META

mHealth: Ethical, Legal, Social aspects in the technological age

PROJECT PORTFOLIO 2018-2019

CONTENT

META – mHealth: Ethical, Legal, Social aspects in the technological age

INSTITUTE OF ETHICS, HISTORY AND THEORY OF MEDICINE, LMU MUNICH

PROJECT LEAD
PD Dr. Verina Wild

TIME
April 2018 - March 2024

FUNDING
German Federal Ministry of Education and Research (BMBF)

Mobile Health (mHealth) technologies such as apps and wearables constitute a rapidly developing field of study. The technologies are increasingly becoming an integral part of human lives and essential tools in promoting healthy lifestyle, disease prevention and disease management.

The **overall goal** of the international and interdisciplinary project META is a thorough analysis of ethical, legal and social aspects of mHealth technologies. The project is funded by the German Federal Ministry of Education and Research (BMBF) and investigates the possibilities, benefits, risks and challenges of mHealth as well as broader aspects of the digital transformation in health and health care on individual, population and global levels.

In the team, we discuss our results from a broader, interdisciplinary perspective, and we work on **joint projects**. For example, we are developing a user-friendly website for the public and policy and private sectors.

In focused **individual projects**, we conduct empirical, conceptual and normative research. These projects span across various spheres of mHealth, with our methods dynamically evolving and adapting to capture novel technologies and the new possibilities and challenges they bring about.

As part of the inquiry, we are identifying opportunities for mHealth to become more inclusive, informed by lived experiences of diverse target groups and beneficent to a wide cohort of users.

Collaborating partners bring in additional ideas and projects. Our international **Advisory Board** supports us virtually and in personal meetings.

Building on multi-disciplinary research findings, the team also offers **consultancy** to mHealth stakeholders with the aim to support responsible, socially sustainable and user-centric innovation in mHealth.

Results of the project are disseminated in **academic publications** and **presentations** and will also be featured on our new user-friendly **META website**.

The META-Team

The vibrant META team involves scholars from various disciplines, currently including philosophy, applied ethics, sociology, law, medicine, epidemiology and public health.

The META-team in Berlin, Sept 2018. From left to right: Tereza Hendl, Katharina Eisenhut, Felix Machleid, Bianca Jansky, Ela Sauerborn, Verina Wild, Niels Nijsingh.

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T◁ mHealth: Ethics,
Law and Society

PROJECT LEAD

PD Dr. Verina Wild
Bio- & Public Health
Ethics, Medicine

POSTDOCTORAL RESEARCHERS

Tereza Hendl, PhD
Bio- & Public Health Ethics,
Philosophy, Gender Studies

Niels Nijsingh, PhD
Bio- & Public Health
Ethics, Philosophy

RESEARCH FELLOW

Bianca Jansky, M.A.
Sociology

STUDENT ASSISTANTS, INTERNS, GRADUATE STUDENTS

Katharina Eisenhut
Medicine, B.A. Philosophy

Felix Machleid
Medicine, B.A. Philosophy

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Physical Therapy,
Epidemiology

Nicole Peter, B.Ed.
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Medicine, B.A. Philosophy

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Jake Ephros, M.A.
Philosophy, Social Policy

AND

Tanja Greiderer
(Medical dissertation)

Noa Niemann
(Medical dissertation)

Eva Späh
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Maria Selmansberger
(Communications Design)

FORMER MEMBER

Sarah Akgül, M.A.
Legal Studies, Philosophy

META — mHealth: Ethics, Law and Society

Joint Projects

Mapping ethical, legal and social aspects of mHealth

The META team is mapping the field of ethical, legal and social aspects of mHealth technologies in a joint effort. We are collecting relevant literature, field notes and experiences and systematizing and structuring the multi-dimensional and complex content. The knowledge we are acquiring here has, for example, led to a fruitful collaboration with the German Bundesvereinigung Prävention und Gesundheitsförderung e.V. (BVPG) for whom we are offering consultancy.

