



Dr. Karin Rolanda Jongsma

Leidseweg 83B – 3531BG Utrecht – The Netherlands

k.r.jongsma@umcutrecht.nl

+316 3004 3012 - Nationality: Dutch - DoB: 08.07.1986

RESEARCH PROFILE

Dementia, Autism, surrogate decision-making, advance directives, dementia research, ageing, health policy, research ethics, (self)representation

RESEARCH EXPERIENCE

UNIVERSITY MEDICAL CENTER UTRECHT.....Utrecht, NL

Assitant Professor 09/2017 - present

Medical Humanities/ Julius Center

(Prof. Dr. A.L Bredenoord)

UNIVERSITY MEDICAL CENTER GÖTTINGEN.....Göttingen, DE

Post-Doctoral Fellow 10/2015 - present

Institut für Ethik und Geschichte der Medizin

(Prof.Dr. S. Schicktanz)

ERASMUS MEDICAL CENTER.....Rotterdam, NL

PhD. Researcher 10/2011 - 9/2015

Department of Medical Ethics and Philosophy of Medicine

(Prof.Dr I.D. de Beaufort, Prof.Dr S van der Vathorst)

EBERHARD KARLS UNIVERSITY.....Tübingen, DE

Visiting researcher 3-5/2014

Department of Medical Ethics and History of Medicine

(Prof. Dr. H-J Ehni)

MINISTRY OF HEALTH.....The Hague/Bilthoven, NL

Junior researcher 3/2010 – 10/2013

(Dr. A.L. Struijs, Prof. Dr. A. De Roda-Husman)

EDUCATION AND TRAINING

VRIJE UNIVERSITEIT	Amsterdam, NL
Master of Science	9/2008 – 11/2010
Management, Policy Analysis and Entrepreneurship in Health and Life Sciences	
MCI – MANAGEMENT CENTRE INNSBRUCK	Innsbruck, AU
International semester	10/2009-2/2010
International Health Care Management	
VRIJE UNIVERSITEIT	Amsterdam, NL
Bachelor of Science, Health Sciences	9/2005 - 9/2008

PRICES GRANTS AND AWARDS

CAROLINE MILES SCHOLARSHIP.....	Oxford, UK
Research Scholarship	
U4 UNIVERSITY NETWORK.....	Göttingen, DE
Mobility grant	
DOROTHEA SCHLÖZER MENTOR PROGRAM.....	Göttingen, DE
Project management, Leadership & Career coaching	2015 -2016
ALZHEIMER NEDERLAND.....	Amersfoort, NL
Dissertation funding for printing and dissemination of results	10/2015
DISSERTATION BONUS GRANT.....	Rotterdam, NL
Granted to 3-8% of All Dutch PhD Students	11/2016
VERENIGING TRUSTFONDS ERASMUS UNIVERSITEIT.....	Rotterdam, NL
Mobility grant	6/2014
VUFONDS.....	Amsterdam, NL
Mobility grant	9/2007

PROFESSIONAL ACTIVITIES

EVENTS ORGANISED

International Workshop	Göttingen, DE
Collective Representation of Autism	27.04.2017
International Expert Workshop	Göttingen, DE
Representation and self-representation in health policy	20.10.2016

Seminar Innsbruck, AU
Die Rolle von Patient/-innen und Betroffenen im Gesundheitswesen 08.07.2016
Expert Workshop Utrecht, NL
Developing medicines for vulnerable populations 14.06.2013

EDITOR

Special Issue; Collective Representation in Health Care Policy (2018)
Journal of Bioethical Inquiry

REVIEWER

American Journal of Bioethics, Bioethics and Journal of Bioethical Inquiry
Professional Memberships

AEM Akademie für Ethik in der Medizin DE
VFG Vereniging voor Filosofie en Geneeskunde NL
OZSE The Netherlands School for Research in Practical Philosophy NL

