



**Empirical research in clinical bioethics:
The “Committed researcher” approach.**

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3 **Empirical research in clinical ethics:**
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5 **The “Committed researcher” approach.**
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12 **Abstract**
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17 After the ‘empirical turn’ in bioethics, few specific approaches have been developed for doing
18 clinical ethics research in close connection with clinical decision-making on a daily basis. In
19 this paper we describe the “committed researcher” approach to research in clinical ethics that
20 we have developed over the years. After comparing it to two similar research methodological
21 approaches, the “Embedded researcher” and the “Deliberative engagement”, we highlight its
22 main features: it is patient-oriented, it is implemented by collegial and multidisciplinary
23 teams, it uses an ethical grid to build the interview guide, and it is geared towards bringing the
24 results to bear on the public debate surrounding the issue at stake. Finally, we position our
25 methodological approach with respect to the “is vs. ought” distinction. We argue that our
26 “Commitment researcher” approach to clinical ethics research takes concerned people’s life-
27 building values as the main data, and compare them to the larger normative framework
28 underlying the medical practice at stake.
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49 **Keywords**
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51 Empirical bioethics, research in clinical ethics, Commitment, Embedded researcher,
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53 Deliberative engagement, Committed researcher
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Introduction

Bioethics research has long been considered a normative-philosophical field. But, in the 1980's, empirical researches were developed to explore the way practitioners dealt with medical practices that raised ethical issues in the clinical setting. The field underwent a radical "empirical turn".¹ The term of "Empirical bioethics" has been increasingly used to describe, what Rachel Davies characterizes as "a particular kind of research endeavor that seeks to ask and answer questions of bioethical interest in a way that draws on the strengths of both philosophical and empirical analysis"². But, as she added, « despite the increased prevalence of bioethics research that seeks to use empirical data to answer normative research questions, there is (still) no consensus as to what an appropriate methodology for this would be ». Indeed, a wealth of papers was published that explored how to establish a good balance between empirical investigations and normative analysis in the field³. The philosophical argument that no "ought" conclusions can be drawn from empirical data (what "is") remains strong, and some questions unresolved as to whether, and how, a normative output can be

¹ Borry, P., Schotsmans, P. & Diericks, K. (2005). The birth of the Empirical Turn in Bioethics. *Bioethics*. 19(1), 49-71; Solbakk, J.H. (2004). Uses and Abuses of Empirical Knowledge in Contemporary Bioethics. *Medicine, Healthcare and Philosophy*. 7(1), 5-16.

² Davies, R, Ives J, Dunn M.(2015). A systematic review of empirical bioethics methodologies. *BMC Med Ethics*. 7;16:15. doi: 10.1186/s12910-015-0010-3.

³ Salloch, S., Schildmann, J. Vollmann, & J. (2012). Empirical Research in Medical Ethics. *BMC Medical Ethics*. 13(5), Retrieved from

<https://bmcomedethics.biomedcentral.com/track/pdf/10.1186/1472-6939-13-5>; Hurst, S. (2010). What 'Empirical Turn' in Bioethics? *Bioethics*. 24(8), 439-444

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3 drawn from empirical studies⁴. In this context, researchers who ambition to characterize a
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5 research methodology in empirical bioethics need to position it with respect to this
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7 controversy.
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12 In this paper, we intend to describe our own way to do research in clinical ethics and to
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14 position it relatively to the “is vs. ought” debate, which remains the core of the discussion
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16 about what empirical bioethics is or should be. Clinical ethics recently emerged at the patient
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18 bedside as a way to help healthcare professionals in “the identification, analysis and
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20 resolution of ethical questions or concerns”⁵ that emerge in a clinical case and obstruct the
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22 decision-making as well as the care process. Accordingly, research in clinical ethics can be
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24 considered as being a subset of what has been defined above as empirical bioethics, dealing
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26 specifically with ethical issues emerging in the medical ward. Firstly, we shall describe our
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28 approach and explain why we call it the “Committed researcher” approach and what we are
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30 committed to - the term of commitment echoing our model of clinical ethics consultation:
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32 (name withheld for refereeing purposes). To describe our approach, we shall highlight four of
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34 its main characteristics, without claiming that any one of them is novel in itself; each of them
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36 is currently used in social science as well as in other empirical bioethics research⁶. Rather, it
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38 is their systematic combination that describes our approach as distinctive.
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- 47 (1) The approach is primarily “patient-oriented”: the interviews mostly concern
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49 patients, while other research studies in clinical ethics described in the
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53 ⁴ De Vries, R. & Gordjin, B. (2009). Empirical Ethics and its Alleged Meta-Ethical
54 Fallacies. *Bioethics*. 23(4), 193-201.

55 ⁵ ASBH (2011). Core Competencies for Health Care Ethics Consultation. Glenview IL, 3.