## Collaborative Auto-Ethnographic Study

We are currently planning a collaborative autoethnographic study. As a team, we will use certain mHealth technologies and observe and discuss our experiences with it. The aim is not only to learn about specific apps, but also to gain more general insights, for example into computer-human interactions. Bianca Jansky takes the methodological lead in this project.

The META-Webpage

"About mHealth"

The META team is developing a website that collates ethical, legal and sociological information on mHealth technologies. The website will be a useful source to anyone interested in information about mHealth (users, health care workers, policy-makers, [social] scientists, ethicists, private sector and others). We are developing the website together with our communications designer Maria Selmansberger. The website provides information about four major areas: 1.) Data, 2.) Technology, 3.) Ethics, 4.) Effects on individuals and society. It also contains a blog, featuring interesting and timely issues.
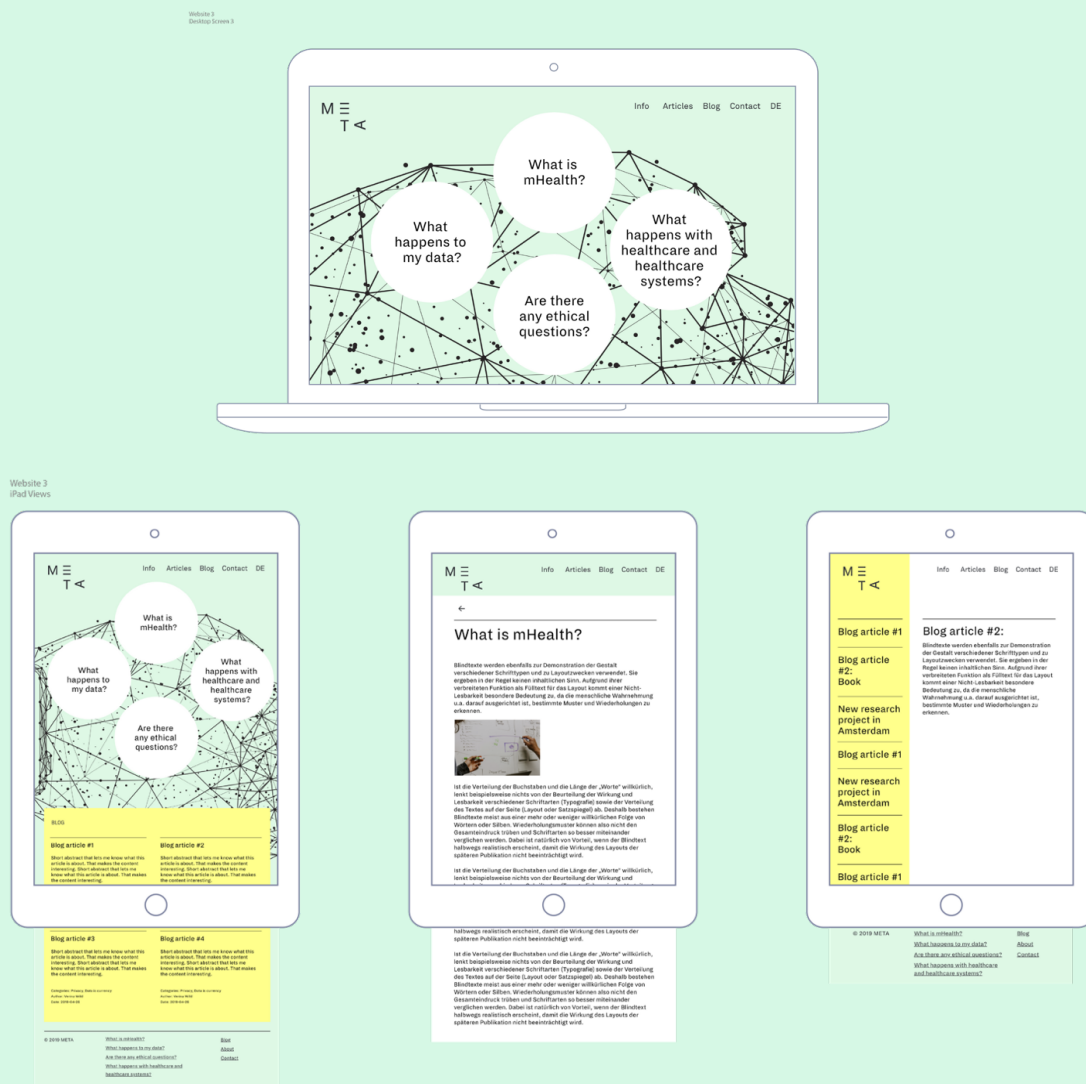
Individual Projects