TEACHING AND TRAINING

UNIVERSITY MEDICAL CENTRE GÖTTINGEN.....Göttingen, DE
Ethics, Theory and History of Medicine II (Medicine students) 2016
Global Health (interdisciplinary course) 2016/2017
ERASMUS MEDICAL CENTRE.....Rotterdam, NL
Undergraduate and Graduate courses (Medicine students) 2011-2015
Supervision of bachelor Thesis
PHILLIPS HEALTH CARE.....Eindhoven, NL
Course for employees: Ethics of Technological Design 2015
MENTORSCHAP NEDERLAND.....NL
Training for voluntary mentors: Ethical aspects of Mentorship 2014

LANGUAGES

Dutch - Native speaker
English - Proficient user
German - Advanced user (level C1)

PUBLIC OUTREACH AND INTERESTS

AEON.....www.aeon.co
Online Journal

Activities: Writing opinion articles on ethical and societal topics

WELCOME DINNER.....Göttingen, DE
Non-profit organisation, dinners for refugees and residents 2015-2017
Activities: organisation, planning, coordination

SWEET COFFEE GROUNDS (CHAIR)..... Amsterdam, NL
Non-profit cooperation project with coffee farmers 2012-2015
Activities: organisation, planning and strategy.

GROENLINKS (Greens)..... Noord-Holland, NL
Candidate for the Provincial State Elections 2015
Activities: Political debates, campaigning, promotion

OTHER INTERESTS Food and culture, yoga, reading, travelling

APPENDIX RESEARCH PROJECTS

A: PRINCIPLE INVESTIGATOR

Project title: *Research participation in dementia research: Motivations, ethics and practical guidelines*

Description: In this project we investigate how health care experts and people with Mild or Subjective Cognitive Impairment look upon the introduction of Advance Directives in Germany in 2018.

Activities: project coordination, academic writing, empirical and theoretical research.

Collaboration: Prof.Dr S. Schicktanz (University Medical Centre Göttingen, Dr. Katrin Radenbach, Prof. Dr. Anja Schneider, Julia Perry (M.A)

2017-2018

Key words: dementia, advance directives, anticipation, incompetence

Funded by: Startförderung of the UMG.

B: POST-DOC RESEARCHER

Project title: *Self-representation and representation by others in health policy- Patient organisations for Autism and Dementia.*

Description: In this project we investigate how members of patient organisations look upon the political representation of their interests by representatives, and analyse cultural differences between Israel and Germany. Furthermore we reflect upon the presumption that patient organization can represent collectives of patients.

Activities: grant proposal writing, project coordination, event organisation and management, academic writing, empirical and theoretical research.

Collaboration: Prof.Dr S. Schicktanz (University Medical Centre Göttingen, Prof.Dr. A. Raz (Ben-Gurion University the Negev), Dr. N. Rimon-Zarfaty (Ben-Gurion University the Negev)

2015-2018

Key words: dementia, autism, (self-)representation, health policy

Funded by: The state of Lower Saxony, Hannover.

C: PHD STUDENT

Project title: Developing medicines for vulnerable populations

Description: The project explores the possibilities of anticipating authorisation to research participation with the use of an Advance Research Directive, from a legal, practical and ethical perspective.

Dissertation: *Advance Directives in Dementia Research - A medical-ethical inquiry.*

Activities: event organisation and management, academic writing, empirical and theoretical research, organisation of internal journal club.

Supervision: Prof.Dr I.D. de Beaufort, Prof.Dr S van der Vathorst)

2011-2016

Key words: dementia, vulnerable populations, research ethics, advance directives

Funded By: ZonMW.

D: JUNIOR RESEARCHER

Centre for Ethics and Health

Projects: 1 Normative aspects of shared decision-making, 2 Public health and global environmental changes

Activities: Writing of scientific papers, writing policy papers, conducting stakeholder-interviews, organisation of discussion sessions, editorial work and work in project groups. Collaboration: Dr. A.J. Struijs, Dr. M. ten Have

Keywords: health policy, decision-making, interdisciplinary research

Council for Public Health and Healthcare (RVZ)

Projects: 1 Depression-prevention; 2 Shared decision-making

Activities: Writing of scientific papers, conducting stakeholder-interviews, organisation of discussion sessions, and work in project groups.

