How do we address the ethical challenges of archiving and re-using qualitative research data?

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ARCH

Applied Research on Communication in Health

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Background

23rd PUBLIC HEALTH
SUMMER SCHOOL
UNIVERSITY OF OTAGO, WELLINGTON

Is it appropriate to archive qualitative (health) data for unspecified future use?

Shift in expectations:



What are the ethical questions and challenges that arise? How might these be addressed?





The nature of qualitative research

Re-use: using data for purposes different from those for which it was originally collected

- Methodological issues: diversity, context & interpretability
- Trust & relationship with participants
- Rights and duties
- Risks and opportunities
- Technical & logistical challenges
- Governance

Broadening the ethical debate



"The debate about ethical re-use needs to be deepened and broadened"

Participant rights

BUT also recognition of other entities

- scholarly community (transparency, professional standards)
- the public (openness, use of public funds

Duties to participants (confidentiality, consent, trust, not mis-representing data)

BUT also minimising burden, respecting altruistic motivations, making diverse perspectives visible, 'adding value'

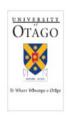
Bishop 2009

Practical considerations



- Considering the whole research journey
- Documentation
- Support for archiving
- Sustainability & governance

ARCH CORPUS OF HEALTH INTERACTIONS



http://tinyurl.com/ARCH-Group



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- A searchable collection of video-recorded health interactions and associated data
- Held at Otago University, Wellington in New Zealand
- Data collected progressively since 2004
- Data & derived resources archived (with consent) for future re-use in research and education.
- Restricted access authorised researchers/educators only







DESIGN PRINCIPLES

Central aims:

- facilitate re-use of data by researchers from a variety of academic/clinical disciplines
- enable micro-level interactional analysis (including CA and interactional linguistics)
- provide research-based resources for health professionals, clinical educators and patient groups

'Evolution by design':

 a 'living database' - has 'grown' organically as an additional output from successive research projects (no funding purely to create a data resource)



Sound, ethical data management:

- A Governance Group oversees access to and uses of the ARCH Corpus
- Balancing: ethical imperatives (maintaining confidentiality/anonymity, data security, respect for contributors, academic fairness); and making the best possible use of this valuable resource.



Online resources/modules, re-usable 'learning objects', training courses, brief interventions, reports, website

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COMPOSITION

Primary audio-visual data

478 consultations/health interactions

156 related research interviews

Involving:

533 participants:

Patients * GPs, nurses, surgeons, specialists, allied health professionals * other participants e.g. interpreters, family

38 health care sites

General practices, community clinics, hospital settings

77 'standalone' research interviews & focus groups

Audio and video recordings

Content summaries

Timed content/action logs

Base transcripts (orthographic plus

key interactional features)

Selected CA transcripts

Verbatim transcripts (interviews)

Derived clips and extracts

Case inventories (longitudinal data)

Other ethnographic & contextual data

Participant information

(Demographics & background information, 'on the day' consultation notes, referral letters)

Field notes

(Site descriptions, incidental observations, photos, informal 'debriefs')

Documents

(Clinical protocols/templates/guidelines, patient education materials)

Administrative data

Consent details (per project & per individual participant)

Data set information (linked files & information)

Data processing history (dates, formats, versions)





'KAUPAPA' (GUIDING PRINCIPLES) FOR THE ARCH GROUP

Kaupapa: a Māori word roughly glossed as 'the guiding philosophy and principles that inform a group's customary ways of doing things' (Royal 2017)

- Central importance of trust and respect in:
 - our relationships with research participants and stakeholders
 - the way we manage the data they have gifted to us
- These principles are reflected in:
 - close attention to how we go about collecting data, and how it is stored, analysed, interpreted and used;
 - a constructive 'appreciative inquiry' approach (Dick 2004) that we apply at all stages of the research process, especially in the dissemination of findings
- Our aim is to engage in 'research for and with' rather than 'research on' by:
 - actively maintaining a two-way dialogue with health professionals, patients/service users
 - contributing to the shared practical goal of improving health.





ETHICAL CONSIDERATIONS

- Establishment of clear ethical & methodological principles from the outset
- These continue to evolve & to guide ongoing development & use of the corpus
 - ethical & methodological implications of archiving data for unspecified future use **in addition to** meeting the research objectives of a given study
 - added complexity of research design & ethical review processes for individual projects
 - access management & ethical review for secondary data uses
- Ethics committees need reassurance that:
 - video-recording health consultations is an acceptable methodology; AND
 - there are good reasons for retaining material beyond the life of a specified project
 - both were unusual in health research at that time we began such sensitivities now re-emerging
- Essential to demonstrate carefully considered protocols in place, to ensure that we:
 - met medico-legal requirements (e.g. patient confidentiality),
 - would not unduly disrupt 'practice as usual',
 - could address perceived reputational risks to individual practitioners or health professional groups
- These points were also crucial to gaining the trust and willing participation of healt providers and patients in our research





