



UiO : **Department of Informatics**
University of Oslo

Participatory design and ethics

IN 5510

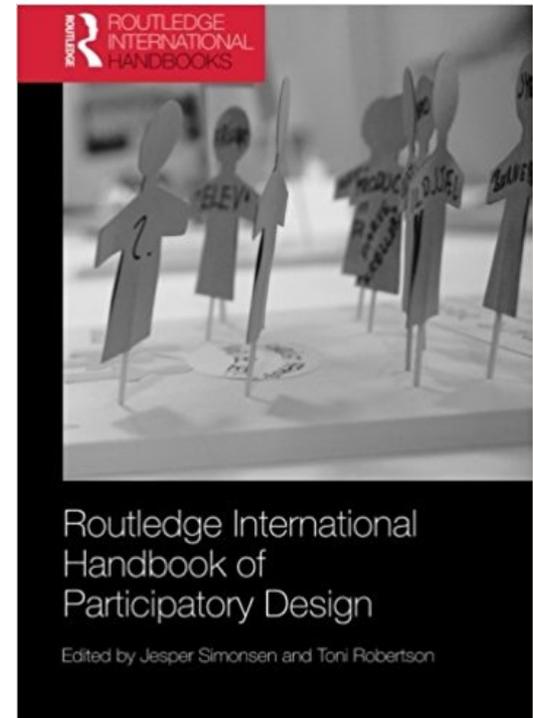
Oct 12, 2021

Guri Verne



Topics

- Ethics and PD
- Ethical theories
- Ethics and technology
- Ethical issues of working with users
- Ethics of technology use
- Norwegian law on research ethics



Toni Robertson



Ina Wagner

An ethical motivation is at PD's core

“Participatory design .. has at its core an ethical motivation to support and enhance how people can engage with others in shaping their world, including their workplaces, over time. This ethical motivation is not some optional extra ... It is its essence and structures its definition and ongoing development.”

(Robertson and Wagner, 2012, p 65)

Ethics and PD

Working together to shape a better future

- People who do an activity know most of how it is done
 - Respect other people's expertise
 - Respect their rights to represent own activities
- **Develop and use tools** that enable designers, users and stakeholders to learn from each other through understanding priorities and perspectives
- People have a basic right to make decisions about how they do their work and activities
 - An emancipatory agenda



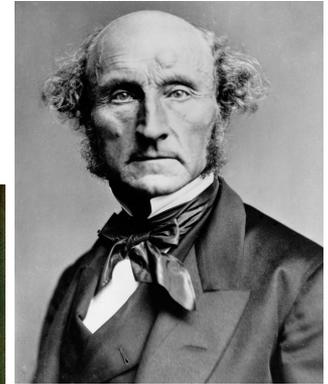
Sentralt, men
omdiskutert

Ethical theories

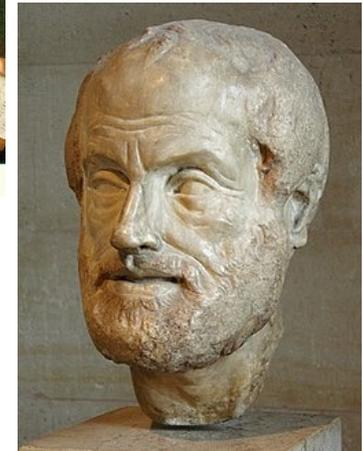
- Moral philosophies
 - How to live a good life?
 - What is a good life?
- Right or wrong acts?
 - its consequences (J. S. Mill)
 - duty (I. Kant)
- Phronesis as a virtue of ethical life (Aristotle)
- Dialogical relations with others
 - Practical, situated ethics