Collaboration: LLM T. Hooghiemstra, LLM M. de Lint, Drs. F. van Sloten

Keywords: depression, decision-making, health policy

The Dutch National Institute for Public Health and the Environment (RIVM)
Project: research project on the prevention of infection and protection of
vulnerable populations for waterborne diseases
Activities: Literature research, writing of policy and scientific papers, grant
proposal writing and presentations
Collaboration: Prof.Dr. A-M de Roda-Husman

APPENDIX PEER-REVIEWED PUBLICATIES

SCIENTIFIC ARTICLES:

1. Gerhards H, Jongsma K, Schicktanz S. (2017). The relevance of different trust models for representation in patient organizations: conceptual considerations. BMC Health Services Research, 17(1):474. DOI : 10.1186/s12913-017-2368-z
2. Jongsma KR and Sand M. (2017). The usual suspects - why techno-fixing Dementia is flawed. Medicine Health Care and Philosophy, 20:119–130.
3. Jongsma KR. (2016). Patientenverfügungen für die Demenzforschung aus ethischer Perspektive betrachtet. Ärzteblatt BW, 12, 612-615.
4. Sand M and Jongsma KR. (2016). Why neural determinism is not real determinism and why mental states cannot act. AJOB Neuroscience, 7(4), 205-207.
5. Jongsma KR. (2016). Advance Directives in Dementia Research - A medical ethical inquiry. ISBN: 978-94-6050-022-0
6. Jongsma KR, Sprangers M and van de Vathorst S. (2016). The implausibility of response shifts in dementia patients. Journal of Medical Ethics, 42:597–600
7. Sand M and Jongsma KR. (2016). Towards an Ageless Society. In: Dominguez-Rue and Nierling: Ageing and Technology: Perspectives of the Social Sciences. Transcript (Aging Studies, 9), pp. 291-310.
8. Andorno R, Gennet E, Jongsma KR and Elger B. (2016) Integrating Advance Research Directives into the European Legal Framework. 23, 49-64.
9. Jongsma KR, van Bruchem-Visser RL, van de Vathorst S and Mattace-Raso FUS. (2016). Has dementia research lost sense of reality? - A descriptive

analysis of eligibility criteria of Dutch dementia research protocols.

Netherlands Journal of Medicine, 74(5), 201-209

10. Jongsma KR and van de Vathorst S. (2015). Beyond Competence: Advance Directives in Dementia Research. *Monash Bioethics*, 33(2), 167-18.
11. Jongsma KR and van de Vathorst S. (2015). Dementia research and advance consent: it is not about critical interest. *Journal of Medical Ethics*; 41(8):708-709.
12. Jongsma KR, Bos W and van de Vathorst S. (2015). Morally relevant similarities and differences between children and dementia patients as research subjects - Representation in legal documents and ethical guidelines. *Bioethics*, 29, 9, 662-670.
13. Jongsma KR and van de Vathorst S. (2015). Advance directives in dementia research: The opinions and arguments of clinical researchers – an empirical study. *Research Ethics*; 11(1):4- 14

