

Data ownership and use

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Why is it important?

- Benatar and Singer[[1](#)] proposed “a new, proactive research ethics... must ultimately be concerned with reducing inequities in health and achieving justice in health research and health care”

Data ownership agreement

- The main purpose of any agreement about data ownership is to maximise community benefits associated with any research enterprise without compromising:
 - Original ethics approval
 - Technical standard of what is produced

Types of data

- Primary data
- Secondary data

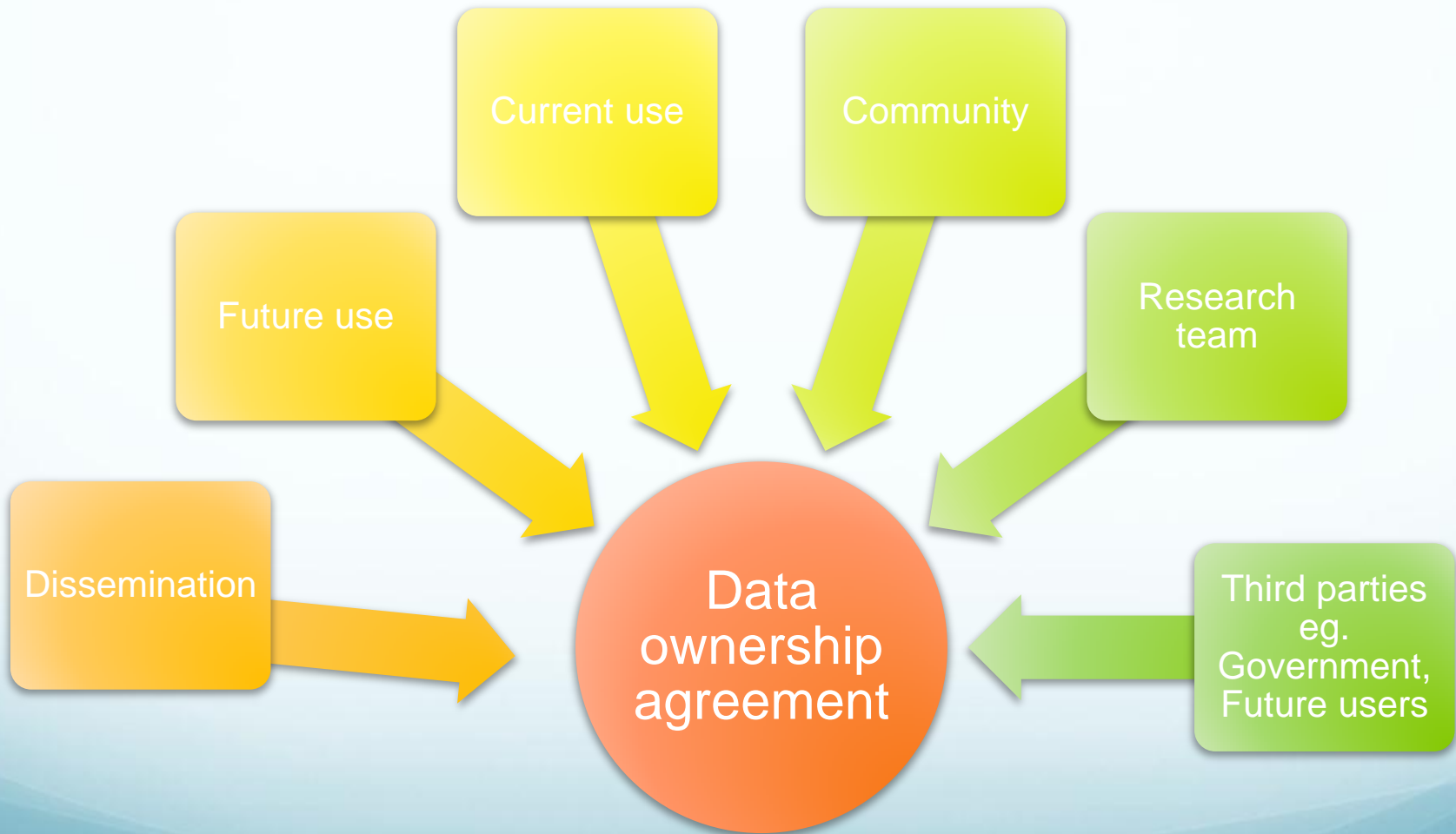
Principles

- Community should determine:
 - Data storage
 - Data access
 - Data use
 - Dissemination of results
 - Knowledge transfer

Primary data

- What agreements already exist?
- Who is the data ownership agreement with?
- Who constitutes community?
- What existing mechanisms are there to support the agreement?

