Experienced Pioneers:  
Uncertainty and Medical Innovation In Neonatal Care  

Jessica Mesman  


Scope and content

The medical-technological advances of the past decades have been such that entirely new and unprecedented opportunities for diagnosis and treatment have become available. In hindsight we clearly see what new medical technology does and what it does not, but initially the intrinsic promise of technology is still fully at work. From this perspective new technological developments are conceived as an answer to each and every problem. It is commonly assumed that with better equipment the problems encountered by today’s physicians will be solved, implying that physicians have to broaden and refine their technological arsenal even further.

However, a substantial amount of qualitative studies demonstrate how new medical advances not only improve medical processes but also complicate them by giving rise to new uncertainties about symptoms and expectations involving diseases and health disorders (e.g Franklin and Roberts, 2006; Lock, Allen et al, 2000). Technological development creates not only new treatment options, but also new questions, new dilemmas and new tragedies. Moreover, these challenges with respect to medical innovations do not limit themselves to medical practices but also have ramifications far beyond biological laboratories and hospital wards. A number of studies on recent medical innovations show how their implications can be found in other realms of society as well, such as in regulatory bodies, insurance practices and family life (see Brown and Webster, 2004; Conrad and Gabe, 1999; Elston, 1997; Franklin and Lock, 2003, Webster, 2006).

Although there has been substantial research on how diagnostic and prognostic innovations change the ways in which we think about issues of life and death, health and disease, and quality of life, there is still little insight into the effects of these societal responses on actual treatment. In other words, the effects of medical innovations have quite specific consequences for medical intervention processes. What are the implications of the various social responses to new medical technologies for the day-to-day experience of health workers? What are, for instance, the consequences of the medical domain’s public accountability for the actual intervention process? How do legal frames affect hospital practices? What are the consequences of changing perceptions on life and death in society for the decision-making process in medical care practices? In what ways are particular social concerns reflected by medical practices inside the hospital walls and how are these effects reshaped in the vortex of activity? This feedback loop needs to be taken into account in our study of medical innovations.

Given the increasing intricacy of the overall health care process, it is also relevant to go beyond the effects of medical and societal outcomes and focus on what actually takes place at the interface of diagnosis and prognosis, of actors and technology, of medical facts and moral concerns. In other words, it seems
increasingly important to examine the interlinked yet discrete processes of diagnosis and prognostication, of establishing facts and values. With the introduction of new medical technologies the diagnostic and prognostic processes have become a much more complicated trajectory, involving more options, other risks, new decision moments, and more pronounced dilemmas for everyone involved. Therefore, the multiple lines of action and reasoning in the day-to-day experience of health care workers are as much in need of scrutiny, notably as to how these activities intersect.

This book provides insights into both the reshaping of the societal responses to health innovations in the concrete work setting of medical care practice, and into what actually happens at the interface of processes of diagnosing and prognostication, of actors and technology, and of establishing facts and values. There is a need for this type of study, I believe, because it is precisely the established routines and practices of actual medical intervention that are constantly destabilized in a health care system that is primarily marked by rapid change. The ensuing uncertainties have contributed to the emergence of a ‘grey area’, one where the established protocols and the conventional answers found in medical handbooks no longer apply. Yet, as before, many clinical conditions still require immediate medical attention and intervention. As I will argue, a focus on the complexities of human decision-making in the face of uncertainty helps us to identify not only the implications of societal responses for concrete medical intervention and decision-making processes, but also what actually happens at the interface of the different constituents of medical practice.