PUBLIC OUTREACH & POLICY PAPERS

14. Jongsma KR and Klar V. (2016). Empathy is an overrated skill when dispensing medical care. AEON. <https://aeon.co/ideas/empathy-is-an-overrated-skill-when-dispensing-medical-care>
15. Jongsma KR (2016). How people with sports addiction are like drug addicts. AEON. <https://aeon.co/ideas/how-people-with-sports-addiction-are-like-drug-addicts>
16. Aartsen JGM and Jongsma KR. (2015). Ouderenmishandeling en de rol van de mentor. *Podium voor Bio-ethiek*. 22(4), 12-14.
17. Struijs AJ en Jongsma KR. (2013). Gezamenlijke besluitvorming door zorgverlener en patiënt - normatieve achtergrond. *Centrum voor Ethiek en Gezondheid* /(CEG).
18. Jongsma KR. (2012). Lost your mind? Wilsonbekwame demente ouderen in de onderzoekscontext. *Podium voor Bio-Ethiek*. 19(4), 27-28.
19. Struijs AJ en Jongsma KR (ed). (2012). De mens centraal? - Ethische dilemma's bij gezondheidsbeleid met goede zorg voor dier en natuur. *Centrum voor Ethiek en Gezondheid (CEG)*; Raad voor de Leefomgeving en de Infrastructuur (RLI), de Raad voor Dierenaangelegenheden (RDA).

PRESENTATIONS ON CONFERENCES

1. Jongsma KR. ARDs in dementia research-what do they solve?
Colloquium Münster, Department of Medical Ethics and History of
Medicine, Bochum, 10.07.2017
2. Jongsma KR. ARDs in dementia research-what do they solve?
Colloquium Bochum, Department of Medical Ethics and History of
Medicine, Bochum, 30.01.2017
3. Jongsma KR, Späth E, Schicktanz S. Epistemic injustice in Autism Patient
organizations. Workshop Collective Representation of Autism, 27.04.2017
4. Jongsma KR. Advance Research Directives- What do they solve? Minerva
Workshop, Judean Hills, Israel, 04.06.2017
5. Jongsma KR. Speaker at panel: Decisional Competence. : Incompetent
research participants: morally relevant differences and similarities between
children and dementia patients
OZSW Conference 2016 (Dutch Graduate school for Philosophy),
Groningen 9-10.12.2016
6. Jongsma KR. The more the merrier? Concepts of representation and shared
decision-making in health care policy.
Conference: Shared decision-making in personalized medicine, Göttingen,
5-6.12.2016
7. Jongsma KR. The relevance of different trust models for representation in
patient organisations.
Conference: Trust in Organisations, Copenhagen 24-25.11.2016
8. Jongsma KR. The implausibility of response shifts in dementia patients.
IAB World Congres 2016 Edinburgh 14-17.06.2016
9. Jongsma KR & Schicktanz S. Empirical-ethical reflection on collective
representation -Autism/Dementia and their representatives.
IAB World Congres Edinburgh 14-17.06.2016, &
International Workshop One for All, All for one 20.10.2016, Göttingen
10. Jongsma KR & Sand M. Techno fixing Dementia, what we can learn from
STS and TA. Colloquium, Department of Medical Ethics and History of
medicine, Mainz

29.01.2016

11. Jongsma KR & Sand M. Towards an Ageless Society.
Workshop Homo Senescens Hannover 1-3.10.2015
 12. Jongsma KR. ARDs in dementia research-what do they solve?
IAB World Congress Mexico City 25-28.06.2014
 13. Jongsma KR, Bos W, van de Vathorst S. Morally relevant differences and similarities of vulnerable research populations: Representation in legal documents and ethical guidelines
IAB World Congress Mexico City 25.28.06.2014
 14. Jongsma KR: Advance Directives in dementia research
University of Basel 29.01.2015
University of Tübingen 13.05.2013
 15. Jongsma KR. Have you lost your mind? - Dementia, identity and advance directives.
IAB World Congress Rotterdam, 26-29.06.2012
 16. Jongsma KR. Advance Research Directives in Dementia Research: Ethical and Legal Considerations.
PGBC conference, Kings College, London, 22-24.05.2013
 17. Jongsma KR & Bos W: Regulation of research with vulnerable groups.
Dutch Central Committee on Research with Human Subjects (CCMO). 24-09.2013
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September 2017

A handwritten signature in blue ink, appearing to be 'K. Jongsma', with a long horizontal stroke extending to the right.