56 ⁶ Mertz, M., Inthorn, J. et al. (2014). Research across the disciplines : a road map for quality criteria in
57 empirical ethics research, *BMC Medical Ethics* 15(17) ; Haimes, E. (2002). What can the social
58 sciences contribute to the study of ethics ? Theoretical, empirical and substantive considerations.
59 *Bioethics* 16(2) :89-113.
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3 literature, including empirical ones, are mostly focused on health-care
4 professionals.
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8 (2) The research team is collegial and multidisciplinary, as is the authors' team of
9 this paper, which includes a philosopher, a sociologist and a medical doctor.
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12 (3) We use an ethics grid to interview people during our research studies: we are
13 mostly inquiring about concerned people's values and the *reasons* they put
14 forward for their choices rather than their bare preferences or other relevant
15 facts. More specifically, the objective is to understand how people argue for
16 their position at the three distinct normative levels of ethics: (i) considering
17 themselves as persons and the respect due to their autonomy; (ii) considering
18 what medicine owes them, in order to respect the beneficence/non maleficence
19 principle; (iii) considering what will be the consequences of the medical
20 decision to be made for several collective interests and for society at large,
21 when the decision respects the patient's position⁷.
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24 (4) The results of the research studies are considered to possibly contribute to the
25 public debate about the ethical controversial issues at stake; as such, the
26 objective of the research is as much professional, i.e. to answer healthcare
27 professional teams' queries, as it is societal, or even political.
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47 In the second part of our paper, we will compare our research approach to two others, also
48 rooted in clinical ethics, the Deliberative engagement and the Embedded researcher
49 methodological approaches. Both were developed in the context of the movement towards a
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54 ⁷ Our ethics grid has been inspired by the four classic principles developed by Beauchamp and
55 Childress' Principles of biomedical ethics, insofar as these ethical references have been inductively
56 identified through a thorough observation of clinical practice. However, these principles are
57 understood in an inclusive rather than exclusive way, and their meaning is not presupposed. Moreover,
58 this generic ethical reference to the four principles in no way implies that we adopt a "principlist",
59 rather than casuistic approach to clinical ethics.
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3 bedside approach to clinical ethics, as for example the one developed by Mark Siegler in
4 Chicago in the late 1970s⁸. The first one, “Deliberative engagement”, was described by Lainie
5 Friedman Ross, a physician and clinical ethicist working at the University of Chicago, in
6 collaboration with other physicians and social scientists (Amy Lemke, Elizabeth Campbell,
7 Colin Halverson). The second one, the “Embedded researcher” approach was developed by
8 Stella Reiter-Theil, a psychologist and clinical ethicist working at the University of Basel
9 (Switzerland).

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21 In the third and final part of the paper, we will position our “Committed researcher” approach
22 with respect to the empirical versus normative debate.
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31 **Part 1- The “Committed researcher” approach**