As an outpost of today’s health care system where the pioneering spirit of medicine reigns supreme, the neonatal intensive care unit (NICU) can serve as an exemplary case for studying some of this system’s vulnerabilities triggered by this permanent dynamic of change. Neonatology is specialized in the care and treatment of newborns. Very young babies end up in the NICU because their lives are seriously at risk on account of their prematurity, complications at birth, congenital diseases, or potentially lethal infections. The NICU is a unique domain for two reasons in particular: this practice finds itself on the cutting edge of medical science and many of its interventions give rise to ethical concerns. As such the NICU constitutes a domain where the challenges and opportunities of new medical knowledge and technology converge. Each chapter of the book zooms in on the NICU as a contact zone of hi-tech medicine and exceptionally vulnerable human beings. In today’s technological culture the NICU has become a site of rapidly changing medical norms and values. This is why this study concentrates on the roles of actors, the meanings of data and the functions of devices. The book follows doctors and nurses in their day-to-day production of workable knowledge and reliable performance, while also the role of parents as knowledge producers is considered. Based on ethnographic research in the Netherlands and the United States, this book provides a multi-level analysis, the objective of which is to identify how treatment trajectories are preserved in uncertain circumstances in ways that are frequently unrecognized or misunderstood without such analysis.

This book, however, should not be viewed as strictly an inductive effort, or as ‘just another case study. Instead, its analytical scope and effort can be understood as an act of exnovation: that which is already present in practice is foregrounded and the implicit is made explicit. Importantly, more than innovation, exnovation does justice to the creativity and experience of the actors involved, as they assert themselves in the particular dynamic of medical practice. It offers a new perspective on their competence and the structure that comes with specific styles of ordering day-to-day practices. Moreover, the analyses in this book elucidate not only the complexity of treatment trajectories and the
inventiveness of those involved, but also the limited power of medical technology, and formal protocols and regulations to solve medical problems.

**Specific features**

*The co-production of facts and values*

The neonatology practice, with its checks and balances and various inputs ranging from technologies and numbers to emotions and uncertainties, is a reflective practice – one in which moral considerations play a major role. This is the case not just in terms of formal ethics or in the retrospective reflection of those explicitly named and recognized as actors, but it is also interwoven with the dynamic of the daily course of affairs and the ordering mechanisms in this practice. Positioning itself in this tradition of empirical ethics, this book considers how the actors – nurses, physicians, and parents – actually arrive at decisions and how they subsequently handle them, rather than addressing the ethical correctness of medical decisions. In other words, it is not concerned with whether the NICU actors follow the proper ethical guidelines, nor is the focus on an evaluation of the existing guidelines and procedures. This implies that the arguments in this book are not designed to support a particular position in ethical debates. Instead, this book, based on its specific concerns, pursues to give another perspective on today's NICU moral practice, and, as such, it may generate insights that can be interesting for neonatology or, for that matter, the ethics of health care. A consideration of how medical processes are resumed, adjusted, and perhaps jumpstarted again provides insight into the ways in which actors in the NICU practice make moral decisions and, potentially, stretch moral boundaries. By situating such decisions within a wider spatial and temporal frame they appear in another light and it becomes possible to reflect on the nature of the moral choices and prognostic facts involved. In the context of the NICU, morality means *demarcation*: the fixing of a moral turning point, a boundary that cannot be crossed. This demarcation is construed on the basis of a range of divergent activities by several actors in various sites and at different moments. Custom-made morality requires testing the robustness of facts and the elasticity of moral categories, exploring the room for medical action, searching the right words, creating a sense of shared concern, exploring disciplinary boundaries and distributing responsibility, and learning to deal with the consequences of decisions.