Phronesis

how to act in
particular
situations

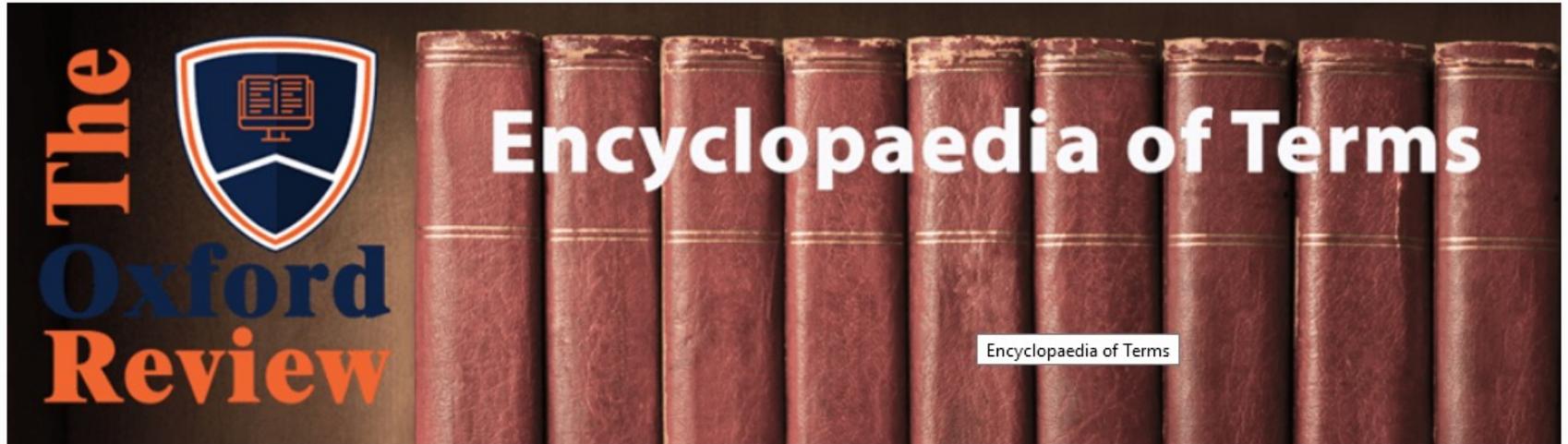


J. S. Mill



Aristotle

Phronesis: definition and meaning



What is Phronesis?

Phronesis is a Greek term which means 'practical wisdom' that has been derived from learning and evidence of practical things. Phronesis leads to breakthrough thinking and creativity and enables the individual to discern and make good judgements about what is the right thing to do in a situation.

[Back to The Oxford Encyclopaedia of Terms](#)

[Looking for research articles? Click here](#)

Talk with your neighbour

- Have you met any ethical issues in your projects? How will you explain them?



The
Imperative
of
Responsibility

*In Search of an Ethics
for the Technological Age*

Hans Jonas

Ethics and technology design

Starting point: Massively increased capacities of human action

Technology design and use is shaping the future

- Hans Jonas:
«The Imperative of Responsibility: In search of an Ethics for the Technological Age»
- Traditional ethics only requires a good understanding of the present situation

A moral basis for choosing between design alternatives



The Imperative of Responsibility

*In Search of an Ethics
for the Technological Age*

Hans Jonas

- *'the indefinite future, rather than the contemporary context of the action, constitutes the relevant horizon of responsibility. This requires imperatives of a new sort. If the realm of making has invaded the space of essential action, then morality must invade the realm of making, from which it had formerly stayed aloof ...'* (Jonas 1984: 9).
- Finding ways to better predict the effect of new technologies as a way to strengthen and improve our decision making about their design and use
- Accountability of technology design and development to the world it creates.
- Are we responsible for unintended consequences of technology?

Ethical issues of working with users

Who do we engage with in a PD project?

Is giving voice to marginalized people or people who inhabit residual categories a moral obligation of Participatory Designers? (Ina Wagner)

Who can provide “voluntary and unconstrained participation”?

Defining those who have a right to participate

Dual loyalties: Being both critical and constructive



How do we engage with participants?

Mutual trust is basic.

Informed consent is a formal way.

Address risks and responsibilities of research vs design

Sensitive issues and vulnerable participants

- Protection vs exclusion

How to avoid a purely instrumental process of “eliciting user requirements”?