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35 The premise of our research studies is always the same and can be expressed as follows: if
36 there is an ethical dilemma about the medical decision we are solicited upon, it is because
37 there is an underlying conflict of value between the respective positions of the different
38 stakeholders involved in the clinical case; this situation is generally due to a gap between the
39 normative framework that justifies a given clinical practice and the patient’s personal ethical
40 perspective that would require a different medical decision than the one suggested. Moreover,
41 if the same ethical dilemma arises in a similar way in a series of successive cases in which the
42 same decision is at stake, we suspect that it might reflect a new emerging societal trend,
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54 ⁸ Siegler, M. (1982). Decision Making Strategy for Clinical-ethical Problems in Medicine, *Arch*
55 *Internal Medicine*. 142(12), 2178-2179; Singer, P., Pellegrino, E. & Siegler, M. (2001). Clinical Ethics
56 Revisited. Retrieved from [https://bmcmedethics.biomedcentral.com/track/](https://bmcmedethics.biomedcentral.com/track/pdf/10.1186/1472-6939-2-1)
57 [pdf/10.1186/1472-6939-2-1](https://bmcmedethics.biomedcentral.com/track/pdf/10.1186/1472-6939-2-1)
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3 founded on authentic ethical arguments. The goal of our research activity is to verify that such
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5 a gap exists, what exactly it consists of, what the ethical arguments behind the patients' claims
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7 are and to explore whether the normative framework should be amended. We do so by using
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9 an approach we progressively elaborated within our research practice and which we can
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11 describe by highlighting four of its main characteristics.
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19 ***a. A "patient-oriented" approach***
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24 It is when people are confronted with issues that are essential to them, either because they
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26 deal with life and death choices, or because they involve other important personal dimensions
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28 of their own self, such as gender identity, sexuality, conjugality or procreation, that they are
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30 likely to hold positions that are at odds with the current normative framework. Their "moral
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32 space", to use Charles Taylor's expression⁹, comes into conflict with the ethical norms
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34 grounding an existing clinical practice. They may refuse the standardized "good" clinical
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36 practice proposed, if they consider it to be in opposition to their own personal choices and
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38 values. Because they are the ones who will directly pay for the (possibly significant)
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40 consequences of the decision in their own body as well as in their life, their arguments should
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42 be carefully considered, not only in relation to the principle of respect for autonomy but also
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44 insofar as they might bring to light the fact that the referent normative system might fail to
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46 account for their own values and choices. We systematically conduct long face-to-face
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48 interviews with the patient and/or her representatives. This is all the more important that their
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50 voice may be downplayed or given less legitimacy in the healthcare system. However, we
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⁹ Taylor, C. (1989). *The Sources of the Self*. Cambridge, Mass: Harvard University Press
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3 meet with healthcare professionals as well in order to investigate their ethical arguments in a
4 detailed manner. Ultimately, our aim is to unveil the values and reasons of different
5 stakeholders in order to highlight the ethical conflict they may give rise to
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12 ***b. A collegial and multidisciplinary research team.***
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17 In do research in clinical bioethics we choose to always work as a multi-disciplinary team.
18 Usually, our research teams are composed of three or four different researchers, coming from
19 medicine, philosophy, sociology, psychology, law, etc. This allows us to investigate the
20 ethical arguments from different perspectives. A second reason for our choice to work
21 collegially, is that it helps us be more reliable in the data we collect and the results we
22 uncover, insofar as it forces us to take into account the diversity of understanding of all the
23 researchers on the team. It helps guarantee the reliability of the results and the quality of the
24 empirical approach. Last but not least, we hope that in working in a multidisciplinary way, we
25 might better succeed in bridging the gap between society at large and the medical field than in
26 working from a unique perspective.
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42 To illustrate this aspect of our approach, we will briefly present the study we conducted a few
43 years ago about the experience of withdrawing artificial nutrition and hydration (WANH) in
44 neonatal intensive care units (NICUs). The research team was made up of four researchers: a
45 philosopher, a legal scholar, a clinical psychologist and a medical doctor. After realizing, as
46 clinical ethics consultants, that the procedure was often an ordeal for caregivers and parents,
47 we decided to undertake a systematic study of how they viewed the practice in retrospect. We
48 explored the cases of infants that underwent WANH as a palliative care practice in an end-of-
49 life context; we conducted interviews with their parents as well as with some members of the
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3 healthcare teams that implemented WANH on these babies¹⁰. Being a multidisciplinary team
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5 of four researchers allowed us to compare our respective analyses of the interviews. We
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7 discussed our discrepancies in categorization, choice and interpretation of significant
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9 quotations, until we reached a consensus. This process contributes to the intersubjective
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11 validity and quality of the conclusions¹¹.
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17 The diversity of our research team also allowed us to gain a deeper understanding of what the
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19 different stakeholders expressed. The medical doctor on the research team was instrumental in
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21 understanding the subtleties of the medical conditions the babies included in the study
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23 suffered from, and to precisely describe medical practices. She was also better able to make
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25 doctors clearly express the medical as well as the ethical and legal rationale for the clinical
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27 strategy they chose to implement and to make them elaborate on the ethical unease they
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29 experienced as professionals. The clinical psychologist was very receptive to the
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31 psychological violence that had been felt, especially by parents, but also by the nurses that
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33 had to participate in implementing the decision to stop feeding a little one. This argument was
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35 one of the strongest that emerged from our analysis and that led us to warn about the ethical
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37 risks involved in the practice. The philosopher and the legal scholar concentrated their
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39 analyses on the role of “intention” behind WANH. The philosopher underlined the tension
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41 inherent in the notion. Indeed, whereas the stated intention—especially for doctors—was to
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43 let nature take its course, it was often clear that in the parents’ eyes, WAHN was intended as a
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45 means to prevent the baby from surviving. This ambiguity is the reason why many
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47 stakeholders, doctors as well as nurses or parents, felt that the practice was hypocritical, a fact
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56 ¹⁰ [reference withheld for refereeing purposes]

