

# An Online Consent Maturity Model

moving from Acceptable Use towards Ethical Practice

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[paper](#)

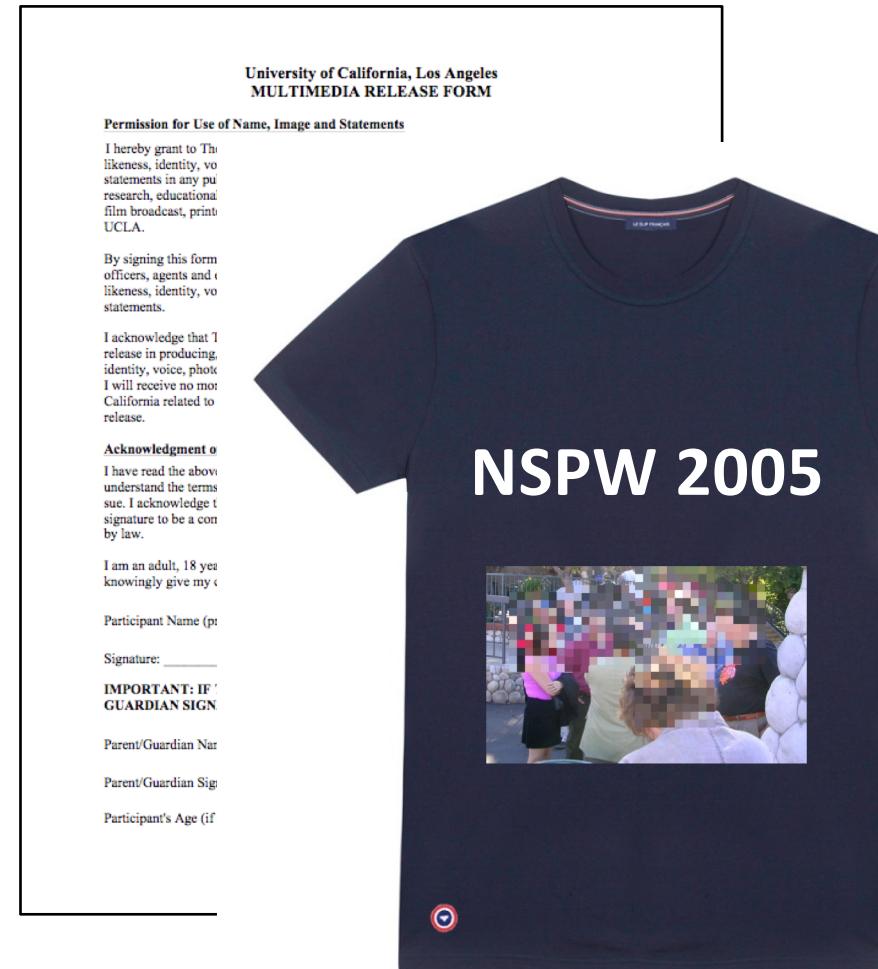
# NSPW Past

UCLA Conference Center at Lake Arrowhead, Sept. 2005



# Dilemma: is it OK to use the photograph?

- A good cause: T-shirt sales fund NSPW reception.
- Acceptable use agreed, 2005.
- Check with everyone: T-shirt OK?
- What about a tagged photo?
- What's the right thing to do?



# What is this data activity like?

## Online [data] analytics

- Gather
- Retain
- Analyse, Link
- Use results
- Consequences
- What's the right thing to do?



## Psychology (qualitative) research

- Gather
- Retain
- Analyse, Link
- Use results
- Consequences
- What's the right thing to do?



**What can we learn about ethics from qualitative research?**

# Qualitative research methods in Psychology

- Understanding how people make sense of their world
  - Human experience of technology
  - Use Qualitative Research Methods
- 
- What about ethics?



# Consent: a utilitarian view

- Moral action judged on its benefits  
Shipwrecked sailors choose cannibalism to survive  
[R v. Dudley and Stephens 1884 QBD 273 DC]
- Milgram's priority was the study of obedience
- Data Initiatives: public interest outweighs consent  
  
*"Your information will continue to be made available only to bona fide researchers undertaking health research that is in the public good"* [UK Biobank]
- The end justifies the means



Public Announcement

WE WILL PAY YOU \$4.00 FOR  
ONE HOUR OF YOUR TIME

**Persons Needed for a Study of Memory**

\*We will pay five hundred New Haven men to help us complete a scientific study of memory and learning. The study is being done at Yale University.  
\*Each person who participates will be paid \$4.00 (plus 50¢ carfare) for approximately 1 hour's time. We need you for only one hour; there are no further obligations. You may choose the time you would like to come (evenings, weekdays, or weekends).

