
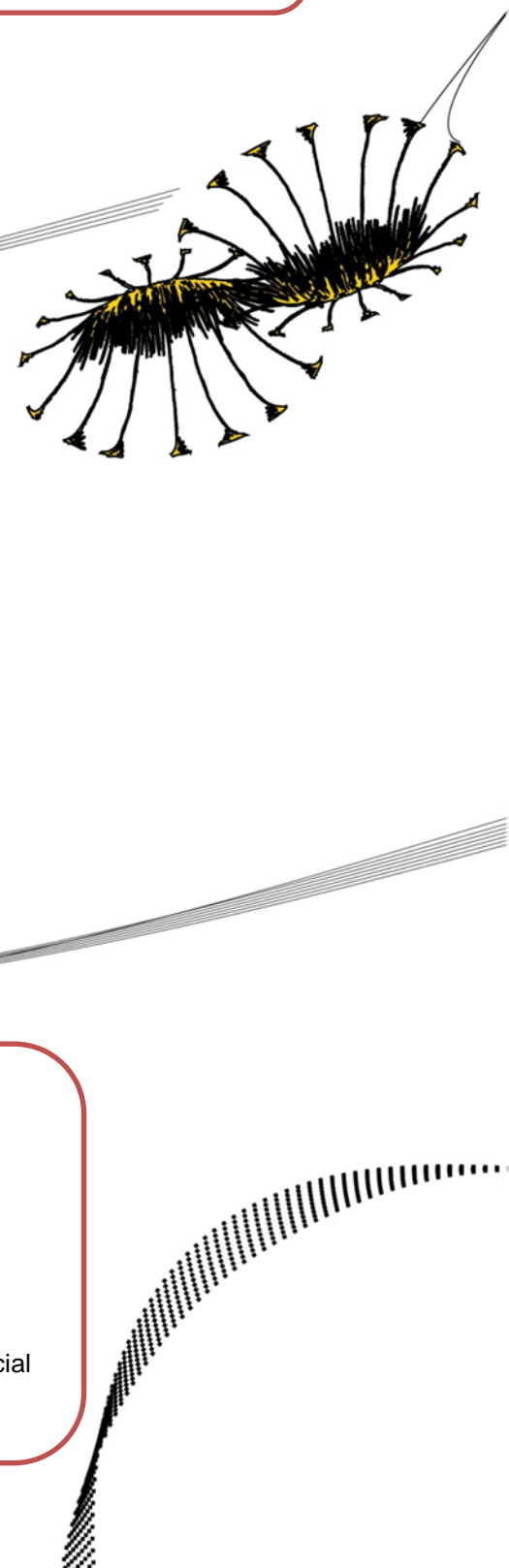




# FACILITATING AND IMPEDING FACTORS OF CHILD HEALTH PROFESSIONALS' ADHERENCE TOWARDS THE PROTOCOL AND GUIDELINE USED AFTER CHILD DEATH.



*A qualitative evaluation of working procedures at the municipal health service Twente.*



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# PREFACE

In front of you lays my thesis with the title 'Facilitating and impeding factors of child health professionals' adherence towards the protocol and guideline used after child death'. For me, it is the last component to graduate from the master programme Health Sciences of the University of Twente. This research was performed at the GGD Twente, where I had the great pleasure of performing my research. Along these lines, I would like to thank GGD Twente by providing me full cooperation and enthusiasm that was needed to execute this research.

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Finally, I would like to thank my boyfriend and my parents for their patience and love, by always giving me the time and space to work on this thesis. Your encouraging and loving words served me well.

I hope all who read this thesis will find it interesting and worth reading.

Sincerely,

*Anne M. Siers*

*Oldenzaal, July 7, 2017*

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# SUMMARY

## Introduction

The death of a child is a great tragedy for parents and others close to the child, and has a major influence on the lives of the remaining ones. Parents might show adverse behaviour such as rejection or overprotection towards siblings of the deceased child. Feelings such as anxiety, guilt, and other negative emotions are experienced frequently, which on the long-term can result in parents experiencing depressive episodes, lower psychological well-being, more health issues, and more risk on marital disruption.

Every child death is one too many, and in the unfortunate event of a child death, care towards the closest ones to the deceased child should be of high quality in order to make their mourning process as comfortable as possible, and to prevent the behaviour and effects mentioned above. Municipal health service Twente uses a protocol in the event of a child death, which consists of a self-made roadmap including a guideline. This roadmap states that it is made in order to inform all child health professionals promptly. With this information, professionals can give their support to parents and it also gives professionals the opportunity to anticipate to potential turmoil at an early stage. In addition to this, the roadmap is made to enable analysis of the provided care and to evaluate whether improvement in the provision of care is possible. Since the implementation of the roadmap, there has not been an evaluation with its users.

## Objective

The objective of this research is to identify facilitating and/or impeding factors in professionals' adherence towards the protocol used after child death. This identification is done from the perspective of child health professionals. In addition to this, it is identified what possible ways are of improving the protocol according to child health professionals. The setting of this research is at the preventative child healthcare department of the municipal health service Twente.

## Methods

Data was collected with qualitative research methods consisting of focus groups and interviews. A total of seventeen participants were included in this research. Eleven health professionals, including child health physicians, child health nurses, and assistants were included in focus groups. Interviews were held with the other six participants: the client administration (two persons), team leader, staff doctor, and head of the preventative child healthcare department. The quality officer was included in both a focus group and an interview. Both focus groups and interviews consisted of questions that were set up on the basis of the Measurement Instrument for Determinants of the Innovation (MIDI-framework) developed by Fleuren et al. The MIDI was designed to improve understanding of the critical determinants that may influence an implementation in order to better target the innovation strategy. Opinions and experiences mentioned in present research were linked to the four concepts of the MIDI: Innovation (the protocol), User (child health professionals), Organisation (municipal health service Twente), Socio-political context (legislation and regulation).

## Results

All four concepts of the MIDI were mentioned in either focus groups or interviews, as facilitating factor, impeding factor, or recommendation: Professionals believe that the protocol is not complete and not clear, as they state that it is unknown which actions need to be done in situations that differ from 'normal' situations, or with notifications other than from the GBA. These impeding factors of the Innovation towards adherence led to recommendations; professionals believe that the protocol can be improved and can be made more complete with the inclusion of role descriptions. Regarding the User of the protocol, professionals were in general positive about their own abilities (MIDI-determinants Self-efficacy, Knowledge, and Awareness of the content of the innovation), which was identified as a facilitating factor of adherence towards the protocol. A facilitating factor regarding the concept Organisation towards adherence of the protocol is that professionals indicated that they prioritize actions in these situations above all other actions. The recommendations given include that information accessibility can be improved when the grieving suitcase returns to the municipal health service Twente. Lastly, some professionals said they do not know what to do in some situations of child deaths, concerning the MIDI-concept Socio-political context. This corresponds with the recommendation given by many professionals to include in the protocol what to do with legislation and regulation in different situations of child death.

## Conclusion

The MIDI-framework appeared to be a useful tool in present research. In practice, when adjusting the protocol, presumably, many impeding factors can be altered into facilitating factors. Results from present research have provided insight in the knowledge gap of the implementation of the roadmap used in situations of child death at the municipal health service Twente. It is tried to provide insight in the factors of adherence towards the roadmap, combining the MIDI-framework by Fleuren et al. with newly collected data consisting of the experiences child health professionals with using the roadmap. Future research should focus on the re-implementation of this protocol at the municipal health service Twente, and on performing this research on a larger scale in the Netherlands.

# SAMENVATTING

## Introductie

Het overlijden van een kind is een grote tragedie voor ouders en hun omgeving en heeft een grote invloed op het leven ouders, broertjes en zusjes. Ouders kunnen afwijkend gedrag tonen tegenover de broertjes/zusjes van het overleden kind, zoals nalatigheid of juist overbescherming. Gevoelens zoals angst, schuld en andere negatieve emoties worden vaak ervaren door ouders, welke op lange termijn kunnen resulteren in depressieve periodes, lager psychologisch welzijn, meer gezondheidsproblemen en meer risico op echtelijke scheidingen.

Elke sterfte van een kind is er een te veel. In het ongelukkige geval van een kindersterfte moet de zorg voor de omgeving van het overleden kind van hoge kwaliteit zijn om het rouwproces zo comfortabel mogelijk te maken en om het pathologische gedrag, zoals hierboven genoemd, te voorkomen.

Gemeentelijke GezondheidsDiensten (GGD) Twente maakt gebruik van een protocol bij een kindersterfte, welke bestaat uit een zelfgemaakte routekaart en een nationale richtlijn. Deze routekaart is gemaakt om alle Jeugd GezondheidsZorg (JGZ) -professionals snel te informeren. Met deze informatie kunnen de JGZ-professionals de ouders steunen en het geeft de professionals ook de mogelijkheid om vroegtijdig te anticiperen op mogelijke onrust in de maatschappij. Daarnaast is de routekaart gemaakt om de gegeven zorg te analyseren en te beoordelen of verbetering in de zorgverlening mogelijk is. Sinds de implementatie van de routekaart is er geen evaluatie geweest van dit protocol.