57 ¹¹ Alonso, W., Hupcey, J.E. & Kitko, L. (2017). Caregivers’ Perceptions of Illness Severity and End of
58 Life Service Utilization in Advanced Heart Failure. *Heart and Lung*. 46, 35-39.
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3 that deepened their moral qualms. According to the legal scholar, the study brought out some
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5 elements that undermined the strength of the intention concept that was the cornerstone of the
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7 2005 law regulating End-of-Life practices in France¹². Indeed, she insisted, the main
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9 preoccupation of French law-makers at the time, was to recommend to always act in such a
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11 way as to *let* death occur, and to prohibit any kind of active assistance in dying. But, at the
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13 same time, the WANH law provided the means to precipitate death with a high degree of
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15 certainty. Wasn't it contradictory?
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20 Our four different and combined analytical perspectives allowed us to propose an ethical
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22 understanding of the unease expressed by the people who experienced first-hand this new
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24 WANH practice in NICUs.
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29 ***c. An ethics grid to analyze the content of interviews.***
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34 To explain what we mean by this third characteristic of our methodological approach, we will
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36 refer to another research study we recently conducted.
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41 We will not summarize the conclusions of the study, but rather use it to illustrate the way we
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43 conduct our interviews. The issue at stake was the new techniques that now make it possible
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45 for women to freeze their own eggs at a young age (<35 yrs.) in order to ensure their
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47 availability in case they experience difficulties becoming pregnant because of ageing. Egg-
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49 freezing for age reasons is still illegal in France¹³, even if it is quite easy for French women to
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51 have access to it in foreign countries close to France such as Belgium, Spain or England. To
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53 contribute to the public debate about whether regulations in our country on this issue should
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57 ¹² Law n. 2005-370 of April 22, 2005, relative to patients' rights and end-of-life.

58 ¹³ It may change in the next few months with the new bioethics law, which is currently in discussion in
59 the parliament.
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3 be changed, we decided to implement a research study to better understand the different
4 positions at hand. We led in-depth qualitative interviews with childless women still in
5 reproductive age as well as with their gynecologists. We began by telling our interlocutors
6 that it was crucial for us to clearly understand their position in order to be able to enlighten
7 the public debate, because they were the ones being directly impacted by the policy. We
8 mostly tried to identify the *values* underlying their position. We investigated these values at
9 the three usual normative levels that the principlist ethical approach has highlighted: (1)
10 *Respect of patient's autonomy*: what these women have to say from the standpoint of their
11 own autonomy; would they be interested by the technique for themselves or not, and for what
12 reasons; how far do they consider that society has a right to interfere with their reproductive
13 liberty and why; (2) *Beneficence/non maleficence*: what do these women consider medicine
14 owes them in order to respect these principles; how should their gynecologists inform them
15 about fertility issues and about the new techniques of egg-freezing, at what age and in which
16 terms; (3) *Justice and the role of society with respect to this question*: should the law evolve
17 and authorize access to these techniques, and why; should the cost of the procedure be
18 covered by the national public health system and why?¹⁴

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45 ***d. The societal or political dimension of our research studies.***
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50 Indeed, after having realized that a gap exists between the normative framework related to a
51 medical practice at a certain point in time, and the value systems of people concerned by the
52 technique, we usually bring our data to the public debate.
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57 ¹⁴ A chapter in a collective volume to appear later this year discusses these results in the larger
58 framework of the regulation of ART : [names and title withheld for refereeing purposes] in : Watson
59 K. & Chor, J. Reproductive Ethics in Clinical Practice. New York : Oxford University Press, USA.
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5 We did that with the two studies we described above. Regarding our research about WANH in
6 NICUs, its results clearly pushed healthcare teams to change their practices. They now act in
7 such a way that lets the parents understand that it is not WANH that provoked their baby's
8 death, but the underlying disease¹⁵. Moreover, we were auditioned as researchers about our
9 results when law-makers decided in 2016 to revise the End-of-Life law in France¹⁶. And it
10 might well be that the terms of the law changed at least in part because of our results and the
11 public debate that ensued: the new law clearly states that WANH should always be
12 implemented together with deep and continuous sedation, at least in patients that are unable to
13 express whether they suffer or not, as newborns are.¹⁷
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28 Concerning our second example, its results also contributed to feed the public debate about
29 whether it is appropriate to change regulations in France and to authorize egg-freezing for
30 reasons of age. With that purpose in mind, we organized a public conference to present our
31 results and to compare them to other existing positions on the topic. We invited national as
32 well as international experts, together with the women who participated in our study. Many
33 attended and actively participated. The debate is still ongoing in our country and the political
34 decision has yet to be made. Our study has facilitated the inclusion of egg freezing for social
35 reasons among the topics to be discussed during the revision of the bioethics law in 2019. As
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47 ¹⁵ [Reference withheld for refereeing purposes]

48 ¹⁶ A report by Didier Sicard, the former President of the French" quoting from our research results,
49 had highlighted the fact that WAHN might expose patients to a long and painful death: "When a
50 person in an end-of-life situation (...) explicitly asks for life-prolonging treatment, including
51 nutrition and hydration, to be withdrawn, it would be cruel to 'let her die', or to 'let her live', without
52 letting doctors perform an action that would hasten death" (See Sicard, D. (2012). Solidarity and end-
53 of-life, p.123. Retrieved from [http://www.ladocumentationfrancaise.fr/var/storage/rapports-
54 publics/124000675.pdf](http://www.ladocumentationfrancaise.fr/var/storage/rapports-publics/124000675.pdf)).

