#### THE SUBPROJECTS

Research subproject PHILOSOPHY
Autonomy and Trust
Leader: Prof. Dr. Holmer Steinfath

Research subproject LEGAL THEORY/MEDICAL LAW
Trust in the Law as Trust in the System. Drawing on the
Example of Medicine and its Legal Regulation
Leader: Prof. Dr. Gunnar Duttge

Research subproject THEOLOGY
Autonomy and Trust as Ambivalent Reference-Points
for Christian-based Agents in Hospital
Leader: Prof. Dr. Reiner Anselm

Research subproject FAMILY LAW/MEDICAL LAW
Autonomy Through Family? - The Role of the Family in
End-of-Life Decisions and Reproductive Medicine
Leader: Prof. Dr. Volker Lipp

Research subproject MEDICAL ETHICS
Reproductive Autonomy as Family Autonomy?
On Family and Trust in Reproductive Medicine
Leader: Prof. Dr. Claudia Wiesemann

Research subproject MEDICAL ETHICS/ SOCIAL PHILOSOPHY Autonomy and Trust with Regard to Patient Associations

Research subproject MEDICINE
Autonomy and Trust within the Clinical and Practical
Context of End-of-Life Treatment Decisions
Leader: Prof. Dr. Friedemann Nauck

#### PROJECT LEADER

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### Interdisciplinary Research Group

# AUTONOMY & TRUST

### IN MODERN MEDICINE

KNOWLEDGE PRACTICE NORM



## AUTONOMY & TRUST IN MODERN MEDICINE

KNOWLEDGE - PRACTICE - NORM

Patients' right to self-determination is rightly held in high esteem in liberal and individualized societies. Yet, in a highly complex world defined by scientific and technological rationalities, autonomous agency can only increase when individuals develop trust in persons and trust in systems.

Autonomy is acknowledged as a key concept in modern liberal societies. The same must be true of trust since patients' and health care professionals' vulnerability and insecurity grow with the options of modern medicine. The research project focuses on approaches that attempt to understand autonomy and trust in the medical context relationally and socially. We examine how patient self-determination on the one hand and interpersonal trust as well as trust in social systems on the other depend on each other, how they are generated or undermined and how they are justified. We explore, in particular, the role of organisations and institutions - like the hospital - and collective actors - like the family or patients groups. Which role do they play regarding interpretation and realization of trust and autonomy in medicine?

Seven mutually interdependent research projects from philosophy, medical law, theology, medical ethics and medicine address these questions on a theoretical and conceptual level.

#### SUBPROJECT PHILOSOPHY

#### Autonomy and Trust

Project Leader Holmer Steinfath, Department of Philosophy Research Fellow Anne-Marie Pindur

Up to the present day the concept and the value of individual autonomy are the focus of a broad variety of diverging philosophical interpretations. The accounts of autonomy which have been predominant in the liberal tradition are confronted with the critique of implying an overly individualistic and hyper-intellectualistic model of human subjects. For this reason they do not seem to be appropriate to do justice to the particular difficulties and possibilities of autonomy in the context of health care. This challenge to provide an adequate account of autonomy is encountered by a close scrutiny of the relation of autonomy and trust. Although the approach is a general one, careful attention is paid to the special questions and problems of the health care context. The pursued analysis of the relation of autonomy and trust is meant to allow for a new perspective on autonomy that is not flawed in the way described. Autonomy as understood here is a complex practical capacity of persons which may deserve specific legal protection.

#### SUBPROJECT LEGAL THEORY/ MEDICAL LAW

Trust in the Law as Trust in the System. Drawing on the Example of Medicine and its Legal Regulation

Project Leader Gunnar Duttge, Center for Medical Law

Research Fellows Derya Er, Eike Sven Fischer

As part of basic research of legal sciences, the subproject deals with the term "trust", drawing on the example of medicine and its fields of application. "Trust in the laws" is examined as a form of trust in the system. However, the law does not only have a trust-building but also a trust-threatening effect. Finding the appropriate degree of legal regulation (in the broader sense, i.e. through legislation, dispensation of justice, and executive acting) requires determination criteria, which are worked out with the aid of a notional and methodical concept.