## Doel

Het doel van dit onderzoek is het identificeren van faciliterende en/of belemmerende factoren in de naleving van het protocol dat na de dood van een kind wordt gebruikt. Deze identificatie wordt gedaan vanuit het perspectief van de JGZ-professionals van de GGD Twente. Daarnaast wordt er door JGZ-professionals geïdentificeerd welke mogelijkheden er zijn in het verbeteren van het protocol, waardoor ook de zorg die verleend wordt rondom de kindersterfte te verbeteren.

## Methode

Gegevens werden verzameld met behulp van kwalitatieve onderzoeksmethoden, bestaande uit focusgroepen en interviews. In dit onderzoek werden in totaal zeventien deelnemers geïnccludeerd. Elf JGZ-professionals, waaronder artsen, verpleegkundigen en doktersassistenten, werden in focusgroepen opgenomen. Er werden interviews gehouden met de cliëntadministratie (twee personen), teamleider, stafarts en hoofd van de JGZ-afdeling. De kwaliteitsfunctionaris nam deel in zowel een focusgroep als een interview. Beide focusgroepen en interviews bestonden uit vragen die werden opgesteld op basis van het Measurement Instrument for Determinants of Innovation (MIDI), ontwikkeld door Fleuren et al. De MIDI is ontworpen om het begrip van de kritische determinanten die een implementatie kunnen beïnvloeden te verbeteren en om zo een betere innovatiestrategie te ontwikkelen. Met behulp van de MIDI werden meningen en ervaringen in dit onderzoek verbonden aan de vier concepten van de MIDI: Innovatie (het protocol bestaande uit de routekaart en de richtlijn), Gebruiker (JGZ-professionals), Organisatie (GGD Twente), Sociaal-politieke context (wetgeving en regelgeving).

## Resultaten

Alle vier concepten van de MIDI zijn door de JGZ-professionals genoemd als faciliterende- of belemmerende factor en/of als aanbeveling: JGZ-professionals vinden over het algemeen dat het protocol niet duidelijk en compleet is; ze weten niet wat er gedaan moet worden in situaties die verschillen van 'normale' kindersterftes, of wanneer kennisgeving anders dan via het GBA is gekomen. Deze belemmerende factoren betreffende het protocol zelf voor het naleven van het protocol hebben geleid tot de volgende aanbeveling: JGZ-professionals denken dat het protocol verbeterd en completer kan worden gemaakt door inclusie van een rolbeschrijving. Verder waren JGZ-professionals over het algemeen positief over hun eigen vaardigheden (MIDI-determinanten Zelfredzaamheid, Kennis, en Bewustzijn over inhoud van het protocol), welke geïdentificeerd zijn als bevorderende factoren betreffende het MIDI-concept Gebruiker. Een bevorderende factor voor het naleven van het protocol betreffende het concept Organisatie is genoemd: werkzaamheden behorende bij situaties van kindersterfte worden geprioriteerd boven alle andere werkzaamheden. Bij het concept Organisatie wordt er aanbevolen door professionals dat het rouwkoortje terugkomt bij de GGD Twente. Als belemmerende factor is genoemd dat sommige JGZ-professionals niet weten hoe er gehandeld moet worden in sommige situaties van kindersterfte, betreffende de wet- en regelgeving. Zij zouden dan ook graag zien dat er in het protocol komt te staan hoe er in bepaalde situaties gehandeld moet worden, maar ook wie er bereikt kunnen worden.

## Conclusie

Het MIDI-framework bleek een nuttig instrument te zijn in het huidige onderzoek. Door aanpassingen te doen in het protocol kunnen veel belemmerende factoren worden veranderd in faciliterende factoren. Resultaten uit het huidige onderzoek hebben inzicht geleverd over de factoren die van invloed zijn in het naleven van het geïmplementeerde protocol die gebruikt wordt in situaties van kindersterfte bij de GGD Twente. Hierbij is gebruik gemaakt van de MIDI door Fleuren et al.; deze werd gecombineerd met de verzamelde data die bestaan uit de meningen van JGZ-medewerkers. Toekomstig onderzoek zou zich moeten focussen op de re-implementatie van een verbeterd protocol en er zou ook onderzoek moeten worden gedaan op een grotere schaal.

# 1 INTRODUCTION

## 1.1 Background of child death

The death of a child is a great tragedy for parents and others close to the child, and has a major influence on the lives of the bereaved ones (1). Parents might show adverse behaviour, such as rejection or overprotection towards siblings of the deceased child. Feelings such as anxiety, guilt and other negative emotions are experienced frequently (1). On the long-term, with an average of 18 years after the death of the child, Rogers et al. (2) found that those parents who had impaired mourning processes, or “lasting-grief”, were more likely to experience depressive episodes, experience a lower psychological well-being, have more health issues, and have a higher risk of a worse relationship with a significant other or even going into marital disruption.

Every child death is one too many, and in the unfortunate event of a child death, care towards the ones close to the deceased child should be of high quality in order to make their mourning process as good as it can be and to prevent the behaviour and effects mentioned above.

## 1.2 Mortality definitions

The World Health Organization (WHO) defines mortality as a core health indicator (3), which means that collecting mortality rates and its causes is prioritized by global communities in order to provide concise information about health trends and situations. The WHO categorizes mortality as ‘adult mortality between 15 and 60 years of age’, ‘under-five mortality’, ‘infant mortality’, ‘neonatal mortality’, and ‘stillbirth mortality’ (3). Infant mortality is mortality of children less than one year of age (4). Neonatal mortality is mortality of children between birth and 28 days of life. According to the WHO, stillbirth mortality is defined as a baby born with no signs of life at or after 28 weeks of pregnancy (5). There is no categorization made by the WHO of mortality in the age of 5-15 years (3).

The term “child death” is defined by the WHO as under-five mortality (6). This categorization is made due to the fact that on a global scale, children under the age of five are most vulnerable to infectious diseases, such as malaria, pneumonia, and diarrhoea (6). Luckily, from 1990 till 2015, on a global scale, child mortality rates have significantly decreased with 53% (7). This decline follows the introduction of the Millennium Development Goals (MDG), where the United Nations signed a declaration for the elimination of global poverty by 2015 (8). One of these MDGs was reducing child mortality by the mass distribution of cheap vaccinations, prioritize infant and young child feeding, and improving healthcare in developing countries to make it easier for parents to receive medication for their child (or themselves)(9).

## 1.3 Causes of child deaths

In the Netherlands, most child deaths are a result of non-infectious diseases, because infectious diseases are mostly prevented through vaccines, are easily treated with medicines, and some infectious diseases are absent in the Netherlands (malaria, for instance) (10,11). In the Netherlands, the term ‘child death’ can be defined as under-five mortality, as well as the death of a person aged 0-18 (12,13). From this point on, there is chosen to use the definition of child death as the death of a person, aged 0-18. Examples of most occurring child deaths in the Netherlands are deaths due to conditions originating from the perinatal period (the period from  $\pm$  28 weeks of pregnancy till 28 days after the birth of the child(14)) or by congenital anomalies (anomalies in a foetus’ development (15)). Most child deaths happen in the first year of life (11).

There are two types of causes of death, *natural causes of death* and *external causes of death* (16). Congenital abnormalities are an example of *natural causes of death*, and in the Netherlands, a natural cause of death is defined as “death by spontaneous illnesses, including complications from executed medical interventions”(16). Logically, death can as well be caused by *unnatural causes*, also called *external causes*. In the Netherlands, external causes of death are defined as “death that is caused (partially) by external (being physical or chemical) violence, and death involving intent or negligence (by the deceased or others)”(16). Most external causes of child death in the Netherlands are caused by transport-related accidents and accidents in and around a home (11).

As children age towards adulthood, in which adulthood is defined as a person from 18 years of age or older, especially death by transport-related accidents and suicide (in rapidly increasing quantities)



occur (17). Suicide rates are assumed to take place from the age of 10, and therefore, there are no rates of suicide under the age of 10 present (18).

In the Netherlands, rates of child mortality of children aged 0-18 have declined with a rate of 49% in the period 1996-2015; there were 1962 child deaths in 1996 and in the years that followed, mortality rates have declined to 922 child deaths in 2015<sup>1</sup>(19). Especially perinatal and neonatal deaths have declined in this period by improved medical care and better intake of nutrition (by the mother) (20).

#### **1.4 Municipal health services & preventative child healthcare**

Municipal health services (in Dutch: GGD, Gemeentelijke GezondheidsDiensten) have a stake in the decline of (child) mortality, as they provide, amongst other services, a large diversity of services directed at prevention of health(related) problems in the Netherlands (21). These services range from infectious disease control to the distribution of vaccinations for children and the provision of advices for healthy living and nutrition (22). A municipal health service consists of a staff department, a department of general municipal health, and a preventative child healthcare department (in Dutch: JGZ, “Jeugdgezondheidszorg”). The goal of municipal health services is to maintain and improve the health of the community it serves (21).

The preventative child healthcare department occupies itself with the health of children aged 0-19 in its broadest sense (23). Child health professionals monitor and signal children’s health and well-being throughout their development into adulthood. This monitoring starts from the moment a child is born. Curves of physical, speech, motorial and psychological development are monitored in nine different time points by child health physicians, child health nurses and assistants (23).