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57 ¹⁷ To ensure this outcome, a new revision of the end-of-life law passed in 2016 has introduced the
58 right to receive "deep continuous sedation" under certain conditions (law n. 2016-87 of February 2nd,
59 2016)
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3 researchers, we were auditioned by many of the official bodies charged with writing
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5 recommendations in the context of the revision process.
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12 **Part 2- The “Committed researcher” approach: similarities and differences**
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14 **with respect to the “Deliberative engagement” and the “Embedded**
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16 **researcher” methodological approaches**
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21 We will describe the “Deliberative engagement” and the “Embedded researcher”
22 methodological approaches before coming back to our own, and explain why we call it the
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24 “Committed researcher”.
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31 **a. The “Deliberative engagement” methodological approach**
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35 The “Deliberative engagement” approach seeks to “increase knowledge and to inform
36 institutional policies”¹⁸. It strives to explore the potential divide between a bioethics policy
37 (normative framework) and citizens’ understanding of, and attitudes towards, this particular
38 policy. The normative dimension serves as the primary entry point to ground a research
39 question, while the purpose of data collection is to understand how the public perceives this
40 normative aspect. Hence, in a study on biobank participation and returning research results to
41 participants¹⁹, the researchers asked a number of preliminary ethical questions: how does one
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53 ¹⁸ Lemke, A., Halverson, C. & Friedman Ross, L. (2012). Biobank Participation and Returning
54 Research Results: Perspectives from a Deliberative Engagement in South Side Chicago. *American*
55 *Journal of Medical Genetics* (Part A). 158A, 1029-1037.

56 ¹⁹ Halverson, C. & Friedman Ross, L. (2012). Incidental Findings of Therapeutic Misconception in
57 Biobank-Based Research. *Genetics in Medicine*. 14, 611-615.
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3 assess the risks and benefits of contributing biological samples to a biobank when the research
4 questions evolve over time? What kind of consent should be sought? Should it be sought as
5 new research questions emerge and are tested on the original samples? Which privacy
6 protections should be put in place? Should aggregate research results be given to individual
7 participants?
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17 The study showed that participants were willing to give broad consent to studies that store and
18 share their genetic information. It also underlined that they wanted to access the results of
19 such studies to improve their well-being and that of their children. As such, justice emerged as
20 a salient issue for them. The research team underlined it and concluded that the broad consent
21 expressed by participants, should benefit them if new treatments emerge as a result.
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31 To define this approach, the term “engagement” is important. It refers to “a modified form of
32 deliberative democracy”²⁰ that promotes citizens’ participation to general normative
33 decisions. As Lainie Friedman Ross writes, “the method views deliberation as central to
34 ensuring that participants are informed and can discuss the specific policy questions [...] so
35 that public participation can become meaningful, and to allow informed citizens to *engage*
36 critically in discussion and policy”²¹. The “Deliberative engagement” researcher recognizes
37 that it is crucial that principles underlying a particular bioethics practice are “inclusive of the
38 values and beliefs of their participants”²². Here, the term “engagement” refers to the subjects
39 of the research, and more generally the users of the medical technique at stake, those who are
40 “engaged” in it.
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57 ²⁰ *Ibid.*

58 ²¹ *Ibid.*: 1030.

59 ²² *Ibid.*: 1029.
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3 **b. The “Embedded researcher” methodological approach**
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8 The objective of the “Embedded researcher” approach is to observe and document decision-
9 making processes in clinical situations that are challenging in terms of ethics: “The aim and
10 the benefit of our empirical research are to provide a realistic view of the decision-making
11 process in the field.”²³ This approach aims at observing how a given clinical practice, defined
12 by certain guidelines (normative dimension) unfolds in hospital wards (empirical aspect). In a
13 study on critical decision-making in neonatology, researchers observed and documented
14 everyday clinical practice related to critical decision-making and end-of-life care. The
15 researchers found that in the vast majority of cases (90%), the medical team had an ethical
16 discussion on critical decision-making, but that sometimes the wishes of the parents were not
17 taken into account²⁴. In this and in similar studies (withholding of treatment in intensive care;
18 doctor-patient conversation at the end of life in oncology), the “embedded” researchers
19 observed clinicians and how they integrated ethical reasoning in their everyday practice.
20 Researchers using this approach remain distinct from the primary people involved, but are
21 sufficiently close to them that they understand the subtle details of clinical practices. This
22 allows them to better check how norms are integrated by the people involved in a given
23 practice. Here, the term “embedded” describes the attitude of the researchers that must remain
24 strictly observational, while in the Deliberative engagement approach, the term “engagement”
25 refers to the stakeholders themselves.
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54 ²³ Reiter-Theil, S. (2004). Does Empirical Research make Bioethics more Relevant? ‘The Embedded
55 Researcher’ as a Methodological Approach. *Medicine, Health Care and Philosophy*. 7, 17-29, p. 22.