\*No special training, education, or experience is needed. We want:  

Factory workers	Businessmen	Construction workers
City employees	Clerks	Salespeople
Laborers	Professional people	White-collar workers
Barbers	Telephone workers	Others

All persons must be between the ages of 20 and 50. High school and college students cannot be used.

\*If you meet these qualifications, fill out the coupon below and mail it now to Professor Stanley Milgram, Department of Psychology, Yale University, New Haven. You will be notified later of the specific time and place of the study. We reserve the right to decline any application.

\*You will be paid \$4.00 (plus 50¢ carfare) as soon as you arrive at the laboratory.

TO:  
PROF. STANLEY MILGRAM, DEPARTMENT OF PSYCHOLOGY,  
YALE UNIVERSITY, NEW HAVEN, CONN. I want to take part in  
this study of memory and learning. I am between the ages of 20 and  
50. I will be paid \$4.00 (plus 50¢ carfare) if I participate.

# Consent: a legalistic view

- Adhere to contract.

A one armed swimmer is disqualified from their win as 'hands' must touch the pool wall.



- Ethnography of village life: consent makes objectification of peoples' lives OK.



- Online: the contract tells you everything

*"We provide clear descriptions of these tools, and robust controls so people can turn them on or off, and delete their histories at any time"* [Google]

- Contract followed, independent of outcome.

Date \_\_\_\_\_

CONSENT TO USE INVESTIGATIONAL DRUGS

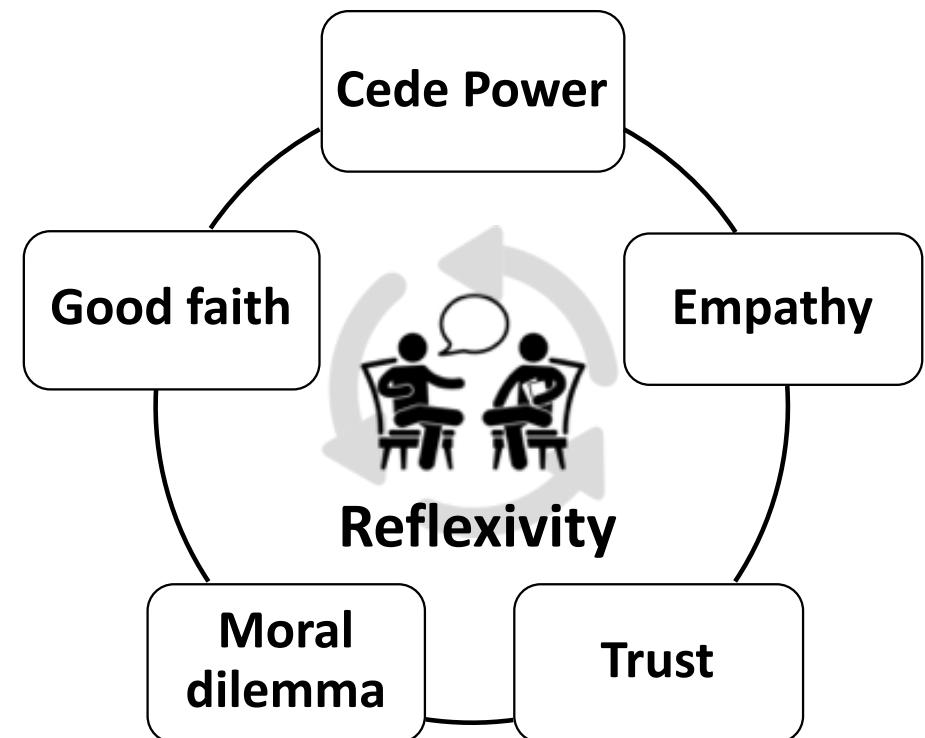
I agree to participate as a subject in the investigation of a drug(s) being evaluated in The Johns Hopkins Hospital, and have been informed as to the nature of the investigation.