*The intermediate zone*

This book articulates the intermediate zone to answer the question of how actors succeed in acting promptly and adequately in situations of diagnostic and prognostic uncertainty and doubt – situations that the actors to some extent actively pursue in this particular setting. In many occasions the NICU staff finds itself in uncharted territory, because a specific technology is new or a certain intervention trajectory poses unknown risks, especially given the extreme fragility of the patients. How, then, do all those involved make sure that the medical intervention process does not founder? In order to identify the various routines and the often, implicit methods and strategies of intervention used by the NICU staff, this book pays special attention to the relationship between the general and the particular; man and machine; formal protocols and the vortex of the treatment trajectory; public and local accountability; facts and values; risk and responsibility; expectation and experience. However, this book is concerned not so much with either one or the other, e.g. the collective structures or the individual case, but with the *in-between zone*, the hinge between the collective and the individual. This intermediate zone is fascinating precisely because it facilitates individual conduct; this zone makes it possible for individuals to act
precisely by setting boundaries as to what we as individuals want to do and can do. On a meta-level the chapters in this book analyze what actually takes place at the interface of the ‘general’ and the ‘particular’. One of the key insights of this book is the identification of the coordination between the individual, collective and systemic resources that are used to enhance the staff’s resilience while acting within a complex critical care unit such as a NICU. Given the importance of acting, reasoning and interacting as coordinative resources in the constitution of the NICU practice, their styles of ordering deserve attention. Analysis of several treatment trajectories shows how those involved rely on different styles of ordering to deploy their knowledge, experience, and technology in the treatment trajectory. Which strategies of ordering are deployed in the NICU to identify, prevent or solve problems? To identify and name different styles of ordering analytic categories, notably ‘repertoire,’ ‘vocabulary’ and ‘script’, will be used as a technique to bring to light implicit matters of actual practice. These meta-level categories make it possible to analyze different positions, different practices, and different repertoires at once while avoiding any absolute categories or distinctions between different kinds of actors.

Control and contingency
The analyses in this book elucidate the tensions that are intrinsic in the ways in which medical technologies, standards and regulations about newborns are reshaped. Medical staff members are generally fully aware that “complete control of a treatment's unfolding is a fiction.” An inherent part of the work of staff in an NICU is sense-making, and in particular about the risks that are taken. I argue that in order to undertake successful work in an environment where risk is embedded in almost every aspect of work practice, it is the overall awareness and professional attitude of staff that enables successful accomplishment and that neither new technologies, protocols or norms will ever entirely prevent uncertainty or mistakes. It is impossible to anticipate and to solve every event that can arise in a critical care environment such as a NICU through monitoring instruments, protocols, guidelines or organization. What is needed, as will be argued, is space for adjustments based on what goes on in actual practices and situations. This is one of the key concerns of the book: what can be anticipated and is built into protocols and what is left to practices in the situation? This study articulates this dilemma through analysis of signification in practice. In each situation, it is the singularity of care for a particular child and its trajectory in the NICU that is centre-stage. The processes analyzed here show how staff members and parents build an understanding of the event and through the process of the event’s unfolding manage, manipulate and employ procedures and artefacts within the formal organization of the work to achieve outcomes of reliable and professional action.

Proposed Content
Please attach a chapter by chapter synopsis of the project’s planned content and main argument(s). We appreciate that this is bound to be provisional in some respects but in order to make a fair assessment of the project’s potential, your initial presentation needs to be as detailed as possible (we would therefore suggest at least half a page per chapter). If you have some sample material available, we would be pleased to consider this as well.

Organizing framework
As a framework for reporting and discussing the findings, the journey metaphor is used. The treatment of children who end up in a hospital’s NICU is like a
journey that from the very start is full of whimsical incidents and incalculable uncertainties: both the destination and the trajectory are all but predictable. Even if the NICU staff has accompanied children on similar journeys numerous times already, the routes and conditions are never entirely the same. By focusing on a number of concrete intervention trajectories, this book traces the various challenges that all those involved have to face along the way.

1. Neonatology: A Practice in a Permanent Dynamic of Change
1.1 machines
1.2 Morality

The first chapter introduces the book by addressing two main characteristics of the Neonatal Intensive Care Unit (NICU): its ongoing concern with the most advanced medical knowledge and technology and its recurring moral dimensions. After an historical sketch about the development of the neonatal intensive care and its additional technological devices, the focus shifts to its related moral problems, life-ending interventions and societal responses to the ever-increasing possibilities of the NICU staff to intervene. After all, behind the dynamic of permanently changing facts, knowledge, standards and experience, the horizon is shifting along. Subsequently the chapter presents the discussion in health ethics and the critique of the procedural approach in ethics, the empirical turn in particular. Within medicine a rule-based ethics has been subjected to criticism from the start. According to a rule-based model, the underlying structure of medical action is constituted by medical principles, deductive reasoning patterns and decision protocols. Based on this, rule-based ethics would ignore the specific situation, the experience of those involved and the complex, unique character of medical practice. To do justice to the latter, so the critics, reflection from within the profession is necessary. This calls for an ethics that does not negate the situation’s special character, but one that precisely starts from it. A situated morality, rather than universal principles, should be the focal point.