Benefits and challenges of mHealth – Now and in the future

This project undertakes empirical research on mobile health technologies in the field of health prevention and health promotion. We are interested in exploring current and future possibilities and challenges. Methods involve an explorative mixed methods study with qualitative expert interviews and a consecutive quantitative survey. The interviews are conducted with a variety of stakeholders in the area of mHealth, including IT experts, technology developers or health care insurance representatives.

MAIN INVESTIGATORS
Nicole Peter, Verina Wild

COLLABORATION
Michaela Coenen (LMU Munich, Chair for Public Health and Health Services Research)

Open-source mHealth

While research and development of medical and health technologies traditionally almost exclusively occurred in the institutionalised frame of university and industry, this situation has been shifting in recent years. With biosensors, wearables or smartphones accessible to many at low cost and the possibility of exchanging knowledge in social media networks, independent of space and time, committed people are starting to modify or build their own medical and health technology outside of the traditional development and research frame. This project interrogates the dynamic complexities of the development and usage of open-source medical and health technologies through an explorative qualitative study. One of the main questions is: How are traditional boundaries transforming or shifting in relation to patients, healthcare professionals, mHealth users, IT-development and the healthcare sector?

MAIN INVESTIGATOR
Bianca Jansky

COLLABORATION/SUPERVISION
Paula-Irene Villa Braslavsky (LMU Munich, Chair of Sociology and Gender Studies)
Henriette Langstrup (University of Copenhagen, Department of Public Health)

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Data, access and consent in mHealth

The use of apps and other mHealth technologies generates vast amounts of potentially sensitive data, which raises questions regarding confidentiality, anonymization and access. Regulating this stream of information requires addressing ethical questions on how to obtain proper informed consent from individual users, as well as a more general reflection on the legitimate use of data obtained in the context of mHealth: who is morally authorised to access which information – and under which conditions?

In order to assist in answering these questions, this project aims to interrogate some of the concepts that are all too often used in a hand-waving manner in the context of m-health technologies: "privacy", "consent", "public interest" and "data". We are developing a conceptual framework applicable to practical questions on interoperability, encryption and standards of consent. We are also analysing existing practices of consent to examine the role which traditional conceptions of informed consent play in the changing landscape of m-Health technologies.

MAIN INVESTIGATORS
Niels Nijsingh, Laura Mertgen

Knowledge production in mHealth

The field of mHealth includes a diverse range of technologies, mobile communication and wearable devices. How do these different technologies produce knowledge? To what extent is this knowledge accurate, reliable or relevant to users? This project is concerned with the epistemology of mHealth. It explores diverse modes of knowledge production, specific to particular technologies, as well as their effects on the data, predictions and user guidance generated by mHealth.

The technologies explored as part of this project include period and fertility tracking mobile applications. The investigators are concerned with interrogating normative assumptions about sex and embodiment, gender, sexuality and procreation, which are at play in these apps, shape their algorithms and impact the knowledge created by these technologies. The very conceptualisation of reproductive health is interrogated as well as the normative linking of periods and sexuality with procreation in applications concerned with women's health.

MAIN INVESTIGATORS
Tereza Hendl, Bianca Jansky

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Regulation of mHealth

We are collecting and analysing legal regulations of mHealth technologies with a focus on European Law. One of the central questions in this context is whether an mHealth technology fits the category of a medical device and falls into the formal regulatory framework appropriate for medical technologies.

