



Dr. Karin Rolanda Jongsma

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+49 176 3297 9209 - 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 CENTRE GÖTTINGEN.....Göttingen, DE

Post-Doctoral Fellow 10/2015 - present

Institut für Ethik und Geschichte der Medizin (Prof.Dr. S. Schicktanz)

ERASMUS MEDICAL CENTRE.....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 (PD. Dr. H-J Ehni)

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

Junior researcher 3/2010 – 10/2013

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

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 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

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

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
UNIVERSITY MEDICAL CENTRE GÖTTINGEN.....Göttingen, DE	
Ethics, Theory and History of Medicine II (Medicine students)	2016
ERASMUS MEDICAL CENTRE.....Rotterdam, NL	
Undergraduate and Graduate courses (Medicine students)	2011-2015
Supervision of bachelor Thesis	

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 2015-2016
 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: 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, 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.

B: 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.

C: 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 PUBLICATIONS

1. Jongsma KR and Sand M. (2016). The usual suspects - why techno-fixing Dementia is flawed. *Medicine Health Care and Philosophy*, published Online First Nov 9th 2016. DOI: 10.1007/s11019-016-9747-9
2. Sand M and Jongsma KR. (2016). Why neural determinism is not real determinism and why mental states cannot act. *AJOB Neuroscience*, 205-207
3. Jongsma KR. (2016). *Advance Directives in Dementia Research - A medical ethical inquiry*. ISBN: 978-94-6050-022-0
4. Jongsma KR, Sprangers M and van de Vathorst S. The implausibility of response shifts in dementia patients. Online First June 2nd 2016, doi:10.1136/medethics-2015-102889
5. 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.
6. Andorno R, Gennet E, Jongsma KR and Elger B. (2016) Integrating Advance Research Directives into the European Legal Framework. 23, 49-64.
7. 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
8. Jongsma KR and van de Vathorst S. (2015). Beyond Competence: Advance Directives in Dementia Research. *Monash Bioethics*, 33(2), 167-18.
9. 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.
10. 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.
11. 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

APPENDIX TALKS (selected)

1. Jongasma 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
2. Jongasma 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
3. Jongasma KR. The relevance of different trust models for representation in patient organisations.
Conference: Trust in Organisations, Copenhagen 24-25.11.2016
4. Jongasma KR. The implausibility of response shifts in dementia patients.
IAB World Congres 2016 Edinburgh 14-17.06.2016
5. Jongasma 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
6. Jongasma KR & Sand M. Towards an Ageless Society.
Workshop Homo Senescens Hannover 1-3.10.2015
7. Jongasma KR. ARDs in dementia research-what do they solve?
IAB World Congres Mexico City 25-28.06.2014
8. Jongasma 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 Congres Mexico City 25.28.06.2014
9. Jongasma KR. Have you lost your mind? - Dementia, identity and advance directives.
IAB World Congres Rotterdam, 26-29.06.2012
10. Jongasma KR. Advance Research Directives in Dementia Research: Ethical and Legal Considerations.
PGBC conference, Kings College, London, 22-24.05.2013

11. Jongsma KR & Sand M: Techno-fixing dementia - what we can learn from STS and TA
University of Mainz, department of medical ethics 26.01.2016
12. Jongsma KR: Advance Directives in dementia research
University of Basel 29.01.2015
University of Tübingen 13.05.2013
13. Jongsma KR & Bos W: Regulation of research with vulnerable groups.
Dutch Central Committee on Research with Human Subjects (CCMO). 24-09.2013