If the discussion on health ethics is mainly conducted within the academic arena, the debate on the deployment of medical technology and the decision power of physicians also takes place in the public domain. The second part of the chapter describes the effects of societal responses to life-ending interventions for the decision-making process in the NICU in the Netherlands over the last two decades. Outsiders are equally concerned about the decisions that are taken in the work floor. For instance, the medical-technological developments are also on the agenda of public forums while commissions periodically assess medical work. In the Netherlands, pediatricians propose criteria for rules of medical intervention in cases of life-extending and life-ending action. This attention for guidelines and regulations in the early nineties was prompted both by the desire of pediatricians to get a handle on the complex moral problems in actual practice as well as they answered the felt need for external social evaluation. In addition to society’s call for transparency and accountability, pediatricians themselves underscored this need for regulation as well and developed protocols for life-ending interventions. Additionally a clear notification procedure and a multidisciplinary monitoring commission is something pediatricians have been pushing for with the government for at least ten years. It was not until 2006 that this procedure was formalized by the Dutch Government. Clearly, in the Netherlands the societal demand for openness, transparency and controllability on life-ending decision-making has affected the decision-making process on the NICU.

The first chapter also introduces the act of exnovation as the analytical scope and effort of the book. It is argued that although various aspects of the contemporary neonatal practice have been studied thoroughly, there is still little insight into the
hidden competence of the actors involved to cope with the complicated interplay of problems and dilemmas associated with the actual processes of managing day-to-day operations in the NICU. At all levels, new professional routines and sophisticated technologies have radically altered the nature of medical practice. The intervention process has become much more complicated. Aside from the ongoing need to develop pragmatic guidelines, the complex problems of our hi-tech health care have to be addressed in new ways. The role of action or intervention in everyday medical practices especially deserves critical examination, and notably from a qualitative angle, because this mode of analysis addresses the interplay of problems and dilemmas, of actors and technology, of professional concerns and the overall moral issues involved in today’s medical practices. To create, reproduce and uphold the social and normative order calls for a substantial effort on the part of those involved. This book primarily concentrates on the views and experiences of the physicians, nurses and parents involved. How do they gain a sense of control in this practice? Which means do they deploy to get the intervention process going again after it halts? Study of these questions may render visible the implicit patterns that are deployed to move a newborn’s treatment trajectory into a positive direction. A detailed study of the strategies used in the NICU to tackle the daily problems that is based on participant observation provides insight into the process in which a treatment trajectory takes shape while simultaneously the social order is upheld. Which ways of reasoning, speaking and acting are deployed in the NICU to identify, prevent or solve problems? To exnovate these processes the analysis in this book relies on several analytic categories, notably ‘repertoire,’ ‘vocabulary’ and ‘script.’ This theoretical framework brings to light implicit aspects of actual practice. As such this study may well be characterized as a theory-guided ethnography. If these analytic categories (second-order) are not part of the discourse used by those involved in the NICU (first-order), I deploy them to define and interpret the styles used by the actors to interpret facts and situations, as well as argue and legitimate them, thus moving beyond this specific practice’s more explicit level.

This introductory chapter concludes with an outline of the book.

2 Newly Born and Indeterminate
2.1 Defining the Specific Situation
2.2 Constructing Child and NICU
   - Defining identity as ordered complex
     - The Child as Construct
     - The NICU as Construct
2.3 Styles of Reasoning
   - The use of repertoires