The preventative child healthcare department plays a large role in the prevention of child health problems, mainly due to the provision of vaccines and by providing information to parents and children, but also because child health professionals are able to signal abnormalities in behaviour and well-being of children (23). When there is any abnormality signalled, these children are monitored more closely or, if necessary, referred to more specialized care (23). The preventative child healthcare department also plays a coordinating role for the health of youth in a broader sense (23). On a national level, this is done by performing research about, for instance, the relation between cot death and sleeping attitude (24). On a local level, this is done, for instance, by advising about safety in the neighbourhood (23).

#### **1.5 Protocol of the preventative child healthcare departments**

Although the preventative child healthcare department cannot provide care anymore to a child when it has died, child health professionals do have other responsibilities and tasks in these situations (25). In case of siblings of the deceased child, child health professionals remain in contact with the parents as the professionals still provide healthcare to these siblings. The impact of a child death on its family is enormous, and child health professionals will monitor more closely whether there is impaired development of siblings of the deceased child (25). When there is an impaired grieving process of parents or siblings, child health professionals can intervene in such process by providing proper care and information. This can be done in the form of emotional, instrumental, and informational support. To provide handles for child health professionals, a guideline was developed in 2009 as a response to experiences from parents of a deceased child and professionals who work at the preventative child healthcare departments of municipal health services (25). This guideline is called “Support/guidance of family when a child death occurs” (in Dutch: Begeleiding gezin bij overlijden kind)(25) and will be discussed more in depth in Chapter 3.

Based on a quick scan at multiple municipal health services and child healthcare services in the east of the Netherlands, insight was gained on whether this guideline is used as a general working method. Municipal health services Twente, IJsselland, and Noord-Oost Gelderland, next to healthcare services Vèrian, Centrum voor Jeugd & Gezin Apeldoorn, Stichting Thuiszorg en Maatschappelijk werk Rivierenland, and Yunio were included in this quick scan. All services use the national guideline and some services have included this guideline in a self-made protocol. Municipal health service Twente is one of three services that included this guideline in a protocol.

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<sup>1</sup> Preliminary figures

## 1.6 Protocol of the municipal health service Twente

The municipal health service Twente uses a protocol in situations after child death. They made a roadmap, which includes the guideline “support/guidance of family when a child death occurs”, which is part of the Quality Manual of the preventative child healthcare department of the municipal health service Twente and is implemented since November 2016 (*personal communication with RH*). This protocol states that it was made in order to inform all child health professionals promptly when a child death has occurred. With this information, professionals can give their support to parents and it also gives professionals the opportunity to anticipate to potential turmoil at an early stage. In addition to this, the protocol was made to enable analysis of the provided care and to evaluate whether improvement in the provision of care is possible (see Appendix 1).

The target audience that is supposed to use the guideline are child health professionals. The target audience to whom professionals provide their support, are the parents and siblings of the deceased child. This target audience includes also parents of first born children, when child health professionals have not yet had contact with the parents, such as in situation of stillbirth, or death during or shortly after labour (25).

During the year 2015, 33 children died that were in care at the municipal health service Twente<sup>2</sup>. At the first of January, 2016, there were 141.493 children in care at the municipal health service Twente<sup>2</sup>. During the year 2016, 34 children died, with a total amount of 139.968 children that were in care at the first of January, 2017<sup>2</sup>. These numbers of child death do not include stillbirth. However, in 2015, it was calculated that on a national level, 4,6‰ of all live and stillborn babies included stillbirth (26). With this promillage, an estimated number of stillbirths in the region of Twente can be calculated. Around 7000 children are born every year in the region of Twente (27). The number of stillbirths is estimated at an amount of  $\pm 32$  ( $4,6\text{‰} \cdot 7000$ ). Thus, looking at the child mortality rates in the region of Twente, the protocol should be used in  $\pm 65$  cases of child death.

## 1.7 Policy evaluation

Since the implementation of the protocol, there has not been a formal evaluation with its users, the child health professionals. However, in informal settings, negative experiences mentioned by child health professionals, were collected by the staff doctor (*personal communication with RH*). It is presumed that using the protocol induces questions about uncertainties, because there lacks description (*personal communication with RH*). Also, there seem to be experiences in which child health professionals notified a child's death by a local newspaper or via social media, and in this way were not able to anticipate to the turmoil that arose in the community (*personal communication with RH*). Some child health professionals also seem to experience problems with the provision of (emotional) support, not only for parents, but also for themselves (*personal communication with RH*). Lastly, it seems that professionals struggle with the juridical matters, due to lack of description about the provision of medical data to parents, confidentiality between different professions, how to act when the police are involved, and file access by the staff doctor for dossier analysis (*personal communication with RH*).

## 1.8 Gap of knowledge

### In scientific sense

Love et al. (28) already defined internal evaluation in 1991 as “the process of using staff members who have the responsibility for evaluating programs of problems of direct relevance to an organization's management”. Love et al. also mentioned potential advantages of internal evaluation. As the internal evaluators are all employees of that organisation, they have the knowledge about that organisation's procedures, personnel, and management for instance. Additionally, commitment on the long-term is also improved as evaluators can also improve their working relationship with the organisation.

Sonnichsen et al. (29) stated that internal evaluations can result in positive change and organisational learning. Sonnichsen et al. also mention that the primary purpose of internal evaluation is that it supports the decision-making process. Improved decision-making leads to an improved organisation's performance. Projecting this on the municipal health service Twente, this means that through internal evaluation, the protocol and the care that is provided can be improved and this means that the organisation's performance can also be improved.

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<sup>2</sup> Numbers obtained from municipal health service Twente.

There is much literature about factors of adherence towards protocols or policies. Rogers et al. (30) stated that the diffusion of an innovation is influenced considerably by the following five characteristics: Relative advantage, Compatibility, Complexity, Triability (the ability to trial an innovation before implementation, henceforth “trial-ability”), and Observability. Adoption of an innovation occurs more rapidly when its users believe the innovation has a greater relative advantage, greater compatibility, greater trial-ability, greater observability, and is less complex than other innovations.

Evaluation of policies in studies with comparable research settings have led to the assembly of the Measurement Instrument of Determinants of an Innovation (MIDI) by Fleuren et al. (31). The researchers composed a list of determinants that influence an implementation in preventive child healthcare. The MIDI is relatively new and only limited research has been done about the validity of this tool (31,32).

Present research will position itself in the knowledge gap of the evaluation of the protocol used in situations of child death. It is tried to provide insight in the factors of adherence towards the protocol, combining the MIDI-framework by Fleuren et al. with newly collected data, consisting of the experiences of child health professionals with using the protocol.

The gap of knowledge will be discussed more in detail in Chapter 4.

#### In practical sense

It is important to formally evaluate whether the above mentioned experiences of child health professionals are genuine and if yes; whether the experiences are shared among multiple professionals who use this protocol.

Subsequently, the social relevance of present research is high, as evaluation of the protocol leads to the improvement of the quality of care that is provided, not only after a child death, but also prior to the death of a child. There might be cases, such as suicide or long-term illnesses, where child health professionals could have provided care and support before the child died.

### **1.9 Research goal**

The goal of this research is to identify barriers and facilitators with using the protocol that is used at the municipal health service Twente from child health professionals’ point-of-view. This evaluation is important for the quality management of the municipal health service Twente and with this evaluation, the existing protocol around the death of a child can possibly be improved. This evaluation does not include opinions of parents and the care they have received.

### **1.10 Research outline**

This thesis started with an introduction about child death, its definitions and causes, and the role of child healthcare services in situations of child death. The protocol of municipal health service Twente, which includes a roadmap and guideline, is briefly addressed. In the gap of knowledge, it was pointed out why the evaluation of this protocol is central in this research.

This thesis is outlined as follows: the research question and the sub questions are given in Chapter 2. Chapter 3 implies a section of background information about what happens after child death. This includes also a more detailed explanation of the existing protocol at the municipal health service Twente. Subsequently, Chapter 4 includes a theoretical framework of literature about this subject. The research methods are explained in Chapter 5 and the results are presented in Chapter 6. In the last Chapter, Chapter 7, the conclusion and discussion are given.

## 2 RESEARCH QUESTION

### Research question

The existing protocol of the municipal health service Twente used when a child death occurs, consists of a roadmap, which includes the child healthcare guideline “support/guidance of family when child death occurs”. As there not yet has been a formal internal evaluation of this protocol, this leads to the following research question:

*What are facilitating and/or impeding factors according to child health professionals of the municipal health service Twente in their adherence towards the protocol used after child death, and, according to these professionals, what are possible ways of improving the protocol, and with this, the care provided to parents and siblings of the deceased child around child death?*

### Sub questions

With the following four sub questions, it should be possible to answer the research question:

1. What are facilitating and/or impeding factors regarding the protocol itself according to child health professionals of the municipal health service Twente in their adherence towards the protocol used after child death, and which recommendations do they provide regarding this protocol?
2. What are facilitating and/or impeding factors regarding the users according to child health professionals of the municipal health service Twente in their adherence towards the protocol used after child death, and which recommendations do they provide regarding the users?
3. What are facilitating and/or impeding factors regarding the organisation according to child health professionals of the municipal health service Twente in their adherence towards the protocol used after child death, and which recommendations do they provide regarding the organisation?
4. What are facilitating and/or impeding factors regarding the socio-political context according to child health professionals of the municipal health service Twente in their adherence towards the protocol used after child death, and which recommendations do they provide regarding the socio-political context?