MAIN INVESTIGATORS
Sarah Akgül
Legal scholar (*to be determined in 2020*)

mHealth and the roles of patients and health care professionals

The digital transformation in health and health care, and mHealth in particular, are transforming the traditional roles of patients and health care professionals. It has been argued that patients are becoming more empowered through the use or even hacking of digital technology to fit their needs and via the establishment of new independent collectives on social media. These developments might result in shifts in the roles of health care professionals, such as physicians, as well as the medical profession. In this project, we interview health care professionals and patients/users to better understand and evaluate the effects of mHealth technologies on the roles of patients/users and health care professionals, medical professionalism and the patient-physician relationship.

MAIN INVESTIGATORS
Tanja Greiderer, Bianca Jansky, Noa Niemann, Verina Wild

mHealth, empowerment, vulnerability and social justice

The rapid development of mHealth technologies, the shift towards digitalisation of health and the push for the inclusion of mHealth into individuals' routines have significant implications for justice and vulnerability in the healthcare context.

However, ethical discussions about social determinants of health, social justice and individual responsibility have not comprehensively addressed the influence of mHealth technologies. Yet, ethically relevant questions arise: is there an increasing trend towards individualisation and personal responsibility? What influence would such a trend have on social justice, disadvantaged groups and solidarity in health?

The project explores the shifts and implications related to mHealth, interrogating them through their impact on individual and social empowerment, justice in healthcare and (non)user vulnerability. It not only investigates risks and possibilities brought forward by mHealth but also opportunities for a more just and empowering field of mHealth technologies.

MAIN INVESTIGATORS
Tereza Hendl, Felix Machleid, Verina Wild

COLLABORATION

Jan-Christoph Heilinger, Eva Parisi
(Munich Center for Ethics, LMU)

*As part of this theme concerned with empowerment, justice and vulnerability, Tereza Hendl has developed the project "*mHealth, self-management and empowerment*", which was awarded the Caroline Miles Visiting Scholarship (May 2019) at the Ethox Centre, University of Oxford.*

The incorporation of mHealth technologies into the daily lives of 'health consumers' is increasingly being promoted as an avenue to strengthening patient autonomy and improving population health outcomes. The routine use of mHealth technologies has been lauded by some for facilitating better-informed patient choices, enabling self-monitoring and self-management and providing access to healthcare to a wider patient cohort at lower costs.
However, the emphasis on self-management implicit in mHealth applications raises ethical concerns.

This project investigates the complex possibilities, tensions and challenges involved in mHealth, aiming to evaluate under which circumstances these technologies can improve public health and empower individuals and communities in a healthcare context.

MAIN INVESTIGATOR
Tereza Hendl

Apps addressing violence against women and girls: an ethical evaluation

Despite their promotion and popularity, mHealth technologies - such as apps or wearables against violence against women and girls - have not been systematically reviewed or classified in academic or grey literature. With our research project, we aim to fill this gap: we collect and map such apps and cluster them with regards to their function. We analyse them from an ethical perspective, with a special focus on epistemic and structural injustice. Ultimately, we are aiming at developing ethically informed quality criteria for the development and use of mHealth technology against violence against women and girls.

MAIN INVESTIGATORS
Katharina Eisenhut, Ela Sauerborn, Verina Wild

COLLABORATION
Agomoni Ganguli Mitra (University of Edinburgh)

Claudia Garcia Moreno (Department of Reproductive Health, WHO, Geneva)

Jan-Christoph Heilinger (Munich Centre for Ethics, LMU)

Collaborative Meeting at WHO January 2019
With Katharina Eisenhut (left), Claudia Garcia Moreno, Ela Sauerborn (right), Verina Wild

Algorithmic fairness in mHealth

As mHealth technologies are increasingly becoming an integral part of preventative health care, it is crucial to understand how they shape human lives. This project investigates the complex ways through which algorithm-generated knowledge produced by mHealth technologies impacts on society, communities and individuals from particular social groups.