For the NICU staff, questions on how to intervene may already arise before the child is born. The problem of intervention is closely tied to the problem of diagnosis and prognosis. Especially in cases that end up in the NICU this involves more than just determining the facts. Chapter Two provides a profound analysis of what happens at the interface of diagnosis and prognosis. It is argued that in the context of NICU practice facts are not so much given but construed on the basis of various sorts of materials, including words, numbers, actions, and objects. From the very start, the staff is engaged in assembling and structuring data that help to determine a child’s medical situation. The child’s identity is established in a process of reading, measuring, calculating, comparing, combining and discussing data, but also through sensory techniques like observation, feeling, and listening. Throughout this process various styles of reasoning are deployed, including so-called ‘case repertoires’ and ‘situational
repertoires. By moving from one repertoire to the next, or by combining or contrasting them, the staff members arrive at a definition of the situation of the child. The effort that goes into defining the child’s situation at the same time helps to shape the NICU as a social practice. In this way the child’s identity and the structure of NICU practice are established in a coeval process. In following this process the second chapter presents what actually happens at the interface of the different elements of medical practice. Additionally, it demonstrates how the legal system outside the hospital affects processes of diagnosis and prognostication before and after birth inside the hospital walls.

3 Co-travelers

3.1 Mutual Expectations
Staff members’ expectations of parents
Parents’ expectations of staff
Representing each other

3.2 Parents as Object of Care

3.3 Parents as Bearers of Parental Authority
It is the doctor who decides
It is the parents who decide
It is the law that decides

3.4 Reconciling Competing Vocabularies
Who decides?
When is a decision taken?

After a child is admitted, its parents become part of NICU life as well. Parents with their own views and backgrounds and staff members with their specific rules and rituals meet each other around the child’s incubator. Of course, the occasion for their encounter is hardly a pleasant one and this puts additional strain on the expectations they have of each other. Chapter Three demonstrates the dominant role of expectations in the organization of the interaction between parents and staff members. How and to what extent are the social interactions between staff members and parents organized by their mutual expectations? In what way, for example, does the public perception of hi-tech medicine, as presented by for example popular television, play a role in family’s expectations of the process of diagnosis and prognosis, and how does it influences their interactions with staff members. These and other examples show how expectations contribute to structuring the social order of the NICU. This chapter also analyzes the various ways in which in the NICU context the interactions between parents and staff are defined and which vocabularies play a major role. Based on a concrete case, two vocabularies are discussed in particular: the psychosocial and the juridical vocabulary. The use of a variety of vocabularies involves more than just a difference in the use of specific words and concepts. The same words may have different meanings when used in other vocabularies. The application of a specific vocabulary creates a reality in which parents and staff members are each allotted their own place and significance. In a psychosocial vocabulary parents are turned into an object of care; this means that parents need to be given support and protection in an atmosphere of togetherness. Thus the psychosocial vocabulary creates a social order that is marked by a sense of solidarity and shared responsibility. The use of the juridical vocabulary, by contrast, establishes a social order in the NICU that is primarily marked by a sense of individual responsibility. In this vocabulary, parents are seen as bearers of parental authority who ought to have a say in everything that concerns their child, and this means that they are directly involved in every relevant decision for which they are also co-responsible. This view of parents as autonomous, knowledgeable discussion partners in the decision process seems to be at odds with the view of
parents as dependent and in need of care: the two vocabularies appear to exclude each other. Yet when difficult decisions have to be made on how a child’s treatment should proceed, the deployment of the two vocabularies does not necessarily result in a deadlock. In some ways, my analysis of the case demonstrates, they even complement each other, because it is impossible to put all responsibility for a medical decision into the hands of the child’s parents who generally lack the expertise to assess medical data properly, while putting all responsibility into the hands of the medical staff would be an unacceptable form of paternalism. The NICU staff, by cautiously manoeuvring with both time and language, succeeds in reconciling the two vocabularies. By distributing the responsibility for difficult decisions among all the parties involved, a mode of speaking emerges that allows one to respect parental authority while at the same time providing support to parents. A detailed analysis of two case studies shows how legal frames, which are the product of social concerns, affect, and sometimes distort, hospital practices.