Patient's Printed Name and Signature,  
History Number or Address; Parent or  
Guardian

Physician's Signature

# Consent: an ethics of virtue view

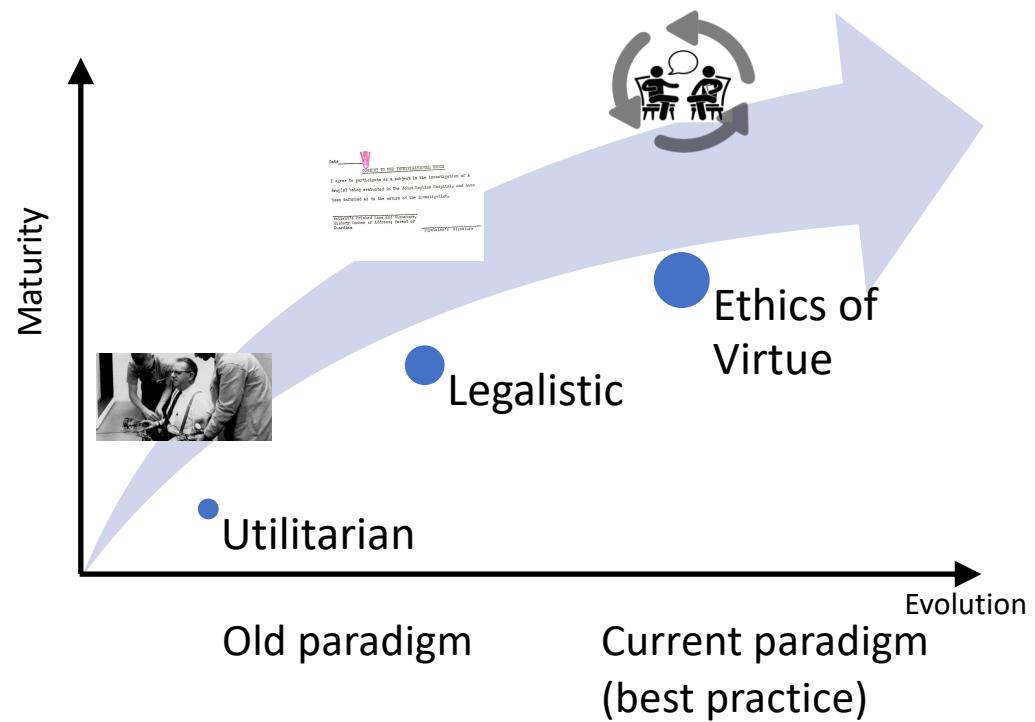
- Aspire to the ideals of human dignity and autonomy
  - Dealing with dilemmas
- Ongoing participatory process
  - Symmetry of power
  - Treat the data as if it's about you
  - Be honest and transparent
  - Always question the use of data
  - Account for everything you do
- All decisions foreground the human.



# Evolution of ethical practice

in Qualitative Research

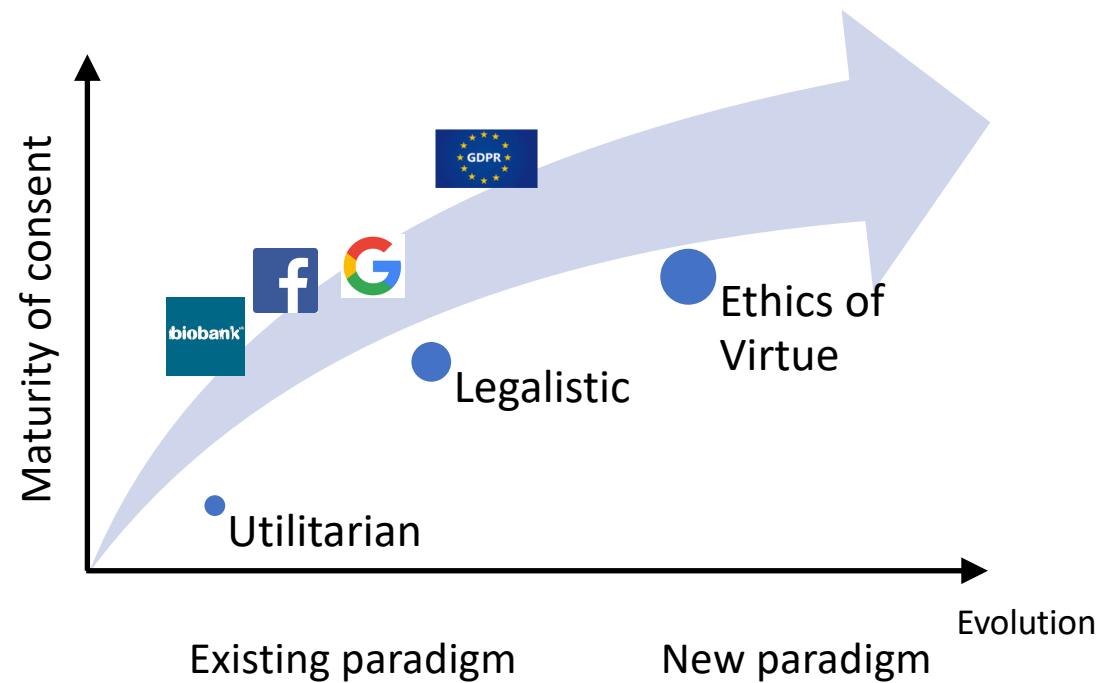
- Utilitarian
  - There's a common good
- Legalistic
  - I've applied the rules
- Ethics of virtue
  - Human centred consent