Negotiating and managing of «practical politics»

PROSJEKT BRIS

UNIVERSITETET I OSLO

Informasjon og samtykkeerklæring

Deltakelse i workshop og utprøving i forskningsprosjektet BRIS

Beskrivelse av forskningsprosjektet

Mitt navn er Guri Verne og jeg er forsker i Post.doc-stilling ved Institutt for Informatikk ved Universitetet i Oslo. Jeg holder på med et forskningsprosjekt om hvordan eldre kan kommunisere med andre via video fra sin egen stue. I dag arrangerer vi en utprøving hvor vi vil høre deres erfaringer med hvordan utstyret kan styres ved hjelp av bevegelser. Deres tanker og erfaringer vil være viktig for den videre utviklingen.

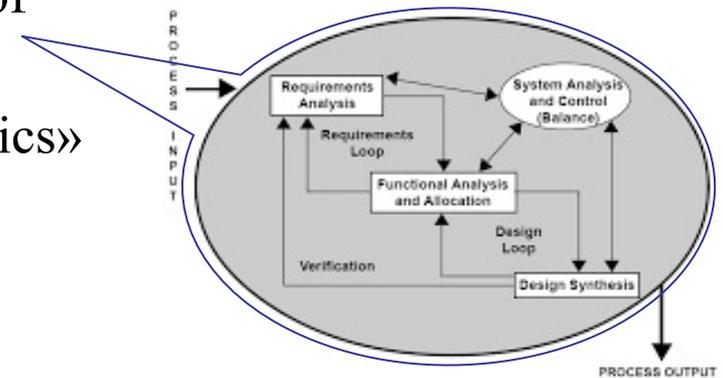
Prosjektets kortnavn BRIS uttrykker at det handler om å utvikle «BRukergrensensnitt for velferdsteknologi i Stua». Prosjektet er finansiert av Regionale forskningsfond, hovedstadsområdet.

Vi ber om samtykke til at din utprøving kan taes opp på video. Videopptakene vil kunne benyttes til å forbedre bevegelsesstyringen.

Frivillig å delta

Deltagelse er frivillig, og du kan trekke deg når som helst. Du kan når som helst avslutte deltagelsen eller trekke tilbake informasjon som er gitt underveis. Du kan kreve at personopplysninger om deg slettes.

Anonymitet



How do we represent participants and their work?

Production of representations is critical

- Representations are not innocent
- Not tell the users what their work is
- Representations can silence
- Misrepresentations of work:

You have, you know, 300 cartons of documents and you tear through them and say, I'm going to put Post-Its on the ones we have to turn over to the other side. And then, ideally, you hire chimpanzees to type in From, To, Date. And then, ideally, you then have lawyers go through it again and read each document, with their brain turned on. (Blomberg et al 1996)

Nurses co-representing their own work: humour

Personal, contingent and sensitive to appropriateness

Normalise practises and descriptions → residual categories

Listening can add to understanding!

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Humor

Definition: Facilitating the patient to perceive, appreciate, and express what is funny, amusing, or to establish relationships, relieve tension, release anger, facilitate learning, or cope with painful feelings

Activities:

- Determine the types of humor appreciated by the patient
- Determine the patient's typical response to humor (e.g., laughter or smiles)
- Determine the time of day that patient is most receptive
- Avoid content areas about which patient is sensitive
- Discuss advantages of laughter with patient
- Select humorous materials that create moderate arousal for the individual
- Make available a selection of humorous games, cartoons, jokes, videos, tapes, books, and so on
- Point out humorous incongruity in a situation
- Encourage visualization with humor (e.g., picture a forbidding authority figure dressed only in underwear)
- Encourage silliness and playfulness
- Remove environmental barriers that prevent or diminish the spontaneous occurrence of humor
- Monitor patient response and discontinue humor strategy if ineffective
- Avoid use with patient who is cognitively impaired
- Demonstrate an appreciative attitude
- Respond positively to humor attempts

1st edition 1992; revised 2008

Background Readings:

Burman, K. (1991). Make room for laughter. *Journal of Holistic Nursing*, 13(1), 46-51.