56 ²⁴ Hentschel, R, Lindner, K. , Krueger, M. & Reiter-Theil, S. (2006). Restrictions on ongoing Intensive
57 Care in Neonates : a Prospective Study. *Pediatrics*. 118(2), 228-234.
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3 The two methodological approaches are similar in that they take a normative issue as the
4 starting point of the research studies. But the questions that each approach focuses on are not
5 the same: the “Embedded researcher” explores whether norms are correctly applied on the
6 ground, while the “Deliberative engagement” researcher is concerned with whether people
7 *engaged* in the practice, i.e. directly concerned by it, feel the relevant norms are ethically
8 appropriate or not. They also differ from each other in that a researcher using the
9 “Deliberative engagement” approach concentrates on health policies, while the “Embedded”
10 researcher studies clinical practices.
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24 **c. *The “Committed researcher” approach***
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28 We shall start with a brief definition of “commitment” and then show how the term is
29 appropriate to describe our approach to empirical bioethics. Social scientists and philosophers
30 use “Commitment” to describe a special way of accounting for social action: “Commitment
31 implies not only the end point but also the motivational process involved. It has enduring
32 motivational quality that conveys energy, direction and investment. It is not just that people
33 have goals; it is that they are committed to these goals, which allows them to strive and persist
34 against negative conditions. People appraise their commitments as important. They are willing
35 to put efforts into them, make them visible to significant others, feel good when they expect to
36 achieve them or are making progress in their direction, and are distressed if they do not”²⁵. As
37 the passage quoted indicates, commitments share two features: first, they structure
38 engagements into a series of coherent actions to the point that they help build a collective
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57 ²⁵ Novacek, J. & Lazarus, R.S. (1990). The Structure of Personal Commitments. *Journal of*
58 *Personality*. 58, 693- 715, p. 696.
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3 identity. Second, they involve the pursuit of important common goals, even against personal
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5 interests.
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10 We feel the term “Commitment” is particularly appropriate to describe our research
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12 methodological approach, as it is to describe our way of doing clinical ethics consultations²⁶.
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14 In both cases, our main goal is to contribute to improve the quality of care for patients on a
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16 case-by-case basis as well as, more indirectly, by enlightening the gap, when it exists,
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18 between the normative ethical framework of society at a given time, and what patients expect
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20 from medicine. This is the reason why, in our ethics consultations activity, we always follow
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22 up on the individual cases we have been solicited upon in order to explore to what extent our
23
24 conclusions have some impact on practices, as we have described in our paper on our model
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26 of clinical ethics consultation. According to the same “committed” perspective that we adopt
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28 in our research activity, we multiply the opportunities to discuss our results, and to contribute
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30 to public debates, as a way to remain more largely engaged in social action, besides doing
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32 clinical ethics.
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40 How does the “Committed researcher” compare to the “Deliberative engagement” and the
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42 “Embedded researcher” approaches? Firstly, like “engagement”, the “commitment” approach
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44 gives pride of place to the view of concerned people, since it also assumes that they have their
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46 personal expertise. However, committed researchers are not interested in knowing what these
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48 people think *about* a norm, but how they live and decide *within* it, or in spite of it.
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50 Researchers strive to seize the inner values of people as they try to decide about their own
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52 lives by deploying what Joseph Raz calls their “building values” within the context of
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59 ²⁶ Reference withheld for refereeing purposes.
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3 accepted norms, and the tensions they experience²⁷. Furthermore, committed researchers are
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5 not themselves “embedded” in a given practice. Rather, it is the stakeholders themselves who
6
7 tell researchers how the practices they are involved in work. Researchers’ role is to elicit
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9 values and preferences from concerned people and help them develop their arguments. They
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11 are committed in two ways: firstly, they are committed to making sure that the voices of all
12
13 concerned people are heard in a fair way, which implies that sometimes the patients’ voice
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15 has to be reinforced to equal that of the other parties involved in the decision; secondly, they
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17 are engaged to take all necessary steps to make the material that emerges in the studies
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19 relevant to the public debate about existing norms, and their need to evolve or to be
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21 adjusted²⁸.
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30 **Part 3- The “Committed researcher” approach and the empirical-**
31 **normative debate about bioethics research**
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40 A good way to explore to what extent a new methodological approach in empirical ethics
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42 research combines the empirical and the normative aspect is to answer two questions: *what* it
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44 explores—facts or values—, and *how* it manages the transition from the understanding of
45
46 what “is”, to the recommendation of what “ought to be”. In the following section, we will
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48 compare the “Committed researcher” to the other two methodological approaches we took as
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50 references in clinical ethics research—the “Deliberative engagement” and the “Embedded
51
52 researcher” approaches—with respect to these two issues.
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57 ²⁷ Raz, J. (2003). *The Practice of Value*. Oxford: Oxford University Press.