Many scholars and data experts have noted that algorithms do not represent 'neutral' mathematical formulas but values embedded in code. As such, they can be grounded in dominant normative assumptions about the world and carry space for algorithmic bias. Biased algorithms skew the knowledge produced by mHealth technologies and in consequence, disadvantage some users and/or exacerbate their vulnerability in a health care context. This way, algorithmic bias contributes to social injustice and discrimination against individuals, particularly those from already marginalised social groups.

Through an investigation of algorithms and algorithm-generated knowledge, this project seeks to promote algorithmic fairness. The creation of fair algorithms is crucial for the designing of just and inclusive mHealth technologies, which will facilitate good public health outcomes and benefit a diverse cohort of users.

MAIN INVESTIGATOR
Tereza Hendl

Future ideas

In the future we will expand on "Global mHealth and Ethics". For this, we have initiated a collaboration with Günter Fröschl (Department of Infectious Diseases & Tropical Medicine, LMU) and Claudia Lang (Department of Social and Cultural Anthropology, LMU).

Further research ideas are currently being developed with Nir Eyal, Associate Professor of Global Health and Population at the Harvard T. H. Chan School of Public Health (from July 2019 at Rutgers University).

We are open to other ideas and collaborations.

Publications
and Presentations

PRESENTATIONS

- Jansky B, Wild V: "From Do-it-Yourself to Do-it-Ourselves: Self-care in Type 1 Diabetes therapy as a collective endeavour", The Digitally Engaged Patient Conference, Copenhagen, 11-12.6.2019.

- Hendl, T, Wild, V: "Beyond Hype: Opportunities and Challenges in mHealth" in the Ethox and the Wellcome Centre for Ethics and Humanities Seminar, the Big Data Institute, University of Oxford. 29.05.2019.

- Hendl, T: "Health, Self-management and Empowerment: mHealth Technologies from a Public Health Perspective", New St Cross Special Ethics Seminar, St Cross College of the University of Oxford, 23.05.0219.

- Hendl, T, Jansky N: "Countering the Suppression of Diversity in Period and Fertility Apps: The Role of Autoethnographic Research", Methods in Questions: Epistemologies of Gender and Sexuality Seminar Series, University of Cambridge Centre for Gender Studies, 22.05.2019.

- Jansky B, Wild V: "From Do-it-Yourself to Do-it-Ourselves: Self-care in Type 1 Diabetes therapy as a collective endeavour", The digitally engaged patient Conference, Copenhagen, 11-12.06.2019

- Jansky B: "Open-source mHealth: development and use of digital do-it-yourself medical and health technologies", 2nd Institute Conference „Wir reflektieren Medizin" (Institute for Ethics, History and Theory of Medicine), Munich, 21.05.2019.

- Nijsingh N: "mHealth data; who should have access?", 2nd Institute Conference „Wir reflektieren Medizin" (Institute for Ethics, History and Theory of Medicine), Munich, 21.05.2019.

- Peter N: "mHealth in der Gesundheitsförderung und Prävention – Status Quo und Prognose", 2nd Institute Conference „Wir reflektieren Medizin" (Institute for Ethics, History and Theory of Medicine), Munich, 21.05.2019.

- Jansky B, Woll S: "Code your own pancreas: technology assessment and sociological perspectives on the visions of do-it-yourself artificial pancreas systems in type 1 diabetes therapy", 18th STS Conference Graz 2019 „Critical Issues in Science, Technology and Society Studies", Graz 6-7.5.2019

- Hendl T, Jansky B for the META team: "Ethical, legal and social aspects of mHealth technologies: Tackling the jumble". International and interdisciplinary conference: The futures of eHealth: Social, legal and ethical challenges, Humboldt Graduate School Berlin, 29-30.04.2019.

- Wild V: Transforming powers, transcending boundaries. A brief overview of ethical, legal and social aspects of mobile health technologies. Conference 'Governance of Big Transformations', TUM, Munich, 21-23.03.2019.