### 3 PROCEDURES AROUND CHILD DEATH

The information presented in this chapter should provide the reader of this thesis a better understanding of different ways in which professionals can support parents and others close to the child, such as siblings of the deceased child. Explanation of this support is also helpful for a better understanding of facilitating and impeding factors towards adherence of the protocol according to child health professionals.

This chapter describes the protocol of the municipal health service Twente. In the first Paragraph, general information about the municipal health service Twente is provided. After this, information is given about what happens when a child dies. Afterwards, the protocol that is used at the municipal health service Twente will be described in more detail.

#### 3.1 Municipal health service Twente

Municipal health service Twente is one of the 22 municipal public healthcare service organisations in the Netherlands (21). The work area of the municipal health service Twente consists of fourteen municipalities (22). The preventative child healthcare department of the municipal health service Twente uses the child healthcare guideline mentioned in the Introduction (Chapter 1) and has integrated this guideline in a self-made roadmap, which is the protocol they use after child death (see Appendix 1). This protocol describes which actions need to be taken, both inside and outside the organisation. Actions outside the organisation are mentioned in the guideline, that is support/guidance for parents and siblings of the deceased child. Inside the organisation, administrative and communicative actions need to be taken, which are described in the protocol.

For a good understanding of the notification routes projected in the roadmap and its guideline, it is helpful to first know what happens after a child dies.

#### 3.2 Determination of a child death

Prior to the notification of a child death at the municipal health service Twente, the death of a child needs to be determined. This is done as follows:

At first, when death is caused by expected and natural circumstances, for example by cancer, it is sufficient that the treating doctor determines that the child has died. In all other cases, whether natural or unnatural, both a treating doctor and an independent municipal coroner have to determine that the child has died. This is according to the Burial and Cremation Act (33) (in Dutch: Wet op de lijkbezorging). When a child death has natural causes, the coroner and/or doctor state that the person is dead (16). Stating a death is done via the first form of declaration, the so-called death certificate or A-form (in Dutch: A-verklaring)(16). They can also state what the cause of natural death is. Stating the cause of death is done via the second form, the B-form (in Dutch: B-verklaring)(16).

When a child death does not have natural causes, the coroner and/or doctor can only state that the person is dead (A-form), and that they suspect that the child has died from external causes (B-form). However, they may not determine what these external causes are. This is carried out by forensic services, who work for the police (16).

When the cause of death in children cannot be identified by forensic services, the NODOK-procedure can be started ("Further investigation cause of child death", in Dutch: "Nader Onderzoek DoodsOorzaak Kind"). This procedure investigates the cause of death in a non-judicial setting (34).

A filled-in A-form is sent, irrespectively of the B-form, to the Municipal Personal Records Database (in Dutch: GBA, "Gemeentelijke BasisAdministratie persoonsgegevens"), and the GBA sends notifications to all municipal services, including the municipal health service.

#### 3.3 Protocol of the municipal health service Twente after the death of a child

The moment that the municipal health service Twente receives the notification that a child has died, the procedure with the protocol starts. As this protocol is specially made for situations after child deaths, the protocol is meant for professionals that work in the preventative child healthcare department of the municipal health service Twente.

The English version of the roadmap can be seen below in Figure 1. It is directly translated from the Dutch version of the roadmap, which can be found in Appendix 1. As can be seen in the roadmap,

different professions have specific tasks to perform. All professionals present in the roadmap are part of the child healthcare department, except for the director of public health.

All three columns start after the client administration receives the notification from the GBA that a child has died. The client administration “removes the child from care”, which means that it is made impossible for the family of the deceased child to still receive requests for revaccination or other appointments.

The client administration subsequently informs the other child health professionals by mail or by telephone. Not all teams of child health professionals are informed. Which team of child health professionals is informed is dependent on the municipality within the Twente region that monitored the deceased child.

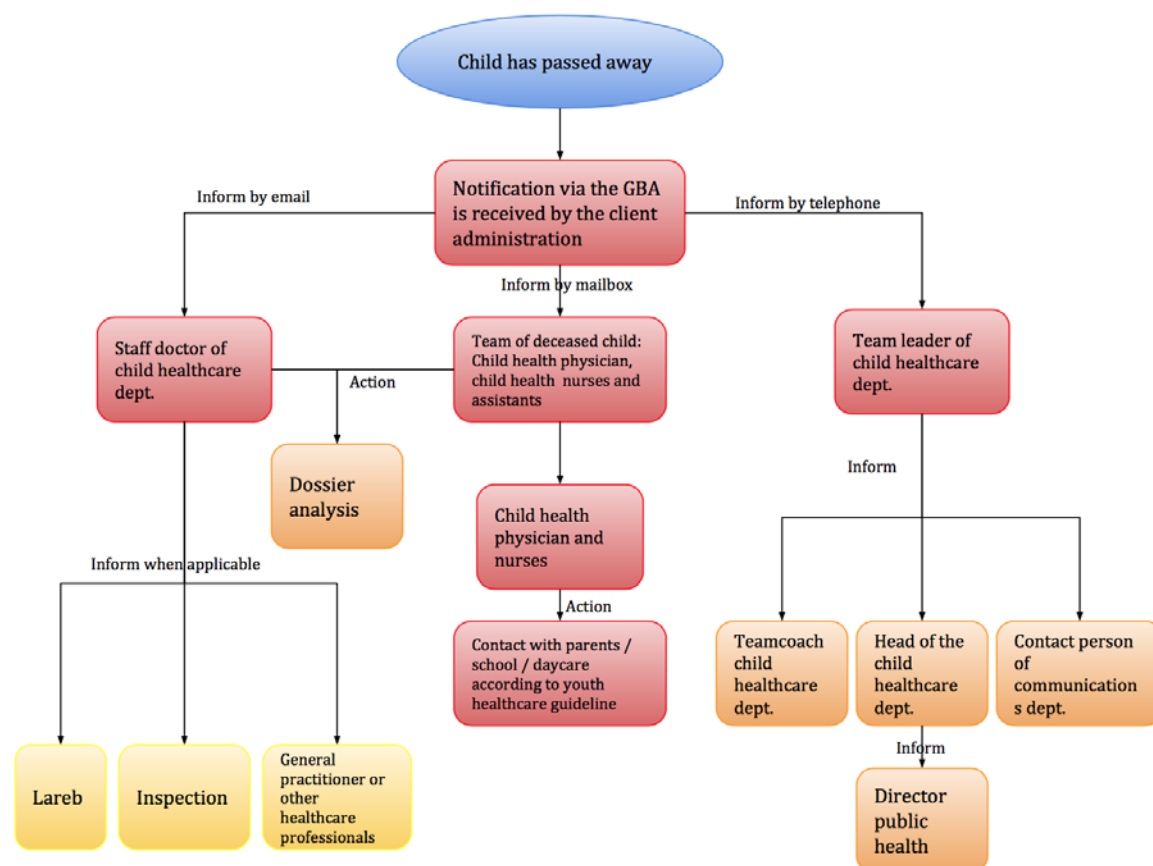


FIGURE 1. ROADMAP OF MUNICIPAL HEALTH SERVICE TWENTE (DIRECTLY TRANSLATED FROM THE DUTCH VERSION)

It is possible that a municipal health service receives the notification of a child death via other ways than the GBA. The following examples are frequently experienced:

- Via the *National Institute for Health and Environment* (in Dutch “RIVM”; Rijksinstituut voor Volksgezondheid en Milieu): The RIVM collects, amongst others, data about foetal death (mortality between 22 and 28 weeks of pregnancy) and perinatal death (mortality after 28 weeks of pregnancy)(14,35). The RIVM analyses trends and possible explanations for this data (36). Legally, parents must request for a birth and death certificate when their child has died in the perinatal period (37). However, it happens regularly that this is not done by parents, due to lack of knowledge about the registration procedure (37). And when the GBA does not receive requests for death certificates, the GBA cannot send any records about that deceased baby to the municipal health service. However, the RIVM can send a record of death notifications to the municipal health service, as it receives information from hospitals. From that point on, the routes of the roadmap can be followed (see roadmap).

- Via the *obstetrician*: notification of a stillborn baby or a baby that shortly dies after labour can reach the municipal health service quicker than via the route of the GBA. This is because parents first have to request for a birth and/or death certificate, while obstetricians can contact the municipal health service by mail or phone. If the obstetrician is aware that there are siblings of the deceased child, a notification is often sent to the team of child health professionals of these siblings and not to the client administration. Further actions performed after notification are fully dependent on the team of child health professionals and whether they inform the client administration and others involved.
- Via *(social) media*: media such as newspapers, Facebook™ or Whatsapp™ can result in quicker notification of a child death at the municipal health service than through the GBA. Dependent on who is notified by the media, further actions can be taken using the roadmap. *(personal communication with RH)*
- Via the *general practitioner* or other health professionals: As mentioned in paragraph 3.2 Determination of death, a general practitioner is able to determine the death of a child. If the general practitioner subsequently informs the municipal health service, this way of informing can be quicker than via the GBA.

There can be other ways of informing a municipal health service about a child death, but the examples mentioned above are frequently experienced.