58 ²⁸ Spranzi, M. (2013). Clinical Ethics and Values: how do Norms evolve from Practice? *The Journal*
59 *of Medicine, Healthcare and Philosophy*. 16(1), 93-103.
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5 As to the kind of data collected and analyzed, the “Deliberative engagement” approach
6 focuses on individual attitudes and beliefs towards a specific policy. In the study on biobank
7 participation mentioned above, researchers assessed the opinions held by participants, and
8 how they might have changed through the deliberation process, inspired by deliberative
9 democracy²⁹. Participants’ values were not explored *per se*, and such as participants
10 understood them. Rather, ethical values, in this case justice, was recovered indirectly from
11 the analysis of beliefs and attitudes expressed: “[...] Participants wanted to be sure that if
12 discoveries from biobank-based research yielded new treatments, they would have equal
13 access to those benefits.”³⁰.
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28 The “Embedded researcher” framework also mostly explores facts, either practices or
29 attitudes, rather than values. By interviewing stakeholders (in some studies, only physicians,
30 in others physicians and patients or their next of kin), researchers map clinical practices and
31 how they are implemented. Researchers thus unveil what is ethically problematic for
32 individuals and groups of individuals (for instance, the fact that clinicians find stopping a
33 treatment ethically more problematic than not initiating it). Stakeholders’ values are not
34 probed as such but they may emerge in the discussion about clinical practices.
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47 In comparison with the two approaches described above, the “Committed researcher” directly
48 explores values and reasons for action that concerned people use to justify their positions. For
49 example, when we decided to study the ethical aspects of WAHN practices, we did not look
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55 ²⁹ Gutmann, A. & Thompson, D.F. (2004). *Why Deliberative Democracy?* Princeton, NJ: Princeton
56 University Press; Fishkin, J.S. (2009). *When the People Speak: Deliberative Democracy and Public*
57 *Consultation*. Oxford/New York: Oxford University Press.

58 ³⁰ Lemke, Halverson, & Friedman Ross, *op. cit.* note 12, p. 1035.

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3 at what people think *about* the practice, we investigated *why*, and under which conditions—in
4 relation to their own *values*, as they understand and express them—involved people, both
5 parents and healthcare professionals, suggested and/or accepted (or did not accept) to use
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10 WAHN in a particular end-of-life situation.

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14 This focus has important consequences as far as the second point is concerned: to what extent
15 are researchers allowed to derive, or at least suggest, the “ought” from the “is” —the norms
16 from the facts—, and how can they justify the move? On this second criterion, the
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19 “Deliberative engagement” approach does not, strictly speaking, aim at deriving an ethical
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22 standpoint (‘ought’) from its empirical data (‘is’). Instead, it sheds light on how a normative
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25 framework (a bioethics-based institutional policy) is perceived by a certain category of
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28 stakeholders. In other words, how stakeholders view a particular policy. In the case of
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31 biobank participation, what are patients and patients’ parents’ attitudes towards participation,
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34 broad consent, return of research results? The researchers then underline the lessons learned
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37 from their empirical analysis and come close to suggesting adjustments to the policy at hand.
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40 Can this be considered a normative result? The answer is open to discussion. In any case, we
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42
43 can argue they come to the very frontier between ‘is’ and ‘ought’.

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46 The aim of the “Embedded researcher” is to elucidate the mechanisms at work in the relations
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49 among different stakeholders in hospital wards (patients, their next of kin, medical teams) and
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52 to highlight ethical issues that may have been ignored or addressed in an unsatisfactory
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55 manner. The results of such studies are used to further ethical discussions about specific
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58 clinical practices and to offer adjustments where ethical problems or bottlenecks have been
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61 identified: “The studies have revealed very clear and concrete problems and yield a good
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64 starting point for tailored interventions such as ethics training, focused work with the team or