# Trajectory for consent

in online analytics

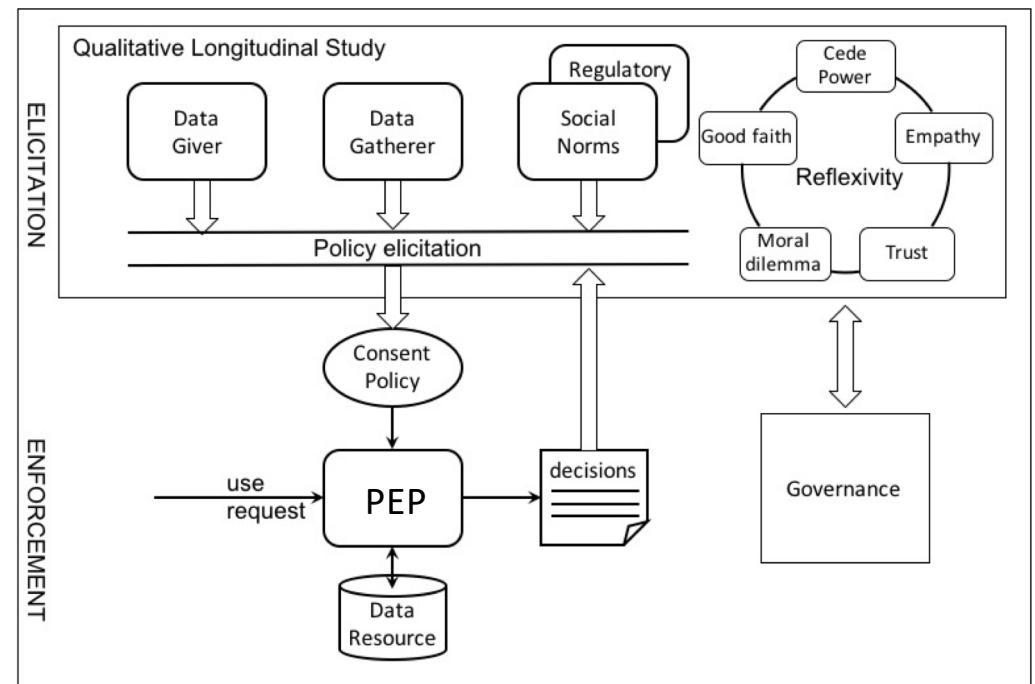
- Utilitarian
  - There's a common good
- Legalistic
  - I've applied the rules
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  - Human centred consent



# Towards 2038: human-centred consent

The new paradigm

- Data scientists work with data
- Applied Psychologists (data controller) work with people to find out how they make sense of their world/data.
- Cognisant of evolving social norms, regulations, etc.
- How will it scale?



# In the meantime ...

A capability maturity model for consent

- How can I judge my treatment of informed consent?
- What are my practices around managing consent: initial consent, altering consent, withdrawing consent, ongoing consent, further consent
- What are my practices around the data and relationships: explaining purpose, maintaining contact, withdrawing data, data reuse, data linking, trust, reflexivity.