4. Uncertain Trajectories

4.1 Determining a Treatment Trajectory
- Time as risk and ally
- The use of guidelines

4.2 Technology’s Role on the Treatment Trajectory
- Technology and care
- Disciplining the treatment practice
- Technology as problem

4.3 Numbers as Compass
- A reliable instrument
- The interpretation of numbers
- Number versus number
- Competing knowledge frames

The shared interest of parents and staff lies in their joint objective: the child’s recovery. The recovery of a child that is admitted to the NICU can never be taken for granted, though. Life in the NICU is characterized by continuous struggle and entirely unpredictable changes. The dynamic of its practice is not only determined by the constant flow of activities, the admission of new cases, and the arrival of ‘new’ parents, but also by the constant fluctuations in the child’s situation. The changeable nature of its condition requires around-the-clock monitoring and frequent adjustments. In chapter four it becomes clear that in the NICU context medical treatment rarely involves merely solving a child’s medical problem. A focus on the overall trajectory of a NICU patient makes it possible to describe the frictions that can occur at the interface of diagnosis and prognosis, of actors and technology, of medical facts and moral concerns. The staff has various strategies at its disposal for dealing with the intrinsic tension between the need for intervention and making adjustments on the one hand and the associated risks and uncertainties on the other. Several factors play a major role when tackling the uncertainties of treatment itself, including time, protocols, technical devices, and numbers. Medical intervention in the NICU context does not always involve a race against time. Certain treatment needs time to catch on, or it may require specific preliminary activities. It is nevertheless true that time is a scarcity in many cases, while it may also be a major risk factor. The protocols that are used by the staff tell them in detail what should be done in a given situation; they provide support and direction, but they offer no guarantee whatsoever that a child’s treatment will actually follow the anticipated trajectory. In some cases treatment requires major deviations from the protocols, or it can be crucial that nothing is done. To be able to respond promptly, permanent
control mechanisms should be in place and to this end a host of medical technologies has become available. The use of technology, however, has various implications. For one thing, technical devices play an active role in structuring the treatment trajectory. The scripts that are inscribed in the various technological devices in part define the roles and tasks of physicians and nurses, and they also may influence the other tools that are used in treatment. For instance, the respirator’s script pre-structures the various options of intervention, but it may also block certain options, complicate a child’s situation, or trigger the need for making adjustments in the planned trajectory. If it comes to worst, the deployment of technology results in irreparable complications. Staff members try to prevent such a scenario by around-the-clock monitoring of the child’s condition. They do so by constantly gathering numbers, calculating ratios and quantities, entering quantitative data on special forms and classifying them, and by interacting with each other in numeric language. Numbers function much like a compass that guides staff members in their effort to pilot the child safely along the planned treatment trajectory. Numbers, however, do not speak for themselves, nor can a large flow of quantitative data do away with each and every uncertainty: medical intervention trajectories in the NICU are always rife with risks and uncertainties.

However, in the decision-making process, doctors do not only have to act in accordance with the standard level of care, but they also have to reckon with juridical rules. Notably in the United States juridical interests easily come into play in all sorts of practices, including medicine. This high degree of juridicalization forces doctors to found their decisions more solidly on quantitative data. To avoid court cases there has been a tendency to deploy all sorts of means and technological tools to generate a large body of test results. In the uncertain world of neonatology numbers provide the only basis for legal certainty. To have evidence in advance, much blood testing is requested and each medical step is recorded. Thus the legal system further pushes up the production of numbers and their recording in medical practice.

**5 Beacons on the Horizon**

5.1 Position and Prognosis
   - The specificity of the gaze
   - The specificity of acting

5.2 A topography of Experience
   - Distance versus proximity
   - Observing versus comparing
   - Hands-on versus hands-off

5.3 Prognostic Markers
   - Exemplary cases
   - Technological markers
   - Rhythm and pace
   - Spatial markers
   - Experience and expectation