Primary data



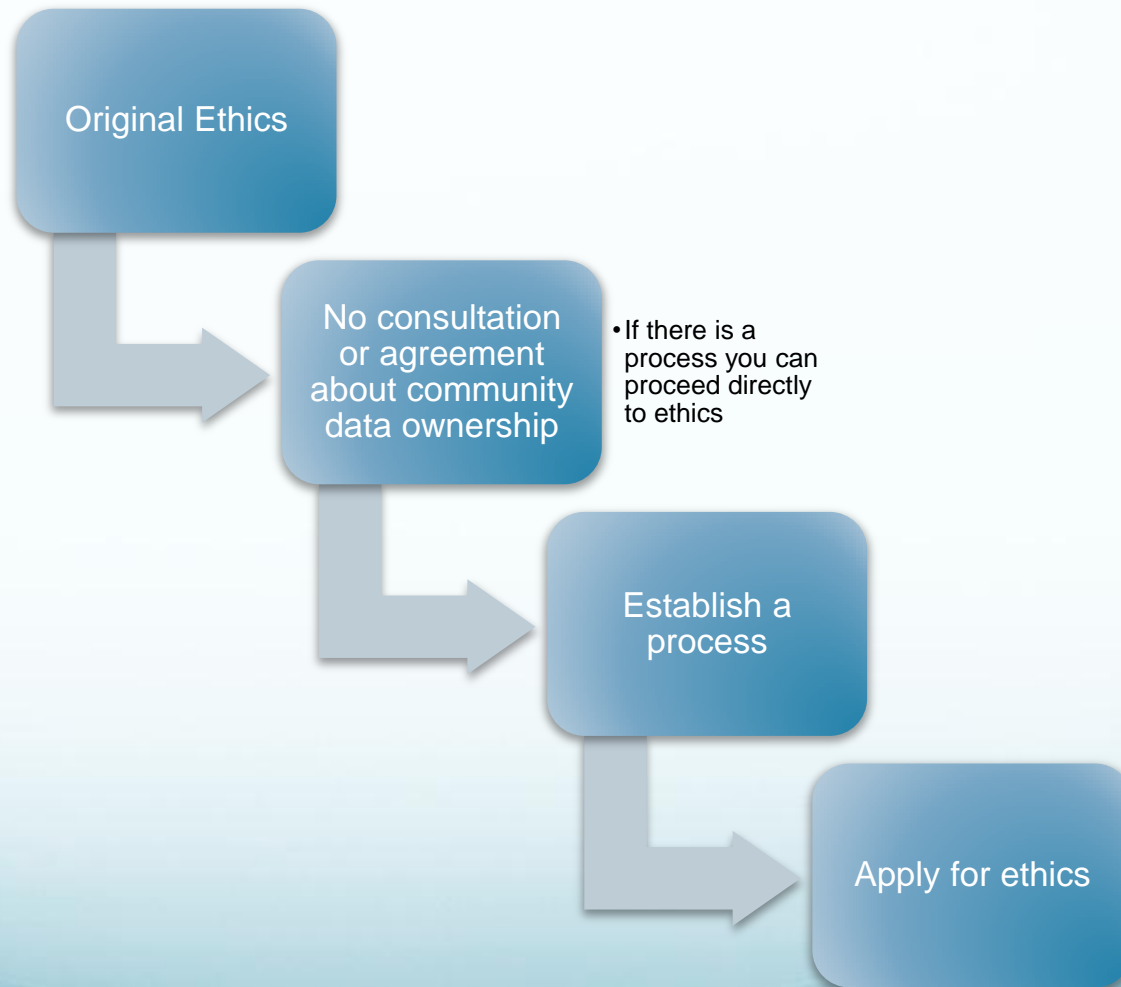
Examples

- Best Start
- Heart project
- Localities Embracing and Accepting Diversity

Secondary data

- Data collection has already occurred
- Agreement is with the data custodian

Secondary data



Adaptive policy

- Data ownership arrangements need to be adaptive in order to meet community needs
- This means that creating mechanisms to revisit arrangements when circumstances change