Criteria	Description	Consent Maturity Levels		
		Utilitarian	Legalistic	Virtue
Initial Consent	Agreement to participate	Opt-out	Opt-in	Opt-in, includes cooling-off period, following which a confirmatory opt-in is required, otherwise refusal is presumed
Altering consent	Modification of the agreement	Not facilitated	Possible, onus on participant to discern procedure	Offered regularly and easily achieved
Withdrawing consent	Revoke the agreement to participate	Not facilitated	Possible, onus on participant to discern procedure	Offered regularly and easily achieved
Scope of initial consent	What is encompassed by any initial agreement	As broad as possible: interpreted inclusively	Interpreted in terms of what is reasonable or in the interest of the common good	Limited to what was conveyed initially: interpreted strictly, erring on the side of exclusion
Ongoing consent	Consent is a process throughout the duration of a project	To be avoided	Avoided, consent is revisited in a strictly formal manner, adhering to the provisions of any agreement	Participants are routinely consulted, reminded of the options available to them, such as withdrawal. Changes in consent are easily achieved.
Further consent	Consent is sought for any further or secondary analysis, Data Initiatives.	Opt-out, covered by initial consent, and if necessitated by legal provisions,	Opt-out, adheres to strict legal requirements.	Opt-in; a lack of response from participants to a request for further consent is regarded as a refusal.

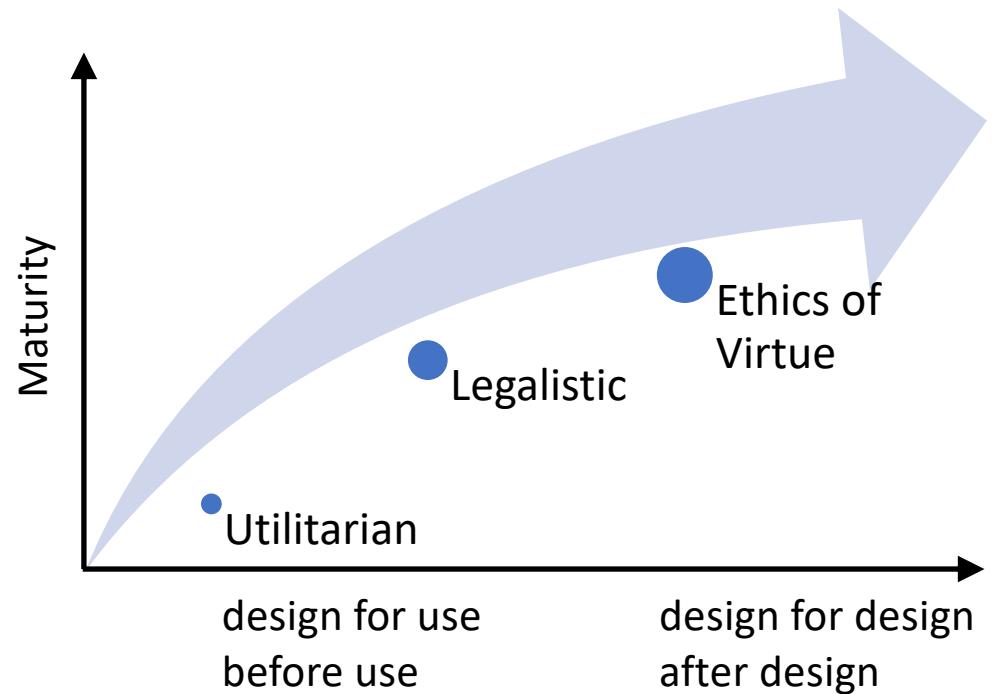
Criteria	Description	Consent Maturity Levels		
		Utilitarian	Legalistic	Virtue
Explanation of project	Comprehensive and relevant information provided	Minimum provided at outset	Specified precisely in legalistic language	Elucidated clearly and accessibly, including possible consequences, updated as necessary, questions invited.
Informing participants	Participants are kept up to date about the project and informed of what emerges from data analysis	Not necessary.	Not envisaged, to be excluded from any agreement with participants	Communicated to participants in an accessible way, along with appraisal, including start and completion date of analysis. Response is invited, and taken on board.
Withdrawing data	Partial or complete withdrawal of data	Not facilitated	Possible, onus on participant to discern procedure	Offered regularly and easily achieved
Reuse of existing data sets	Existing data is subject to secondary analysis, such as Data Initiatives	Acceptable	Allowable if deemed to be in the interest of the common good and/or in line with current social norms	Not envisaged: once initial purpose is complete, further use requires consent 'ab initio'
Linking of data sets	Data Sets can be linked for analytic purposes	Acceptable	Allowable if deemed to be in the interest of the common good and/or in line with current social norms	Not envisaged: once initial purpose is complete, further use requires consent 'ab initio'
Trust	Mutual trust is built and maintained through fostering openness and equity	Not envisaged.	Not envisaged, access to information available as required by legal agreement.	An intrinsic part of the approach, including easy access to information regarding past data breaches, remedies implemented, a history of the organisation's activities.
Reflexivity	Engaging in ongoing critical self-analysis of the project to improve and adapt	Not considered	To be avoided, as required by legal provisions	Intrinsic to the approach, including challenges/difficulties with the substance and procedure of the project, decisions taken are subject to scrutiny by interested parties, stakeholders and participants