- Machleid F, Wild V: "Mobile Gesundheitstechnologien, Eigenverantwortung für Gesundheit und soziale Gerechtigkeit", Kongress Armut und Gesundheit, Berlin, 15.03.2019.

- Wild V, Eisenhut K, Sauerborn E: "Apps against Violence against Women (VAW): A systematic review of 171 anti-VAW and some ethical reflections" at the WHO Department for Reproductive Health, 25.01.2019.

- Jansky B for the META team: "META - mHealth: Ethical, legal and social aspects. Project introduction". 1. Treffen zu KI und Big Data in der medizinischen Forschung an der LMU, Centrum für Schlaganfall- und Demenzforschung, 25.01.2019.

- Hendl T, Jansky B: "Empowering women through an mHealth interface? The epistemology of period and feritilty tracking apps", Munich, 17.01.2019, Workshop with Mary Fissell and Paula-Irene Villa.

- The META Team: "META - mHealth: Ethical, legal and social aspects. Project progress". Forschungskolloquium Institut für Ethik, Geschichte und Theorie der Medizin. 9.1.2019 Peter N: "mHealth – Status Quo und Prognose: Eine Mixed Methods Experten-Befragung zum Ist-Zustand und den Erwartungen an mobile Gesundheitstechnologien". Seminar Methodenreflexion Institut für Ethik, Geschichte und Theorie der Medizin, 12.12.2018.

- Hendl T: "The future of mHealth technologies from a public health perspective". 11th International Conference on Applied Ethics at the University of Kyoto, 16.12.2018.

- Eisenhut K, Sauerborn E, Ganguli-Mitra A, Wild V: "Supporting women's rights with mobile health technologies? The case of Apps against Gender Based Violence", Poster at World Congress of Bioethics, International Society of Bioethics (IAB), Bengaluru, India, 5-7.12.2018.

- Jansky B: "Scannen statt Stechen – Eine sozialempirische Situationsanalyse zum Einsatz sensorbasierter Glukosemesssysteme in der Diabetestherapie.", Workshop 'Wer (oder was) versorgt uns(ere) Patienten?, Computerisierung von Diagnostik, Therapie und Pflege', Munich, 8-11.11.2018.

- Hendl T, Jansky B: "Empowered through an mHealth interface? The epistemology of period and fertility tracker apps", Workshop 'Feminist Philosophy of Technology', Vienna, 25-26.10.2018.

- Eisenhut K, Sauerborn E, Wild V: "Epistemic injustice and mobile health technologies: The case of gender-based-violence-apps in India." Workshop 'Feminist Philosophy of Technology', Vienna, 25-26.10.2018.

- Wild V: "Überblick über internationale Trends der Public Health Ethik", Workshop 'Ethik und Gesundheitsförderung'. Hessische Landesvertretung, Berlin, 25.10.2018.

- Jansky B: "DIY Diabetes: Exploring the appropriation of glucose monitoring devices in a digital global diabetes community" Seminar 'Appropriating technologies: the political economy and routinization of artefacts and devices', Copenhagen, 24-25.09.2018 The META Team: "META - mHealth: Ethical, legal and social aspects." BMBF Kick-Off- Workshop ELSA Forschungsgruppen. Grenanderhaus, Berlin, 20.09.2018.

- Eisenhut K, Wild V: "Gewalt gegen Frauen mittels App verhindern? Für eine ethisch- normative Einbettung von Apps im Bereich Gesundheit und Prävention". AEM Jahrestagung, Cologne, 13-15.09.2018.

- Eisenhut K, Ganguli Mitra A, Wild V: "Mobile technologies against Gender Based Violence? The ethics including women's voices, relations and structural background conditions", European Society of Philosophy in Medicine and Healthcare (ESPMH) Conference, Lisbon, Portugal, 7-10.08.2018.

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PRESS

- 19.02.2019: Tereza Hendl contributes to discussions on Facebook's "suicide prevention service", published by: welt.de, Science Media Center Germany, msn-news.
- 11/2018: Report on the META project in the German online-Magazine "Gerechte Gesundheit".
- 29.08.2019: Interview with Verina Wild in the LMU Research Magazine "Einsichten".
- 24.04.2018: LMU press release for the launch of the META project.