#### SUBPROJECT THEOLOGY

Autonomy and Trust as Ambivalent Reference-Points for Christian-based Agents in Hospitals

Project Leader Reiner Anselm,

Faculty of Theology

Research Fellow Ulrike Butz

The research project explores how autonomy and trust relate to each other in those contexts of clinical practice that are governed by Protestant guiding principles. The central research question asks to what extent traditional theological patterns of argumentation influence the actions of the different agents in the organizational setting of the hospital or are refracted by those action patterns and especially by organizational norms. There are two ways to answer this question. One is the theoretical-theological research which focusses on the end of life in clinical contexts and the meaning of trust in these situations/contexts. The other is an empirical study based on interviews to explore the interaction of autonomy and trust in the organization of a hospital.

# SUBPROJECT FAMILY LAW/MEDICAL LAW Autonomy Through Family? – The Role of the Family in End-of-Life Decisions and Reproductive Medicine

Project Leader Volker Lipp,

Center for Medical Law
Research Fellow, Daniel Brauer

Patient autonomy is a key concept in modern medical law. The research project explores how to determine the relation between individual autonomy and the family as proximal environment from a juridical point of view, considering the family as a trust-based social organization in the context of medical decisions. The focus here is on German Law but results from comparative law will also be included. On the one hand, the research project poses the question of the role of family members in the context of medical treatment at the end of life. On the other hand, the legal position of the partner and the unborn child concerning reproductive measures will be reflected.

#### SUBPROJECT MEDICAL ETHICS

Reproductive Autonomy as Family Autonomy?
On Family and Trust in Reproductive Medicine

Project Leader Claudia Wiesemann,

Dept. of Medical Ethics and History of Medicine Research Fellows Katharina Beier, Katharina Lüttich

The subproject is dedicated to the family as a subject of collective autonomy and as a prototype of trust-based social groups, using the example of reproductive medicine. In this context the following questions will be explored: Should the moral status of the child be defined in terms of trust implying a revision of the prevailing paradigm that tends to capture the child's relations towards others exclusively in terms of (limited) autonomy? With regard to controversial practices in modern reproductive medicine (e.g. surrogacy) we will ask if and how 'reproductive autonomy' can be conceived as 'family autonomy'? In addition to a fundamental discussion of the concept of 'reproductive autonomy', the project will also clarify, from an ethical point of view, the interdependence of a potential concept of family autonomy and the trust-building capacity of the family in modern society as a whole.

### SUBPROJECT MEDICAL ETHICS/SOCIAL PHILOSOPHY Autonomy and Trust with Regard to Patient Associations

Project Leader Silke Schicktanz,

Dept. of Medical Ethics and History of Medicine Research Fellows Isabella Jordan, Katharina Lüttich

This project is dedicated to patient associations as subjects of collective autonomy in bioethical and health policy decision-making processes from a social philosophic and medical ethical point of view. Trust and autonomy are interdependent mechanisms of internal and external legitimacy of collective agents. On the one hand, possibilities and limits of collective autonomy of patient associations regarded as stakeholders are explored on a theoretical conceptual as well as on an empirical basis. On the other hand, the role of trust as to internal decision-making processes and communication as well as the external representation of interests via representatives is investigated from a descriptive and a normative stance.

#### SUBPROJECT MEDICINE

Autonomy and Trust within the Clinical and Practical Context of End-of-Life Treatment Decisions

Project Leader Friedemann Nauck,

Dept. of Palliative Medicine Research Fellows Gabriella Marx, Sonja Owusu Boakye, Bernd Alt-Epping

The numerous and increasingly complex treatment options in highly developed medicine make it difficult for patients to decide for or against a certain type of treatment. The subproject aims at exploring the interdependence of individual autonomy and trust in persons and institutions in the context of decision-making in the course of a life-limiting condition.

To allow for the attendant internal and external conditions of decision-making, which we conceive as a process, the qualitative-empirical research will not only include the patients' but also the medical team's perspectives. These will be analyzed according to the subproject's focus.

#### OUR RESEARCH GROUP