# Human centred consent in 2038

for online analytics

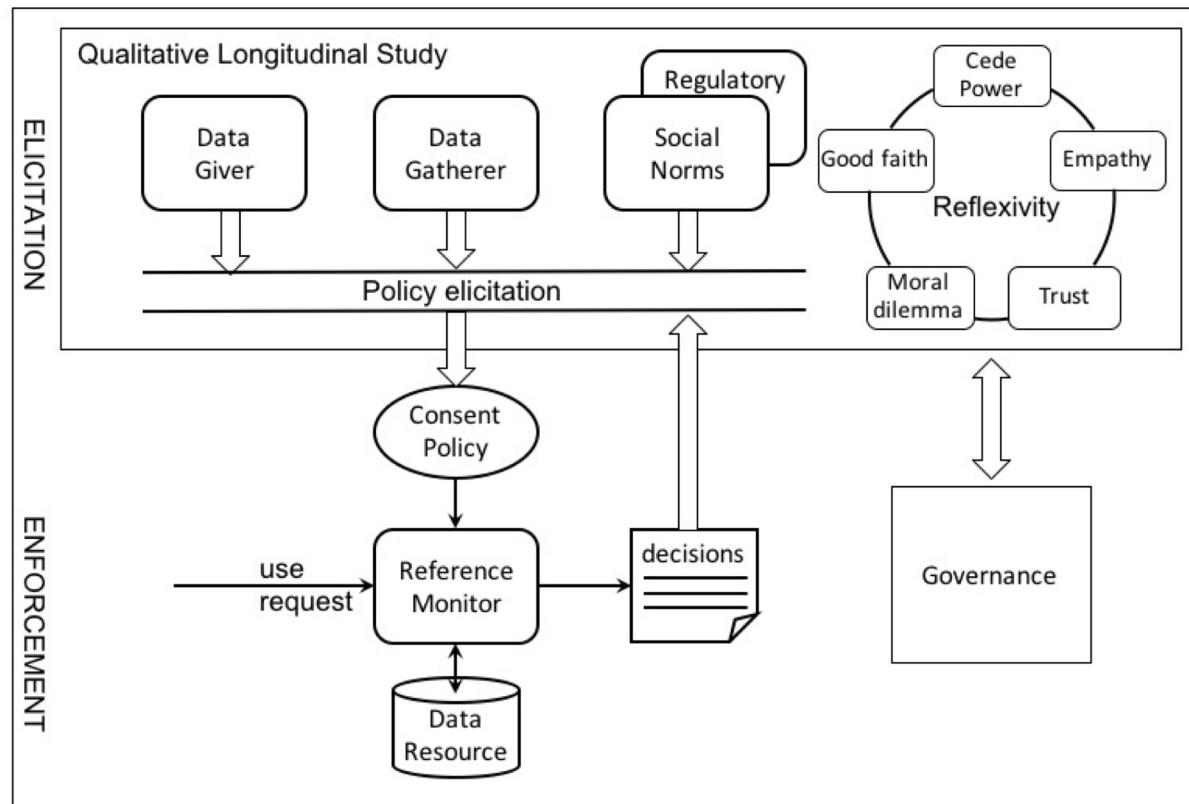
# Socio-technical systems of consent

- Consent by design
  - Utilitarian, Legalistic.
  - Symmetry of ignorance between data gatherer and data giver.
  - Design for use before use.
- Human centred consent
  - Ethics of virtue.
  - Consent as part of data activity
  - Design for design after design