PUBLICATIONS

Forthcoming

- Wild V (forthcoming 2019): Digitalisierte Gesundheit: Eine ethische Reflexion. In: Dockweiler C, Fischer F (Hrsg.): ePublic Health. Hogrefe, Göttingen.
- The META Team 2019: Ethical, legal and social aspects of mHealth technologies: Navigating the field. In: Bächle, T.C., & Wernick, A. (eds.). 2019. The Futures of eHealth. Social, legal and ethical challenges. Berlin: Humboldt Institute for Internet and Society.
- Hendl T, Jansky B, Wild V (forthcoming 2019): Why mHealth needs a feminist perspective. In: Loh J, Coeckelberg M (Eds.): The Anthology of Feminist Philosophy of Technology. Stuttgart: Metzler.

Papers under review (Topic areas)

- Open access, Data, Power
- Digital health technologies, Social media, and Do-it-yourself approaches
- Mobile applications addressing Violence Against Women and Girls

Additional papers in preparation

Collaborating Partners

- **Bundesvereinigung Prävention und Gesundheitsförderung e.V.** (BVPG).

- **Department of Reproductive Health and Research**, World Health Organization (WHO).

- **International research association iCARE-PD:** Integrated Parkinson Care Networks: addressing complex care in Parkinson disease in contemporary society. Overall Coordinator: Tiago Mestre, The Ottawa Hospital Research Institute/University of Ottawa, Canada. Ethics lead in Germany: Prof. Christiane Woopen, University of Cologne.

- **Subsection Global mHealth in the global health focus of CAS, LMU Munich**. Joint foundation of the subsection with Günter Fröschl, Claudia Lang (both LMU). Research cooperation planned with Jimma University Ethiopia.

- **TUM School of Governance.** Joint conference "Digital Behavioural Technology, Vulnerability and Justice" from 1-3 July 2019, organized together with Prof. Lisa Herzog (TUM).

Advisory Board

- **Angus Dawson**, Sydney Health Ethics, School of Public Health, University of Sydney
- **Nir Eyal**, Program in Ethics and Health, Harvard University (From July 2019: Rutgers University)
- **Jakob Futorjanski**, IT-development, NeuroNation – Fitness for your Brain
- **Jessica Haberer,** Massachusetts General Hospital Center for Global Health and Harvard Medical School, Boston
- **Jan-Christoph Heilinger**, Center for Ethics, LMU Munich
- **Manuel Heuer**, IT-development, Chief Operating Officer dacadoo
- **Verena Hoffmann & Michael Hölscher**, Division of Infectious Diseases & Tropical Medicine, LMU München
- **Rolf Holle**, Institute of Health Economics and Health Care Management, Helmholtz Zentrum München
- **Christian Janke**, European Medical Corps Project / German Red Cross
- **Stephan Jonas**, mHealth Division, Medical Informatics, RWTH Aachen University
- **Ulrich Mansmann**, Institute for Medical Information Processing, Biometry, and Epidemiology, LMU Munich
- **Markus Müschenich**, Bundesverband Internetmedizin
- **Markus Pratschke**, Novartis Business Services
- **Andreas Reis**, World Health Organisation, Geneva
- **Andreas Spickhoff**, Faculty of Law, LMU Munich
- **Alison Thompson**, Faculty of Pharmacy, University of Toronto
- **Hella von Unger**, Department of Sociology, LMU
- **Heather Widdows**, Department of Philosophy, University of Birmingham
- **Manfred Wildner**, Institute for Medical Information Processing, Biometry, and Epidemiology, LMU Munich and Bayerisches Landesamt für Gesundheit und Lebensmittelsicherheit

METHODOLOGICAL ADVICE

- **Tanja Krones**, University of Zurich
- **Katja Kühlmeyer**, LMU Munich
- **Margrit Schreier**, Jacobs University Bremen

WITH SPECIAL THANKS TO

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