Kilkenner, L. G. (1988). Play and laughter. In B. M. Doneyk, L. Keegan, C. E. Goetta, & L. M. Doneyk (Eds.), *Nursing: A handbook for practice* (pp. 289-300). Philadelphia: J.B. Lippincott.

Smith, K. (2006). Humor. In M. Snyder & R. Lin (Eds.), *Alternative therapies in nursing* (3th ed., pp. 9-15). Philadelphia: Elsevier.

Sullivan, J. L., & Devine, D. M. (1988). Humor. *Psychological Nursing*, 14(1), 20-24.

220 Hyperglycemia Management (2120)

Hyperglycemia Management

Definition: Preventing and treating above-normal blood glucose levels

- Activities:**
- Monitor blood glucose levels, as indicated
 - Monitor for signs and symptoms of hyperglycemia: polyuria, polydipsia, polyphagia, weakness, lethargy, malaise, blurring of vision, or headache
 - Review blood glucose records with patient
 - Instruct on urine ketone testing, as appropriate
 - Instruct on indications for, and significance of, testing, if appropriate
 - Instruct patient to report moderate or severe hypoglycemia

Working with vulnerable users



What is vulnerability?

Unclear - being prone to harm or adverse impacts
(Wrigley and Dawson, 2016, in Sommervold 2017)

Children under 18 considered vulnerable
(Heiberg & Undlien 2013 in Sommervold 2017)

Sommervold (2017) chose methods in respect for the
participating sick children/adolescents:

- Plasticized materials for disinfection

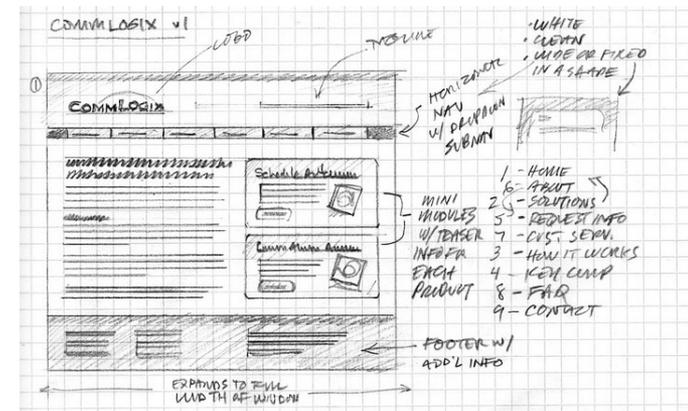
- Magnetic boards to be used with one arm

- Starting from “cool” design -> appropriating to their needs

- Turn to ethics of care: “central focus is attending to and meeting needs of people for whom we are responsible”



What can we offer participants?



What if no technology is designed for the participants?

- Incomplete design delivered
- No learning from use
- Researchers can harvest findings also from a failed project
- We often receive more than we can give

PD - as responsible and reflective practice - can offer

- Joyful participation
- Making their own representations
- Mutual learning

«Understand the politics of change and where you stand within them» (Blomberg et al 1996)

Following up for a project to grow

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Micro-ethical choices

Ethical choices with unknown consequences in the course of events

- Negotiating multiple agendas (parents', teachers')
- Being at risk – balancing professional and personal conduct
- On being Care-ful e.g. in working with children
- Acknowledging Personal Context – gender expressions and body influence participation
- Ethical principles came in conflict with micro-ethics

(Spiel et al., 2013)

Ethical principles versus micro-ethics strategies

| Ethical Principles | Strategies in Micro-Ethics |
|--------------------------|---|
| full context of children | navigation of carers priorisation of topics |
| do no harm | complex risk assessment making judgements |
| child-led PD | negotiation of needs being responsible |
| professional conduct | personal relationships commitment to participants embodied research |

Table 1: Tensions between ethical principles stemming from virtue ethics and strategies used in micro-ethics