Despite the staff’s expertise, the available medical technologies, and a ton of data, a child’s treatment can still go way off course, making its recovery highly uncertain. This forces the staff to reformulate the treatment's objectives and the child’s prognosis. The parties involved may have quite different views on a particular child’s prognosis. Chapter Five is devoted to the phenomenon of prognostic difference and it argues that such difference cannot solely be explained on the basis of the different formal roles of physicians, nurses, and parents in the NICU. In addition to professional expertise, which is generally
based on education and knowledge of the relevant literature, more subjective knowledge that is based in personal experience and contact with the child may equally be relevant. It is argued that circumstantial elements, the NICU’s local history, and individual knowledge and experience of those involved must be taken into account. The way in which those involved actually spend time with the child or near its incubator, conceived in terms of distance versus proximity, involvement versus detachment, and observation versus touching, results in knowledge that plays a major role in the prognostic process. Furthermore, there are several points of reference that staff or parents rely on when articulating a child’s prognosis, such as their knowledge of other children or cases, the technological support mechanisms a child needs, and the temporal and spatial order. The fact that a NICU child’s condition is subject to sharp fluctuations seriously complicates the proper assessment of its prognosis. This in part explains why the various incidents that occur in the course of the treatment trajectory have a strong influence on how each one involved arrives at a specific prognosis. Since their concrete knowledge and experience of the child is quite different, they tend to emphasize divergent aspects in its condition. By capitalizing on prognostic markers as an analytical category, it becomes possible to study these differences between professionals and parents and analyze how they use similar reasoning to reach substantively different conclusions. The argument of the chapter underscores that only a multi-layered analysis of these processes accounts for actors’ divergent prognoses.

6 The Moral Load
6.1 The Nature of the Decision
   Evidence
   Asymmetry
6.2 The Functionality of Relocation
   Robustness
   Creating a basis for consensus
6.3 Another Trajectory, another Order

The child’s prognosis largely determines the course of treatment. In case of a bad prognosis, the self-evidence of the treatment’s continuation may be questioned or it may even be decided to stop treatment. Chapter Six examines in detail the interlinked process of establishing medical facts and moral concerns in life-ending decisions. The dilemmas involved in such a decision are discussed in this chapter. Each of the options has serious ramifications. If staff members decide to discontinue a child’s treatment they may rob it of its final chance of recovery, but the opposite decision implies the risk that their effort only contributes to the child’s senseless suffering. Such moral dilemmas may already come up before a child’s birth, the question then being whether treatment should be initiated after it is born. Regulations and guidelines, in the form of assessment schemes or decision procedures, aim to guide and direct the NICU staff in taking the proper decision. These guidelines originate from both a societal call and medical need to regulate decisions on life-ending action. The analysis in Chapter Six of situations in which guidelines apply show that existing rules come with a specific notion of the practice involved and that this notion is not always in line with the actual practice. These guidelines start from a problem or situation that is not always identical to the situation at hand. In everyday NICU practice, general moral principles always have to be applied in idiosyncratic ways: they have to be ‘custom-made’ so as to fit the concrete situation. Basically, the issue of morality in the NICU context involves a decision about fixing a demarcation point, a boundary beyond which intervention is discontinued. To generate a custom-made morality in specific cases, several activities at various moments
are required: testing the robustness of facts as well as the flexibility of moral categories; exploring the available manoeuvring space; examining disciplinary boundaries and the distribution of responsibilities; searching for the right words; constructing a consensus; and learning to deal with the consequences of a decision. The challenges of NICU life, in other words, require a situated morality in which the distinction between ‘general moral category’ and ‘the child’s unique situation’ is resolved.

Chapter Six demonstrates how the testing of prognostic facts and the testing of values go hand in hand. Questions addressing the prognostic nature of a case and how to act properly cannot be dealt with in isolation: a specific answer to one question implies a particular answer to another, and vice versa. Facts, values, and medical actions are mutually interdependent. Furthermore, this chapter illustrates in detail how formal regulations are reshaped in the vortex of medical practice.

7 The End of the Journey
7.1 Moments of Reflection
Rewriting the past in reflection
7.2 Situating Knowledge and Morality in Treatment Processes
Styles of ordering
Reflective practitioners

The world of the NICU is all but a neatly arranged world. Here values do not come before or after the facts, but the two categories constantly mingle. Strikingly, though, moral decisions are often seen as a separate category next to medical decisions. The reason for this distinction is found in the difference between action and reflection. It is only afterwards, in reflection, that we can see the reality of deductive moral decisions. The final chapter underscores the significance of this retrospective gaze. Knowing how a particular story is concluded makes a world of difference. In their reflection on a particular course of treatment, those involved have the opportunity to see a neatly ordered world of facts and values, of main issues and side issues. This allows them to review the actions and re-assess the choices that were made. Moral reflection emerges out of the order that is retrospectively construed. The intervention trajectory – once so full of unexpected surprises – is now a logical narrative, one that can be interpreted and debated in terms of the moral nature of the acts involved.