Understanding Communication in Primary Health Care

Consent form for Clinicians

P	Please tick Yes or No for each item:								
1.	 I agree to take part in this study. I have read the Information Sheet concerning this study and understand the aims of this research project. 								
2.	I have had sufficient time to talk with other people of my choice about participating in the study.								
3.	. All my questions about the project have been answered to my satisfaction. I understand that I am free to request further information at any stage.								
4.	I know that my participation in the withdraw from the project at any								
5.	I agree to having my interactions with participating patients recorded on video and audio devices. I understand that the recording will be transcribed.								
6.	I agree that the researchers may make a copy of the medical records associated with the consultations recorded for the purposes of this research, with the consent of the patients involved.								
7.	I agree to having a short inte researcher recorded on an audio d								
8.	 I agree that the researchers may use the material collected for research and educational purposes, including publications and presentations. 								
9.	 I understand that information about me collected as part of this study is confidential, and understand that any material which could identify me will only be used with my explicit consent (see separate consent form) 								
10	10. I agree that my information may be included in a permanent archive to provide a corpus of health communication data for research or educational purposes. Any new projects using this permanent archive will be approved by an accredited research ethics committee.								
Si	igned:								
N	ame:		Date:						
A	Address:								
P	hone: (Cell)	(Home)	(Work)						
E	Fmail:								
N	ame of person taking consent:		Date:						
_	Admin use only	Date: Pa	articipant code:						





YES NO

Understanding Communication in Primary Health Care

Consent form for use of data in an on-line educational resource

1.	I understand that this form refers to video and audio recordings collected by the research team as part of a study of communication in primary health care.				
2.	I consent to having selected clips and corresponding transcripts made available as an on-line resource in the following format. (Please tick all or any that apply):				
	Video-recording - original, unanonymised, plus transcript				
	Video-recording – made anonymous (faces blurred), plus transcript				
	Audio-recording – not changed, plus transcript				
	Audio-recording – made anonymous (sound changed), plus transcript				
	Written transcript only				
3.	 I have had the opportunity to discuss the implications of being identified in an on- line resource with the researcher, whanau/family and friends and/or my colleagues in the practice team. 				
4.	4. I understand that the University of Otago Wellington will hold copyright over all material published on-line including my data. This means data cannot legally be reproduced by anyone else without our permission, and my data will only be used in the manner set out above. I accept that it may not be possible to prevent the making of unauthorised copies of material published online.				
Signed: Name: Date:					
Name of person taking consent: Date:					
Na	me of person taking consent: Date:				



GOVERNANCE OF DATA ACCESS & RE-USE

- A Governance Group currently oversees access to and uses of the ARCH Corpus, guided by a set of protocols, & subject to approval by an accredited health research ethics committees
- A conservative approach to data security and access, and to the video data in particular.
- With advances in information technology it is now easy to move and copy large digital files, so stringent processes are required to ensure confidentiality and prevent accidental 'escape' of the data.





GOVERNANCE OF DATA ACCESS & RE-USE (2)

- Access to Corpus data by people outside the core ARCH Group research team is restricted to the data subset actually required to complete their project
- Everyone who does access the data (researchers and project staff, associate and student researchers) is required to sign and abide by a confidentiality agreement, and must agree to strictly follow agreed data-handling protocols to ensure the confidentiality and security of the data at all times.
- Current practice is that even in settings such as one-off professional or academic seminars and workshops we generally play only selected anonymised excerpts, unless we have asked for and received explicit permission to do so from the participants, and we do not circulate full transcripts or other documentary material in such contexts
- The ARCH Governance Group reserves the right to review and exercise sign off on any publications, presentations or other outputs based on data held in the ARCH Corpus to ensure that the conditions of use have been met and that the work is consistent with the overall philosophy of 'appreciative inquiry' and respect for our research participants



Applied Research on Communication in Health
WELLINGTON SCHOOL OF MEDICINE AND HEALTH SCIENCES
DEPARTMENT OF PRIMARY HEALTH CARE AND GENERAL PRACTICE

CONFIDENTIALITY AND DATA USE AGREEMENT

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I understand that this confidentiality and data use agreement applies to all information I have access to while working with audio/video recordings or any other data collected as part of ARCH group research.

I agree to keep all information confidential and to securely store and transmit any digital or paper files in my possession, in accordance with the following:

- 1. ARCH data access and handling protocols
- 2. Specific conditions of use for this project / dataset
- 3. Approval(s) given by the relevant Ethics Committee(s)
- Privacy Act 1993 and Health Information Privacy Code 1994 (these requirements are encompassed in the ARCH Corpus protocols in (1) above).

If I find any information I see or hear is affecting me personally in such a way that it is in my interests to talk to someone, I agree to discuss this with a member of the research team.

Purpose of access to data:

Data provided: As listed overleaf (See Specific Conditions of Use over page)

Access period:

Name Institution	Witness	
Signature	Signature	
Date	Date	



Specific Conditions of Use

ARCH Corpus: Protocols Governing Data Access and Data Handling

- 1. Access to data
- 2. Data handling
- 3. Dissemination of data
- 4. Intellectual property



Discussion



- Is there an ethical difference between archiving/re-using qualitative data and other kinds of personal data?
- Do you agree that "too much emphasis on rights risks neglect of corresponding duties"?
- Who should be able to use what data for what purposes and who should decide?