Ethical issues of design in and for use

- Issues that arise in use, strategies for resolving them
- Does the design increase the power-to?
- Challenges - design is completed in use
- Monitoring and surveillance

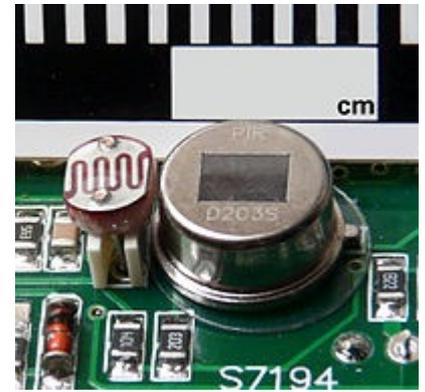


Questions to guide ongoing ethical reflection

- Do users actually have decision power? If so what kind?
- Does a design method, tool or process recognise and encourage participants' abilities to learn?
- Does a design method, tool or process guide designers and researchers to analyse and develop their interests and attitude towards participants?
- Does a design method, tool or process include participants' evaluations not just of what is being designed but of the design process itself, including the opportunities for and process of participation?
- Does a design method, tool or process deal with a justified loss or change of design focus, for example when participants identify problems that require non-information technology solutions while the process was initiated to design information technology)?

Examples

- Surveillance versus communication (BRIS-project)
- What is «good» for the participant/user?



Rettskilder

Lov om organisering av forskningsetisk arbeid

Innholdsfortegnelse ▾

Lovens forskrifter



§ Lover

Stortingsvedtak

Sentrale forskrifter

Lokale forskrifter

Norsk Lovtidend

EØS-avtalen

Norges traktater

Dommer

Tariffavtaler

Statens
personalhåndbok§ Oversatte lover /
Translated Acts§ Oversatte forskrifter /
Translated regulations§ Oversatte avgjørelser
/ Translated decisions[➔ Gå til opprinnelig kungjort versjon](#)

Lov om organisering av forskningsetisk arbeid (forskningsetikkloven)

| | |
|----------------|-----------------------------------|
| Dato | LOV-2017-04-28-23 |
| Departement | Kunnskapsdepartementet |
| Ikrafttredelse | 01.05.2017 |
| Endrer | LOV-2006-06-30-56 |
| Kungjort | 28.04.2017 |
| Korttittel | Forskningsetikkloven |

Jf. tidligere lov 30 juni 2006 nr. 56.

§ 1. **Formål**

Loven skal bidra til at forskning i offentlig og privat regi skjer i henhold til anerkjente forskningsetiske normer.

§ 2. **Virkeområde**

Loven gjelder forskere og forskning i Norge. På Svalbard og Jan Mayen gjelder loven dersom forskningen drives av forskere ansatt av norsk arbeidsgiver eller dersom en vesentlig del av midlene kommer fra Norge.

Granskingsutvalget kan videre uttale seg om forskning i utlandet dersom forskningen drives av forsker ansatt av norsk arbeidsgiver eller dersom en vesentlig del av midlene kommer fra Norge.

§ 3. **Uavhengighet**

Final words

Participation as a means of resolving conflicts that emerge in technology use – more than merely observing, analysing, monitoring consequences.

References not in the reading list

Heiberg and Undlien, 2013, Genetisk forskning på barn, in: Fossheim, H., Hølen, J., Ingierd, H. (eds), Barn i Forskning: Etske dimensjoner, Forskningsetiske komiteer.

Sommervold, Margaret Machniack, 2017, «In illness and in health» A critical inquiry of the potential of digital health technology for supporting youth in health care transitions, Ph.D. Thesis, UiO.

Weizenbaum, J. (1976). *Computer Power and Human Reason: From Judgment to Calculation*, W.H. Freeman and Company.

Wrigley and Dawson, 2016, Vulnerability and Marginalized Populations, in: Public Health Ethics: Cases Spanning the Globe, Springer, pp. 203-240.