why have them?

- Limit liability
- Clear communication of intent
- Clear communication of responsibilities
- Exit strategy / termination
- Accountability
- Legal certainty
- Clarity of IP ownership
Agreements

Final comments

- Developing agreements
  - who needs to be involved,
  - how to get started and lead-in times,
  - potential problems,
  - start up timing with the project
- Broader Policy Issues - repository closure
- Who to sign a written legal agreement
- What happens when cloud services are used
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QUESTIONS?

This presentation contains general information only, not legal advice.