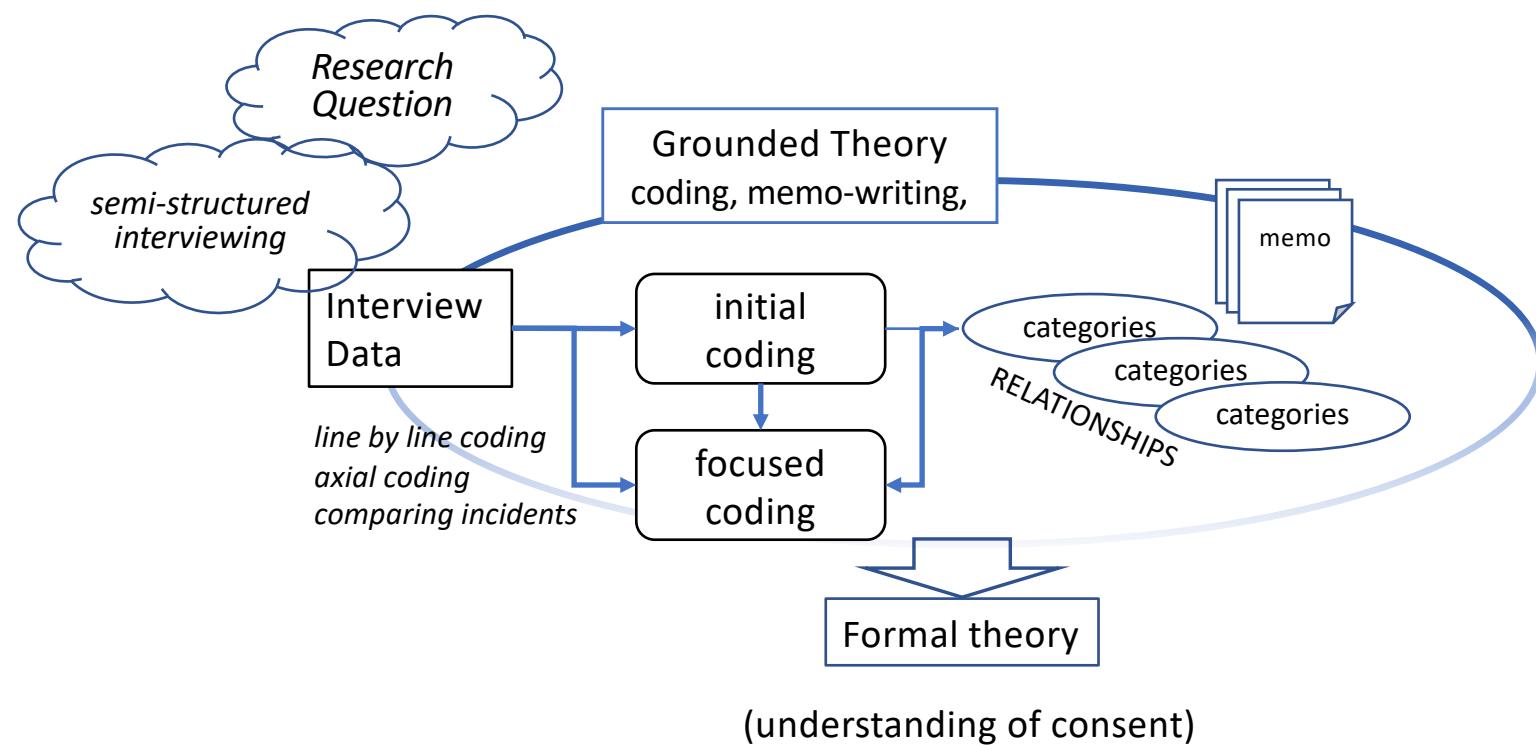


# The new paradigm: human-centred consent

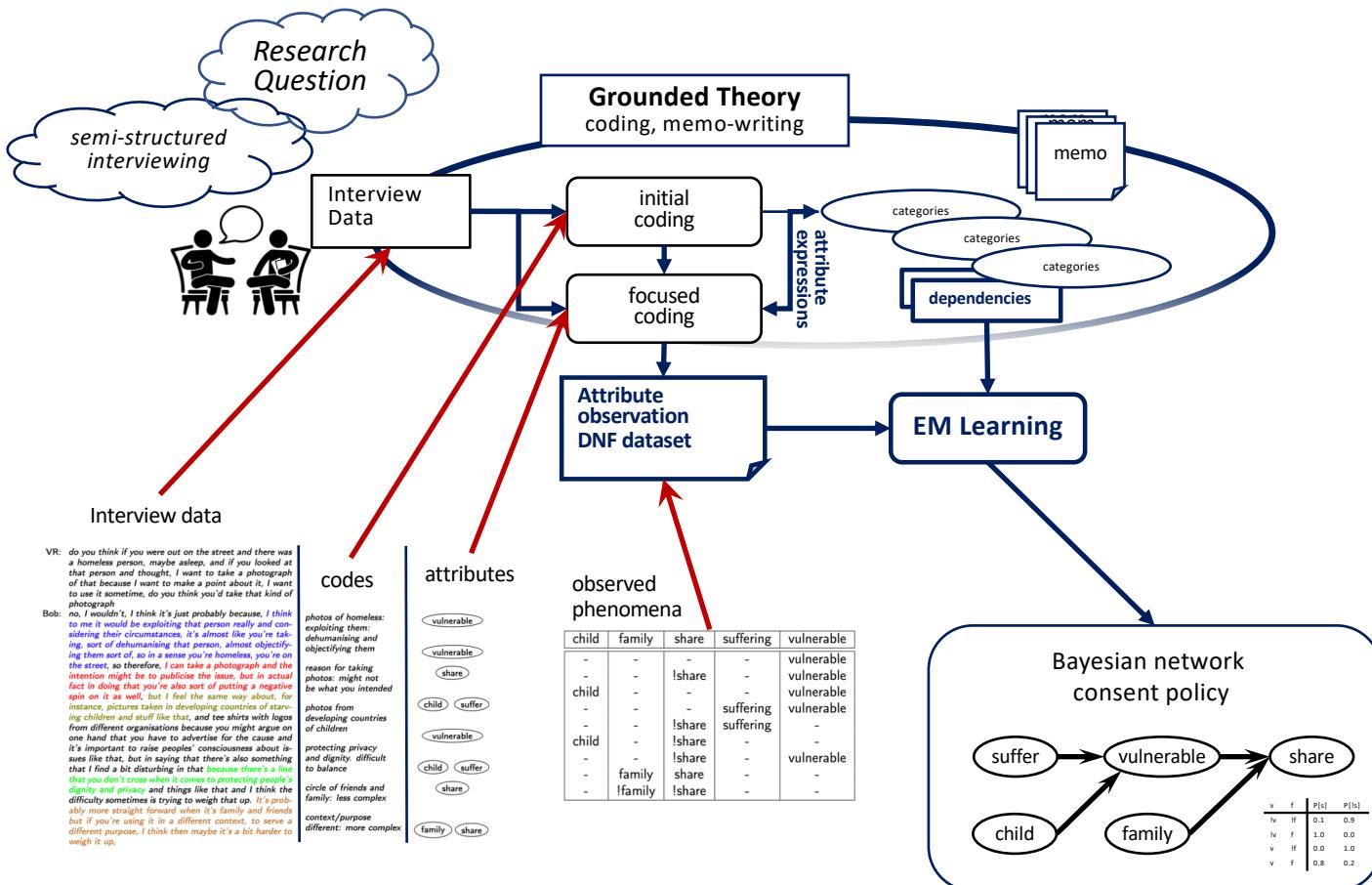
Consent as Qualitative Longitudinal Research



# Example of a Qualitative Research method



# Consent policy elicitation using Grounded Theory



In the meantime ...

# Judging maturity: consent actions

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Further consent	Consent is sought for any further or secondary analysis, Data Initiatives.	Opt-out, covered by initial consent, and if necessitated by legal provisions, is presented in a way that requires agreement in order to access information/services.	Opt-out, adheres to strict legal requirements.	Opt-in; a lack of response from participants to a request for further consent is regarded as a refusal.

# Judging maturity: data and relationships

Criteria	Description	Consent Maturity Levels		
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