The left column of the roadmap states what the staff doctor needs to do when applicable. “When applicable” means when the death of a child causes turmoil in its broadest sense. This could be turmoil in the organisation itself, where it can be questioned whether the child health professionals have delivered care properly, or outside the organisation, for instance when death is a result of suspected child abuse or is caused by a traffic accident, as this frequently causes turmoil in the community *(personal communication with RH)*.

The right column of the roadmap states what the team leader should do. According to the roadmap, the team leader informs the team coach, the head of the preventative child healthcare department, and the contact person of the communication department at municipal health service Twente. The head of the preventative child healthcare department informs the director of public health.

The middle column of the roadmap explains which tasks the child health physicians and child health nurses are supposed to do. These tasks are described in the box at the bottom of the column “Contact with...guideline”. This guideline is the national child healthcare guideline “guidance/support parents after child death”, for child health professionals to use. Lastly, together with the staff doctor, the team of child health professionals (which involves assistants next to child health physicians and child health nurses) are supposed to perform an analysis of the dossier of the deceased child.

### 3.4 Child healthcare guideline

According to the Dutch Centre of Child healthcare, (in Dutch: NCJ, “Nederlands Centrum Jeugdgezondheid”), who issued the guideline, the child healthcare guideline consists of four themes (25):

1. Support in bereavement for parents by a preventative child healthcare department;
2. Guide for the preventative child healthcare organisation;
3. Guide for child health professionals (administrative);
4. Communication towards parents.

#### 1. Support in bereavement for parents by the preventative child healthcare department

This theme explains that the aim of using the guideline is to prevent an impaired grieving process. Tasks of child health professionals can be found in the basic program of preventative child healthcare (in Dutch: “nationaal basistakenpakket”), and are divided in six tasks: signalling and monitoring, assessing care needs, screenings and vaccinations, provision of information and advice, analysis of potential threats, and identifying network partners. Providing support to parents in situations of child death can be in the form of assessing the care needs of parents, providing information and advice for (future) children, and also signalling and monitoring abnormalities in behaviour of parents and siblings of the deceased child.

#### 2. Guide for the preventative child healthcare organisation

After a child dies, it has to be “removed from healthcare”, which means that it has to be made impossible for parents to receive appointment-requests for re-vaccination (for instance) of the deceased child. At the municipal health service Twente, the client administration executes this task, but this can differ per organisation. Additionally, in the (medical) files of siblings of the deceased child, a notification of the child’s death needs to be made. Lastly, parents and siblings can also be offered a “grieving suitcase” (in Dutch: “rouwkoffer”), in which books, flyers, and (internet) addresses are offered for the family in order to make the grieving process as comfortable as possible.

### 3. Guide for child health professionals

This section explains what actions should be taken from child health professionals with regard to verifying the death and what to do with the (medical) files of the deceased child and its siblings, as mentioned in the section directly above.

### 4. Communication with the parents

This section explains in what form, how, why, and when the communication with parents of a deceased child should take place.

Recapitulating, this chapter provided information about what happens after a child has died, and what subsequently happens according to the protocol that is used at the municipal health service Twente. A role description of all professionals involved in this protocol was provided, and possible ways of notification of a child death other than through the GBA was given. Lastly, a detailed description of the guideline that is included in the protocol was provided. The next chapter consists of the theoretical framework and a literature overview of factors of adherence towards protocols.



## 4 THEORETICAL FRAMEWORK

The theoretical framework helps in understanding the answers to the research question. It helps in interpreting results and places these results in a broader perspective, questioning whether it is logical that answers were given. The results of present research will be compared to factors of adherence of other studies. The factors of adherence of other studies are provided in this chapter. First, a description will be given of literature concerning support after child death. After that, literature on guidelines and procedures of child death will be addressed. In addition to this, a description of the factors of adherence to guidelines in general and to guidelines used in situations of child deaths will be addressed. Lastly, three methods of evaluating implementations will be addressed and discussed. One of these three methods will be chosen as present research' framework.

### 4.1 Previous research concerning child death

Gijzen et al. (38) performed research about how parents evaluate the support they have received when their child died. This qualitative research is done with four online focus groups with 64 participants. These participants were recruited from three different parents' associations of deceased children. The research showed that in the Netherlands, 52% of the participants feel that they have received insufficient emotional support after their child has died. Informational support was insufficient in 25% of the parents. Participants of this study especially felt very concerned in later pregnancies when they lost a child shortly after birth. They also said that they have missed emotional and informational support on the long term after their child died.

The subjects of Gijzen et al. and present research are dissimilar, as Gijzen et al. (38) evaluated the support given to parents, and present research evaluates factors of adherence towards the protocol. Results of the Gijzen study can complement to present research. Child health professionals can receive more handles in the provision of support, in order to make the grieving process of parents as comfortable as possible.

### 4.2 Previous research concerning guidelines/procedures after child death

Worldwide, there are guidelines for health professionals how they can support parents in their bereavement after a child death (39–41). However, next to the child healthcare guideline, there seems no other guideline available for the support of family after child death in preventative primary care settings in the Netherlands and worldwide. Most of the guidelines that are available for health professionals, are for hospital settings (39–41). All these guidelines have somewhat overlapping goals, which is support of parents and siblings of the deceased child, but can differ in actions. Some are specified for a specific department, such as the neonatal, oncology or emergency department, while others account for hospital deaths in general. One can imagine that procedures in emergency settings differ in terms of resuscitation, identification, and autopsy of the child, resulting in different communication to parents, then compared to procedures in oncological settings.

The study of DeCinque et al. (39) evaluated current practices in oncology hospital-based bereavement support programmes towards parents. DeCinque et al. undertook a survey at ten major tertiary paediatric oncology units in New Zealand. They found that of the nine hospitals that participated in this study, only two formally evaluate their support programmes. However, the researchers state that undertaking formal evaluation of support programmes is necessary to ensure provision of best practice and to provide evidence to support the ongoing provision of resources to these support programmes. This study also found that there were unmet needs, and DeCinque et al. state that this can be mirrored to the absence of evaluation. When there is no evaluation, it is also unknown whether there is adherence to these procedures. Their conclusion is that there is need for the further development of bereavement programmes, to improve education for staff about support, and to increase available resources in the area of New Zealand.

A problem that O'Malley et al. (40) addresses in their technical report, is that there is no universal guideline that consist of a baseline of care that at least should be given to parents. O'Malley et al. tried to make a revised report and a corresponding policy that includes "baseline-care" in an Emergency-

department-setting in American hospitals. The researchers made a table with essential components of actions that, from O'Malley et al. 's point-of-view, should be taken. This table can be seen below in Table 1. They categorized the actions into Clinical actions, Operational actions, Legal and Forensic actions, Ethical actions, Spiritual and Emotional actions, Follow-up care for family – actions, and Follow-up care for team – actions.

TABLE 1. TABLE WITH BASELINE-CARE IN AN EMERGENCY DEPARTMENT-SETTING FROM THE ARTICLE OF O'MALLEY ET AL. (40). RED ARROW-HEADS "←" ARE INCLUDED TO INDICATE ACTIONS DESCRIBED BOTH IN THE DUTCH NATIONAL CHILD HEALTHCARE GUIDELINE (25) AND IN THE STUDY OF O'MALLEY ET AL.

<b>Clinical actions</b>
Resuscitation best practice
Termination of resuscitation
Identifying, validating, and respecting advanced care directives
<b>Operational actions</b>
Staff training in communication
Team response (including readily available support staff such as security, child life, chaplaincy, social work) ←
Family presence policy
Communication with medical home
Defusing/debriefing for team
Private location for family to be with deceased, means and location to conduct rituals
<b>Legal and Forensic actions</b>
Organ donation
Autopsy
Working with police and coroner/medical examiner ←
Child protective services ←
Child fatality review team ←
Documentation in medical record ←
Preservation of evidence ←
<b>Ethical actions</b>
Resuscitation: how long is too long?
Prolongation of resuscitation efforts for family presence/organ donation
Practice on newly deceased
Initiation of resuscitation at the border of viability in extreme preterm birth
<b>Spiritual and Emotional actions</b>
Needs of family, including saying goodbye, memory making ←
Needs of multidisciplinary team
Envisioning a "good death" in the ED
<b>Follow-up Care for Family actions</b>
Helping family to know everything was done ←
Assisting family in explaining to siblings, family, friends ←
Assisting family in locating community support to address grief and bereavement ←
Plan for post autopsy meeting to answer questions
Plan for scheduled follow-ups and marking of meaningful dates ←
<b>Follow-up Care for Team actions</b>
Scheduled voluntary defusing/debriefing with all members of the emergency care team who wish to participate

Comparing the actions that were recommended as baseline-care in this table with the national child healthcare guideline used in present research, there are many differences in actions between hospital-based settings and preventative child healthcare-based settings. These differences can be explained by the fact that child health professionals of municipal health services are (in theory) never present at the moment of death. Especially the Clinical actions described in Table 1 are not present in municipal health settings. Looking at the actions with "←", these actions are equivalent to the actions described in the child healthcare guideline. O'Malley et al. (40) recommended protocols and guides for health professionals on how to support parents of children that deceased in emergency department settings. They found that knowledge about proper communication between health professionals and parents is often lacking. With present research, it can be investigated whether the problems that O'Malley et al. addresses, are also present in preventative child healthcare settings. Even though guidelines for hospital-based settings and preventative child healthcare-settings probably remain to have differences, the results and recommendations from the study of O'Malley can be a start towards universal working methods that help professionals in providing support to parents who have lost their child.