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3 the development of ethics consultation well suited to the practical requirements and needs.”³¹.
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5 The aim is thus to work within an existing normative framework, to propose modifications
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7 which might improve its implementation, but not to call its justification into question. Formal
8
9 normative outputs are not systematically elaborated from the results of the “Embedded
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11 researchers” empirical studies. Should we consider that because its ambition is not to
12
13 fundamentally change an ethically informed clinical practice or guideline, this approach stays
14
15 within the realm of empirical work and analysis? The answer varies depending on the studies.
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17 In discussing the results of some of them, Reiter-Theil underlines that some descriptive
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19 results, which she calls ethically relevant facts, are grounded in the empirical field, but that
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21 they have clear normative implications at the individual and at the political or institutional
22
23 levels. The “Embedded researcher” methodological approach thus does not shy away from the
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25 normative dimension, at least in some of its studies. In both cases, the normative element is
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27 added by the researcher herself and not directly inferred from the stakeholders’ own words.
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35 The “Committed researcher” shares with the “Deliberative engagement” and the “Embedded
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37 researcher” approaches the fact of supposing that what *is*, is indeed relevant for evaluating
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39 what *ought* to be. However, since we consider that the most ethically relevant material
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41 collected through the research is people’s values and reasons for engaging in a given practice,
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43 the gap is not so much between the empirical and the normative but rather between different
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45 kinds of values: those that ground the positions of the different stakeholders directly
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47 confronted with the clinical situation at hand and those that underlie the existing norms, be
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49 they legal or moral. The question is not: “Do affected people approve of the existing norms?
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51 But rather: “Are existing norms in contradiction with their personal values?” Indeed, this may
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53 well be the case. For example, the actual norm in France states that whenever doctors consider
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59 ³¹ Reiter-Theil, *op. cit.* note 17, p. 28
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3 that artificial hydration and nutrition are futile, they can withdraw them even in babies, and let
4 them die. However, what some involved parents value most is a good-timed, peaceful and
5 proper death. This in turn can only be achieved by acknowledging that WAHN is not a way of
6 letting a natural dying process take its course, but that it implies intending death, what the law
7 denies, but parents consider as perfectly acceptable, and even conducive to facilitating death
8 in various ways. Once these values have emerged during our qualitative interviews, the next
9 question is: shouldn't current norms be changed in such a way as to respect the important
10 parents' values unveiled by the research? Although research results do not dictate what a new
11 norm should be like, they directly suggest a direction in which the norm should evolve:
12 instead of authorizing a lethal injection, the law might make it explicitly acceptable, once
13 WAHN has been decided, for HCP to shorten the dying process in such a way as to make it
14 acceptable to parents, instead of letting a baby starve for weeks.

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16
17 In the three approaches, the "Deliberative engagement", the "Embedded researcher" and the
18 "Committed researcher", norms are the entry point into the investigation: in the first two, the
19 purpose of the research is to discover how norms are accepted and used by studying facts and
20 practices. In the third one, by contrast, the research is implemented because a standard clinical
21 practice, designed to respect some existing norms, causes frequent ethical dilemma. It is the
22 tension between the norms and concerned people's values that is explored. The committed
23 researcher directly explores life-building values, values that people use to engage in a given
24 practice or to resist it, rather than the values underlying the existing norms or their
25 relationship to practices. As such, the normative dimension is at the core of our interest in the
26 commitment approach: we explore it when interviewing the different stakeholders; we
27 question it in the analysis of our material; and we bring it to the public debate for discussion.

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3 We don't usually propose a new normative framework, but show how the existing one is
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5 challenged by patients.
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11 **Conclusion**

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17 As we implemented our clinical ethics program, we had to imagine how to respond to our
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19 colleagues' requests to help them address the ethical challenges they face in their daily
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21 clinical practice. We therefore developed our research approach in a pragmatic and
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23 experimental way, without relying on *a priori* methodological references, at least at the initial
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25 stage. Some years later, we felt the need to analyze retrospectively our own way of doing
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27 research and to compare it with other empirical approaches used in clinical ethics research.
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29 We named our own approach the "Committed researcher" approach for the reasons we
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31 described in this paper. We found that it is very similar to other approaches, at least the ones
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33 that were developed concomitantly with the turn towards a bedside approach to clinical ethics,
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35 as are the "Deliberative engagement" or the "Embedded researcher" methodological
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37 approaches. Our own approach shares with them the concern for engaging the relationship
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39 between the empirical and the normative dimensions and for finding a way to bridge the "is
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41 vs. ought" distinction. However, the "Committed researcher" differs from the other two
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43 insofar as she thinks that the purpose of clinical ethics is not to judge how norms should
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45 evolve in order to meet people wishes or experiences, and neither to suggest how clinical
46
47 practices should evolve in order to better meet the existing norms. Rather, she presupposes
48
49 that norms are always somewhat in tension with practices, and that they are in need of
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51 perpetual questioning and adjustment. Indeed, the bioethics norms are constantly challenged
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53 by a continually changing social reality. According to the "Committed researcher", the role
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3 of bioethical norms should not be to dictate practices but rather to establish a coherent and
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5 viable framework to regulate unfolding practices in a way that honor at best the essential life-
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7 building values of all the concerned people.
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For Peer Review