

# Reflection

## Methodology

This research on which this thesis has been based is comprised of 4 distinct parts: (1) literature review, (2) expert panels, (3) experiment design and (4) statistical analysis.

The literature provided insight in the neonatal intensive care unit, several health concepts such as family centered care and healing environment. The main aim of the literature research was to identify which factors, referred to as attributes, were found to contribute to the wellbeing of parents and medical professionals. Because the author loves to go deep in the study matter, the first straw of the literature research was rather extensive.

The literature study was first focused on three relevant groups: the parents, medical professionals and their children. The latter is was regarded as very import though infeasible within the scope of a master thesis. Inclusion of the newborns meant including means and measures to estimate the relative wellbeing of the newborns. These measures are currently under debate and require access to medical data for which the approval of the medical ethical committee of each hospital is required. Simple admissions were deemed feasible, as shown in this work. Though an full blown medical approval requires at least several months to compose, followed by revisions, etc. The realization of this aspect lead to the drop of the newborns as one of the groups to be included in this research.

The expert panels were held in two hospitals and yielded new insights for the author. Especially the realization that results from literature are not necessarily shared by the medical professionals. The big picture corroborated with the findings from literature, though there were various deviations from the experts in how they experienced certain attributes. The main observation of the author was that the situation in literature was depicted more negatively compared to the experts experiences. Thus this proved to be a good test for the literature review and the authors overall view of the NICU. Interviews with parents would have been a valuable addition to view of the literature and the medical professionals. Interviews with parents were always intended to include when this was allowed by the amount of time. Unfortunately the long approval process of the medical ethical committees required more time than initially intended and interviews with parents were skipped. The experience of parents concerning birth has been experienced by the author during the process of this thesis. Fortunately, situations as experienced by parents from newborns in the NICU did not occur and a healthy young boy was born.

Designing of the experiment was done using SAS to generate a choice set design, Excel to translate the choices to Maya code, for import in SPSS and as input for merge in InDesign. Generate a choice set design was done by following Kuhfeld's (2010) manual and by examining syntaxes. Building the syntax in SAS was now and then a challenge for one mistake can grind the whole process to a hold. Altogether it provided a good insight in how the choice set generation works and how it can be customized.

Transferring the SAS output to Maya proved to be a challenge because there was no documentation on how to do this with ease. Maya was the intended software because this allowed the usage of the

BK-renderfarm. The BK-renderfarm allows rendering of multiple Maya scenes simultaneously which was an a priori requirement. Unfortunately rendering with the BK-renderfarm did not go as expected: the render process stopped when 4 to 5 images were rendered. The solution proved to be rendering camera's separately. The process of generating a choice set design and integrating the design in Maya, so the vignettes correspond with the choice set design, was genuine trial and error. Though a hassle, the process gave rise to the idea that SAS could be bypassed by Maya. Since Maya works with MEL and python, creating a script that generates a choice set design should be feasible. This would be a huge time investment but it would also be a major contribution to DCE with vignettes. It will save a lot of time and errors arising from half-baked solutions. This will also make execution of pilot studies prior to a full blown study much more feasible, contributing to the overall quality of vignettes based DCE's.

Previous students have used SAS to do the statistical analysis. This was a good alternative given the robustness and versatility of SAS. Aside from the benefits SAS has, it is a rather inaccessible and complex statistical package. This means that most students at the faculty of Architecture need to learn how to use the package (including the author), which takes some time. SPSS, on the other hand, is a more user friendly package which allows quick calculations. When DCE were first executed at the faculty of architecture, SPSS was not capable of analysing DCE. Now, SPSS is capable and thus offers a more easy way into analysing DCE's. Unfortunately, the generation of complex choice sets is still not possible in SPSS. To compare the results, the analysis has been done both in SPSS and in SAS, which yielded reasonable similar results.

### Site visits

The site visits were, next to functional, very fun to do. The visits showed how various NICU's operate, how the medical professionals work and how the NICU atmosphere is. The site visits had one main goal: introducing the research to the responsible medical professionals and asking if they were willing to participate in the research. The additional conversations showed the author how dedicated the medical professionals are in their work and how much they value the wellbeing of the parents and neonates. The contact with the medical professionals has been experienced as very positive and pleasant. These kinds of visits are necessary when executing any research in an hospital setting. Such environments, and especially an intensive care environment, need human attention. People in these settings deal with sever emotions every day, leaving very little room for students entering this environment to make errors.

### Ethics

Hospitals value and respect the privacy of their employees and patients. Hospitals, and especially university medical centres, also value research. Since in (medical) research the privacy and interests of the patients and other participants need to be covered, hospitals have independent committees in charge of judging the quality of the research and whether the research meets all the (legal) demands. A second incentive for hospitals is that the hospitals are only insured when the research meet the legal conditions set to research with humans. A medical ethics committee (MEC) thus assesses and evaluates medical research involving human subjects. In the Netherlands the MEC assesses and

evaluates according to the act “*Wet medisch-wetenschappelijk onderzoek met mensen*” or WMO (act medical scientific research with human beings). Please refer to the Ministry of Public health, Welfare and Sport (VWS, 2015). A similar legal basis is used in Belgium.

At first the assumption was made that there was no approval needed for a research that did not include any medical interventions or manipulations with humans. This was based on conversations with various medical professionals and thus approval by an MEC was deemed not necessary. Eventually, in the Netherlands, some hospitals required approval and others did not. In Belgium, all four required approval. This meant that request for approval needed to be written in a hurry: the questionnaire was nearing completion. The approval in the Netherlands came down to an assessment of the act WMO. When an MEC concluded that the act WMO was not applicable to this research this meant a green light and the research could start. This process of writing the proposal, submitting the proposal and receiving the verdict took about 6 weeks for hospitals in the Netherlands.

For hospitals in Belgium, the demands were stricter and required a complete proposal. The same procedure in Belgium, with stricter demands, took about 9 weeks before a verdict was given for one of the four hospitals. The others were still in the process of the verdict, eventually leading to just one participating hospital in Belgium.

This is a major learned lesson for the author and a warning for future students wanting to do any research in a medical setting, regardless of the nature of the research. When doing research in a medical setting, especially in an university medical centre, prepare for MEC admissions in time. An admission requires at least the following key elements:

- Accurate description of the research .
  - » What are you going to do?
  - » Rationale behind the research.
  - » How do you intend to approach respondents?
- Overview of the methodology.
- Intended start and stop dates as the number of respondents.
- Informed consent and detailed respondent information.
- Privacy regulation (how will you deal with sensitive information).
- Final questionnaires used in the research (all versions).
- Other materials needed for respondent inclusion.

This short overview illustrates that you cannot start the MEC application procedure prior to completing the operationalization of your research. The questionnaire(s), and thus the methodology and all that underlies the questionnaire(s), needs to be finished. Also prepare for refusal of your admission. In short: take at least 3 weeks to write a simple proposal (when only tested against the act WMO) and prepare for at least 4 weeks before the verdict is given.