### **4.3 Previous research concerning adherence to guidelines/procedures in general**

If we look broader to adherence of professionals towards other protocols or procedures, there is much literature available. One widely used theory about adoption of innovations is the Diffusion-model by Rogers et al. (30). Rogers et al. describe in their research which factors are of influence on the rate of adoption of an innovation by members of a social system. Rogers et al. state that the following five characteristics determine an innovation's rate of adoption: Relative advantage, Compatibility, Complexity, Triability (henceforth trial-ability), and Observability. Adoption of an innovation occurs more rapidly when its users believe the innovation has a greater relative advantage, greater compatibility, greater trial-ability, greater observability, and is less complex than other innovations. Translating this to present research, it can be concluded that adherence to the protocol used after child death at the municipal health service Twente will be greater when its users (the child health professionals) believe there is great relative advantage, compatibility, trial-ability, observability, and low complexity.

#### **4.3.1 Previous research concerning adherence to guidelines after child death**

Konijnendijk et al. (32) performed research about facilitating and impeding factors of adherence to child abuse prevention guidelines in Dutch preventative child healthcare. This was a qualitative and explorative research in which Konijnendijk et al. used the MIDI- determinants by Fleuren et al. (31) to identify factors of adherence towards child abuse prevention guidelines. Fourteen participants in three focus groups gave the following facilitating factors: familiarity with the content of the guidelines, a working environment that is supportive, and a good cooperation between different agencies. Impeding factors were: caregivers not willing to cooperate, low self-efficiency, and poor cooperation between different agencies.

The research of Konijnendijk et al. considers a dissimilar subject compared to present research, but looks alike with its research question and setting. Therefore, the Konijnendijk et al. research could be of inspiration when choosing a research method, as it evaluates adherence to a guideline. In a later stadium, it is evaluated whether results from the research of Konijnendijk et al. are equal to results of present research.

Gijzen et al. performed a pilot study on the implementation of Child Death Review (CDR) in the Netherlands (41). CDR can be used to analyse child deaths systematically to identify factors that may have contributed to a death, and that could have been prevented. Strengths, Weaknesses, Opportunities, and Threats (SWOT) were identified in the pilot-implementation of the CDR. The researchers identified expertise and cooperation of the CDR team, and available materials as most important strengths in the implementation. The most important weakness was poor cooperation of some professional groups. An opportunity provided by parents and professionals was that both think that the purpose of performing a CDR is important. And lastly, a threat was identified in the lack of statutory basis. The conclusion of this research was that many obstacles needed to be taken away before implementation of CDR on a nation-wide level.

This research of Gijzen et al. evaluates the implementation of the CDR. The factors that influenced implementation were identified and these factors can be compared to the factors that will be identified in present research.

### **4.4 Methods of internal evaluation of implementations**

Three methods of evaluating implementations will be evaluated for assessment in this research and one will be chosen as framework for present research. The three methods include the Normalization Process Theory, Strengths-Weaknesses-Opportunities-Threats, and the Measurement Instrument for Determinants of the Innovation. The first two methods are chosen for the evaluation, because of their broad theoretical base (42,43). The third method is chosen for evaluation, as it was mentioned in the study of Konijnendijk et al. (32), that has a similar research question and setting as present research.

#### **4.4.1 Normalization Process Theory (NPT)**

The Normalization Process Theory (NPT) is developed by May et al. (42) in 2006, which, in the first place, was made for business processes and healthcare interventions. NPT is a theoretical model that helps to understand what the processes are when implementing an innovation and why some innovations are integrated more easily into working life than others. May et al. state that this model

can also help in planning and evaluating the implementation of that specific innovation. It consists of four mechanisms: Coherence, Cognitive participation, Collective action, Reflexive monitoring. Coherence is defined as the meaning and relevance of a new innovation. Cognitive participation means whether the user is able to use the innovation in the first place. The third mechanism, collective action, describes that collaboration is important in order to let an implementation succeed. With the last mechanism, reflexive monitoring, it can be investigated whether the user of the innovation believes that the innovation is relevant. Where mechanism coherence involves a point-of-view from the innovation, reflexive monitoring has a user point-of-view. Every mechanism consists of four components, thus a total of 16 components. An overview of all mechanisms and their components can be seen below in Table 2.

TABLE 2. MECHANISMS AND COMPONENTS OF THE NORMALIZATION PROCESS THEORY (NPT) BY MAY ET AL. (42).

<b>Coherence</b>	<b>Cognitive participation</b>
1. Differentiation	9. Initiation
2. Individual specification	10. Legitimation
3. Communal specification	11. Enrolment
4. Internalization	12. Activation
<b>Collective action</b>	<b>Reflexive monitoring</b>
5. Interactional workability	13. Systemization
6. Relational integration	14. Individual appraisal
7. Contextual integration	15. Communal appraisal
8. Skill set workability	16. Reconfiguration

Advantages of using the NPT is that it has broad theoretical base and originates in the business and healthcare sector. There are also disadvantages of using the NPT. The NPT does not take into account what the organisation can do to help embedding the innovation. Furthermore, the NPT was initially made to help implementation and to understand the different processes of implementation. Evaluation after implementation, what is done in present research, is more difficult with this framework, as provided recommendations for the innovation cannot be linked directly to a mechanism or component.

#### 4.4.2 Strengths-Weaknesses-Opportunities-Threats (SWOT)

The SWOT-analysis was made between 1960-1970 by Humphrey et al. (43) at the Stanford Research Institute. SWOT was made as a tool specially for companies to be able to identify the problems around a certain case of failure. The SWOT-analysis is a widely used model in economic businesses. All input of participants of a SWOT-analysis can be linked to Strengths, Weaknesses, Opportunities or Threats. There is no further specification of these categories. This is an advantage, as one is free to use this model in any case-analysis. On the contrary, this model is general and in present research, analysis with this model would be rather difficult because of this generality. SWOT as a guiding framework does not give the amount of support compared to what the NPT-model gives, and it is believed that in present research, analysis would be more easy to do with more support than the SWOT-analysis provides.

#### 4.4.3 Measurement Instrument for Determinants of the Innovation (MIDI)

Fleuren et al. (31) developed the Measurement Instrument for Determinants of Innovation (MIDI) in 2014. The researchers state that this instrument is *“designed to improve our understanding of the critical determinants that may affect implementation in order to better target the innovation strategy”*. The MIDI is specially made to be used in preventative child healthcare-settings. This is an advantage in this research, but a disadvantage in research that take place in other settings as it is more difficult to generalize. The MIDI is also a relatively new instrument to use in research, and therefore does not have a broad theoretical base compared to NPT and SWOT. Like the NPT, the MIDI-instrument consists also of four mechanisms, named concepts, of which determinants can be associated with. These four concepts are the innovation itself, the adopting person (user), the organisation, and the socio-political context.

Reflecting the MIDI on present research, the innovation is the now-existing protocol, the users are the child health professionals, the organisation is the preventative child healthcare department, and the socio-political context are external factors such as legislation, regulation, medical confidentiality. In

every concept, there are determinants that fall under a concept. An overview of all determinants and the concepts can be seen below in Table 3. The total number of determinants in the MIDI-framework is 29.

TABLE 3. CONCEPTS AND DETERMINANTS OF THE MEASUREMENT INSTRUMENT OF DETERMINANTS OF INNOVATION (MIDI) BY FLEUREN ET AL. (31).

<b>Determinants associated with the innovation</b>	
1. Procedural clarity	5. Compatibility
2. Correctness	6. Observability
3. Completeness	7. Relevance for the client
4. Complexity	
<b>Determinants associated with the user</b>	
8. Personal benefits/drawbacks	14. Descriptive norm
9. Outcome expectations	15. Subjective norm
10. Professionals obligation	16. Self-efficacy
11. Client/patient satisfaction	17. Knowledge
12. Client/patient cooperation	18. Awareness of content of the innovation
13. Social support	
<b>Determinants association with the organisation</b>	
19. Formal ratification by management	24. Material resources and facilities
20. Replacement when staff leaves	25. Coordinator
21. Staff capacity	26. Unsettled organisation
22. Financial resources	27. Information accessible about the innovation
23. Time available	28. Performance feedback
<b>Determinants associated with the socio-political context</b>	
29. Legislation and regulation	

Determinants that are associated with the user are comparable with the mechanism Cognitive Participation of the NPT.

#### 4.4.4 Comparing MIDI to NPT and SWOT

There are multiple reasons to choose for the MIDI as framework for present research. The MIDI takes into account determinants that can be associated with the organisation, which the NPT does not take into account. The MIDI consists also of more specified determinants than NPT, which makes analysis with MIDI easier in present research. Another reason to choose for the MIDI instead of the NPT is that this instrument can be used more easily in evaluation after implementing an innovation, because the MIDI is made for both implementation and evaluation of an implementation, where NPT is more applicable to use in the implementation-process of an innovation.