The second part of this last chapter recapitulates and evaluates the analytical focus of the book on styles of ordering as an act of exnovation. To keep complex treatment processes going more appears needed than merely the presence of knowledge, experience, and technology. Given the importance of acting, reasoning and interacting in the constitution of the NICU practice, its styles of ordering deserve attention. Throughout the book fine-grained analysis of several case studies demonstrate how those involved rely on different styles of ordering to deploy their knowledge, experience, and technology in the treatment trajectory. Their application is not automatic but requires active involvement from doctors, nurses and parents. They have several styles of ordering and interpreting at their disposal: reasoning and legitimizing (repertoires), speaking and interpreting (vocabularies), and more or less explicit directions for action (scripts). Each chapter reveals in its own way the hidden competence of the actors to use specific repertoires, vocabularies and scripts which allows them to face up to uncertainties, neutralize tensions, handle random incidents and solve dilemmas, thus to ensure the continuation of the treatment process. Exnovation of the styles of ordering reveals how facts, values, and medical actions are mutually interdependent and enables us to define what takes place in the
intermediate zone of diagnosis and prognoses, of actors and technology and medical facts and moral concern. Close analysis of what happens at the intersections of the various constituents of medical practice offers insight into how medical facts and moral choices are made in the NICU. Study of this effort reveals that the NICU practice implies not so much an ongoing struggle over the discrepancies between general moral categories and unique cases or situations; rather, situated knowledge and morality are produced in one and the same movement, whereby various kinds of repertoires, vocabularies, and scripts can be deployed. However, the various ways of reasoning, speaking, and acting intervene differently in the constitution of facts, values, and actions. In some cases “second-order level” coordination is necessary because specific styles may clash. Situating of knowledge and morality therefore requires coordination not only at the level of the individual case (the construction of facts, the robustness of a moral turning point or the choice of a treatment trajectory), but also at the level of repertoires, vocabularies and scripts. In other words, securing the treatment trajectory’s progress calls for coordination at the level of the individual case as well as at a meta-level. To foreground these acts of coordination offers not only a new perspective on the competence of the actors involved, but also on the ordering character of reasoning, speaking, and acting.

The conclusion of this book reconsiders the question with which it began: what actually takes place at the interface of the different constituents of medical practice and in the processes in which the societal responses to health innovations in the concrete work setting of medical care practice are reshaped? Each chapter reveals how guidelines and regulations, perceptions and expectations, legal frames and social roles, triggered by societal processes, shape medical practices while at the same time are reshaped in the vortex of these practices. By focusing on moments of uncertainty the previous chapters have shown that for the alignment of the different constituents of medical practice as to ensure the continuation of the various processes that are part of a treatment trajectory, more is needed than expertise, experience, and technology. It turns out that in addition to the more tangible and concrete actions and interventions of the NICU staff members, more abstract processes are at work as well, and prominently so. Specifically, various styles of arranging and interpretation play a major role in decisions on treatment: repertoires guide processes of reasoning and legitimating, vocabularies suggest ways of speaking and interpreting, and scripts imply more or less explicit directions for action. Moreover, it has become clear that protocols and medical technologies have only a limited potential when it comes to facilitating a sound decision process in the NICU context. Technological innovations do not only create new treatment opportunities, but also new questions and dilemmas, as well as new tragic cases; sooner or later, new tragedies and uncertainties will catch up with technological advances. That medical progress causes the boundaries of medical intervention to shift all the time underscores the significance of having protocols and guidelines that allow space for adjustments based on what goes on in actual practice. Finally, it cannot be denied that as a medical practice the NICU – given the particular dynamic of its task and the changing nature of medical facts, norms, expertise, and experience – will always have an uncertain future, just like its staff members will always continue to be pioneers.