The main reason to choose for the MIDI as the framework for present research compared to the SWOT-analysis, is that the MIDI-instrument provides more support and guidance in the analysis, with its 29 determinants. It is thought that the SWOT-analysis is too general to function as a framework for present research. Thus, compared to NPT and the SWOT-analysis, MIDI is believed to be the most suitable for this research.

Furthermore, Konijnendijk et al. (32) stated that the MIDI was a valuable framework in their research. Konijnendijk et al. had a similar research setting and a similar research question. This is another reason to choose for the MIDI as framework in present research. Next to this, Fleuren et al. (31) state that the MIDI is made for preventative child healthcare settings.

The MIDI will therefore be used as framework for the evaluation of current working procedure, which includes the protocol with child healthcare guideline, and factors of adherence according to child health professionals. The four sub questions stated in Chapter 2 consist of the four concepts of the MIDI-framework (innovation, user, organisation, socio-political context).

Recapitulating, the theoretical framework has described which studies have been done concerning factors of adherence towards protocols. Subsequently, in the second half of this theoretical framework, three methods for evaluation of implementations have been discussed: NPT, SWOT, and MIDI. The MIDI has been chosen to serve as the theoretical framework for present research and the reasons why were presented in this chapter. The next Chapter, Chapter 5, describes how the MIDI was used in present research as Chapter 5 will discuss the research methodology and how the research question will be answered.

## 5 RESEARCH METHODOLOGY

The research methodology describes which steps and actions were undertaken in order to answer the research question via the sub questions. Data collection, stakeholder identification, and data analysis are part of this research methodology.

### 5.1 Data collection

#### Stakeholder identification

A stakeholder identification was done in order to decide which professions needed to be included in present research. Not all stakeholders present in the protocol needed to be included, because some stakeholders play a larger role than other stakeholders, after child death. Identifying stakeholders was done with the stakeholder mapping technique of Imperial College London (44) and of Mendelow et al. (45), called the Influence-Interest grid or the Power-Interest grid. This mapping technique was chosen because it provides a general overview of stakeholders, with only four divisions. It is thought that there was no need for a more detailed stakeholder identification-method, such as the mapping techniques of Mitchell et al. (46), who use classification of eight different stakeholders. All stakeholders in present research can be classified in one of the four divisions. In this research, there was chosen to make no distinction between power and influence. An example of the grid can be seen in Figure 2. When a stakeholder is closer to the arrowhead of the horizontal or vertical arrow, the higher the interest or influence/power of this stakeholder is.

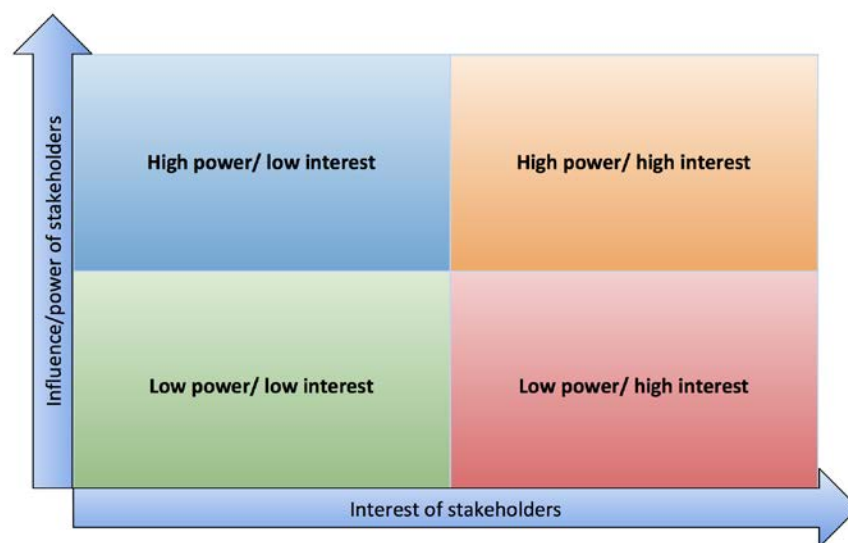


FIGURE 2. INFLUENCE/POWER – INTEREST GRID BY IMPERIAL COLLEGE LONDON (44) AND MENDELOW ET AL. (45)

The first option for a stakeholder was to have **high influence/power** and **high interest (upper right grid)**. These stakeholders include all executive professionals, the team leader, the staff doctor, and the client administration. They have direct influence on the care they provide to parents, are the first contact persons to school and parents, or are key players and fulfil essential positions in the for proper execution of the protocol.

The second option for a stakeholder was to have **low influence/power** and **high interest (bottom right grid)**. This stakeholder includes the quality officer of the preventative child healthcare department. The quality officer helped developing this protocol. Although this position is not mentioned in the protocol, it does fulfil an important responsibility in the quality management of the municipal health service Twente. The quality officer does not provide direct care to parents, and therefore, this stakeholder has a high interest and low influence/power.

The third option for a stakeholder was to have **low influence/power** and **low interest (bottom left grid)**. These stakeholders mentioned in the protocol include other health professionals/organisations, the team coach, contact person of the communication department, and the director of public health. These stakeholders are included in this grid, because in most situations of child death, these professionals are not involved and informed. Examples of involvement of these stakeholders are when the death of a child raises questions about the functioning of health professionals, induces turmoil (by the media), or needs further investigation about the cause of death. Then, these professionals take further actions.

The fourth option for a stakeholder was to have **high influence/power** and **low interest (upper left grid)**. This stakeholder includes the head of the preventative child healthcare department. This stakeholder is also only involved in cases of child deaths such as mentioned right above. However, this stakeholder is presumed to have more influence than the stakeholders mentioned in the bottom left grid, because this stakeholder is not a final link projected in the protocol. This means that a proper execution of the protocol relies somewhat more on this stakeholder than on the stakeholders mentioned in the bottom left grid. Therefore, the influence is higher of the head of the preventative child healthcare department than the professionals in the lower left grid.

This leads to the following influence/power-interest grid, which can be seen in Figure 3.

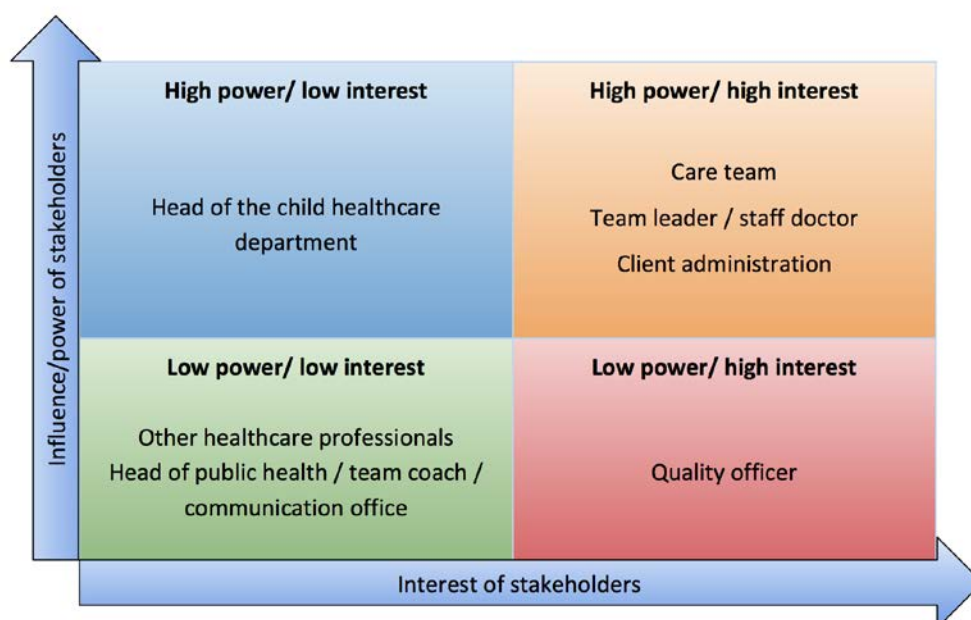


FIGURE 3. INFLUENCE/POWER-INTEREST GRID CORRESPONDING TO THE PROTOCOL OF THE MUNICIPAL HEALTH SERVICE TWENTE

It was chosen to include only the professionals with a high interest and/or influence/power, because of the following arguments: Mitchell et al. (47) and Mark et al. (48) state that with limited energy, time, and resources, managers may do nothing with the stakeholders they believe possessing insufficient involvement in a certain issue. Mark et al. additionally state that exclusion of stakeholders with low power and low interest seems a logical step, as it seems that these stakeholders do not deserve empowerment in evaluations.

Stakeholders with both low power/influence and low interest were not included for participation in present research, because these stakeholders are not involved in most situations of child death. It was thought that the four sub questions, and therefore the research question, could be answered with the inclusion of the stakeholders with either high interest and/or high influence/power.

Stakeholders that were included for participation in present research, could participate in focus groups and/or interviews.

### Focus groups

Focus groups are widely used in qualitative research, because they have as advantage that they are able to identify inspirational information (49). This is an advantage when comparing focus groups to



interviews, because discussion can take place in focus groups and in this way, thoughts of others can induce inspiring answers. Focus groups can be already efficient when three people are included, and are most efficient when 6-8 people are included (49). Including multiple persons in one session is an advantage compared to doing interviews one-on-one. Additionally, focus groups save time in logistics and time in analysis compared to interviews, as, depending on the complexity of the subject, most information can be identified after only a few sessions of focus groups (49). Another benefit of focus groups and interviews is that stakeholders feel they are respected and involved in the process of improvement, which could lead to a better re-implementation (49). Involving stakeholders in the process of improvement is also pointed out by Rogers et al. (30) as a facilitator for diffusion of the innovation. Because of the reasons stated above, there was chosen for focus groups as a method for identifying factors of adherence. The focus groups were intended for those professionals that deliver care to parents and siblings of the deceased child after a child has died, thus the executive professionals, including child health physicians, child health nurses, and assistants. Child health physicians and child health nurses can work in age category 0-4 (preschool children) and/or 4-18 (school children) years of age. Distinctions were made between these two categories, as they may give different facilitating or impeding factors towards adherence of the protocol.

### Interviews

Conducting interviews are also widely used in qualitative research (49). Interviews have the benefit of providing more in depth answers and it is believed that interviews provide complementary information in present research. Looking at the stakeholder identification, those professionals that work 'individually', thus the client administration, staff doctor, team leader, and head of the preventative child healthcare department, were interviewed as an addition to the focus groups. Next to these professions, also the quality officer was interviewed, being responsible for quality management and helped developing the protocol.

Important for focus groups and interviews is that the quality of both research methods greatly depends on the matrix of questions (49). In this research, semi-structured focus groups and interviews were held. This means that the question matrix used in this research consist of open questions and closed questions. Questions that provided yes/no answers, were followed by open questions to explain the previous answer.

#### 5.1.1 Sample size

Literature states that, to retrieve information as efficient as possible, the ideal number of participants participating in focus groups is 6-8, with a heterogeneous composition of participants (49). A focus group was started when at least three participants were able to participate.

It was expected that enough information would be collected after three focus groups. After the last focus group, it was decided whether any new focus groups should be started. The quality officer was asked to join in one focus group and afterwards participate in an interview. This was done to provide insight of practical actions performed by the team of child health professionals, as, in contrary to all other included professions, a quality officer has no executive role during situations of child death. The aim was to include a total of 25 participants for the focus groups (8 participants x 3 focus groups + 1 quality officer). The aim was to interview a total of 6 participants in 5 interviews. These included staff doctor, client administration (two persons), team leader, quality officer, and the head of the preventative child healthcare department. The client administration consists of two employees who perform tasks after a child death and were therefore interviewed together. This concludes to an aimed total amount of participants participating in this research is 31 (25 participants + 6 participants).

#### 5.1.2 Study procedure

At first, all eligible participants were informed by electronic mail. This mail consists of information and the request to sign in for participation, irrespectively of this being for focus groups or interviews. For focus groups, next to electronic mail, information and requests were also posted in the private Facebook-group of the child health professionals of municipal health service Twente.

At the commencement of focus groups and interviews, participants were orally informed about the research again, and after that, participants made the decision whether to participate. This information also included about the focus groups and interviews being voice-recorded. After collecting the informed consents, voice-recording began, and the focus groups and interviews started according to the question matrix, which follows the MIDI-strategy of evaluation. Every focus group was moderated



by researcher AS, and assisted by supervisors SG and/or RH. All interviews were moderated by researcher AS.

#### Matrix and agenda for focus groups and interviews

The question matrix and agenda were set up using the MIDI-strategy in a semi-structured direction of questions. The order of the four concepts of the MIDI (the innovation, user, organisation, and socio-political context) were maintained. The word 'innovation' in this research can be somewhat confusing, because of the absence of a new innovation, but meant is the protocol after child death used at the municipal health service Twente.

First, more general questions were asked. To begin with, it was asked what care is provided to whom and which actions were taken when there is a notification of a child death. Thereafter, it was asked whether a protocol is used after notification of a child death and if yes; which protocol is used. Subsequently, it was asked whether the protocol of the municipal health service Twente is known and in what ways it is known/unknown. Finally, professionals were asked what they think is necessary to include in a protocol around child death, whether at this moment, child health professionals evaluate the provided care around a child death, and whether evaluation of provided care should be included in the protocol.

The second set of questions was about the users. It contained questions about the extent of using the protocol of the municipal health service Twente and the reasons for using or not using the protocol. Professionals were also asked what they think is necessary to use the protocol properly. Then, professionals were asked whether they use the child healthcare guideline that is included in the protocol and what they think is necessary the properly use this guideline.

The third set of questions was about whether and in what ways the organization is supportive about using the protocol, and what is necessary from the organization to let the users use the innovation optimally.

The last set of questions was about the socio-political context, meaning the law and regulation around the provided care, and whether child health professionals think law and regulation acts as impeders or facilitator to provide care according to the protocol and guideline. It was also asked whether child health professionals experience difficulties with law and regulation, and why.

Every focus group and interview took a maximal time of 60 minutes to collect all recorded data. The question matrix was slightly adjusted per interview, in order to have questions applicable to every professional.

For the design of the focus groups is in English, and can be seen in Appendix 2. For the interview-matrices used (in Dutch), see Appendix 3.

## **5.2 Data analysis**

Transcribing took place after the recorded data was collected, and was executed with an *edited transcription formatting* (50), which means that "uhms", errors in speech, or other words that in no way contribute to the content of a record, were removed. Voice recording was done with GarageBand™ of Apple Inc. Transcribing was done as well with GarageBand and subsequently transferred to Microsoft Word™.

The analysis of the transcripts was done with Atlas.ti™. A codebook was made and can be seen in Appendix 4. Relevant text fragments were selected by researcher AS. The relevant text fragments received codes, which correspond to the MIDI-determinants. This accounts for a total of 29 codes. These 29 codes also receive the labels that indicate the nature of the content. These labels were given the label F for a facilitating factor, I for impeding factor, or R for recommendation. Combining the code with a label results in the following codes: 1F, 1I, 1R, 2F, 2I, 2R, 3F ... 29R. A facilitating factor is described as factors that facilitate in the adherence of the protocol. An impeding factor is described as a factor that impedes the adherence towards the protocol. Lastly, recommendations are described as advice or suggested improvements that could induce a better adherence towards the protocol.

In order to maintain the quality of this research, Chapter 6 of manual Healthcare Research by Plochg et al. (51) was used as a guidance throughout this research. Analysing the transcripts, and even

transcribing the recorded data itself are susceptible for reporting bias. To minimize this beforehand, transcription and analysis as mentioned above were done by researcher (AS). The encoded transcripts of focus group 1 and 2 were reviewed by an independent researcher (AvA) as a control. Additionally, the encoded focus group 1 was also reviewed by mentor (SG) as a control. Whenever there was a misunderstanding or a difference in interpretation, this was discussed until agreement was reached. Looking at the manual of Healthcare Research, where Plochg et al. (51) stated that qualitative research consists of Observation, Communication, and Interpretation, the transcripts that were made out of the recorded data are a form of observation. It is interpreted that when a facilitating or impeding factor, or recommendation is mentioned multiple times in a comparable manner, these were linked to each other. Interpretation was done in Paragraph 6.3 in order to keep the overview clearer and more understandable for the reader. It was possible that some quotes were linked to two determinants. Occurrence of a quote being linked to two determinants, was mentioned explicitly in the Results section of Chapter 6.

### **5.3 Data safety protection**

Participants were coded in a separate file under a random numeric code. Thus, participants in this research are not anonymous, though identification is only possible through converting the subject identification code. Data is stored securely in an external hard drive, which will be stored at the municipal health service Twente, and is only accessible via the researcher.

### **5.4 Permission ethical committee/informed consent**

Performing research with both these research methods requires permission from the Ethical Committee of the faculty of Behaviour, Management, and Social Sciences (BMS) of the University of Twente. Permission has been granted under file number BCE17120.

The informed consent that will be given to participants can be seen in Appendix 5. All informed consents were stored securely at the municipal health service Twente.

This chapter explained the research methodology and what needs to be done in order to answer the research question. It was explained that focus groups and interviews were used with the stakeholders appointed in the stakeholder identification-section. The MIDI as question matrix and corresponding codes were discussed in detail and the study procedure was enlightened. Lastly, data analysis was described; vocal recording, Atlas.ti, encoding, and reviewing with independent researcher were the base for present research' data analysis. In the next chapter, the results of this research methodology will be presented, and the four sub questions will be answered.

## 6 RESULTS

This chapter explains the results obtained in this research. This chapter also answers the sub research questions. At first, the characteristics of the participants are presented. After that, results from the transcripts and encoding are described. Paragraph 6.3 provides general information concerning the MIDI-framework, and from Paragraph 6.4 onwards, answers per sub question are provided.

### 6.1 Characteristics of participants

In total, combining the focus groups and interviews, seventeen participants were included in the research. Of the eleven executive professionals that signed in for the focus groups, three child health physicians, three child health nurses, and five assistants were included. One interview was conducted with both employees of the client administration. Furthermore, the team leader, staff doctor, and head of the preventative child healthcare department were interviewed one-on-one. The quality officer participated in both a focus group and an interview.

All executive professionals (child health physicians, child health nurses, and assistants) were divided in three focus groups. After three focus groups, it was decided to not start any new focus group, because there seemed sufficient amount of saturation of answers. The composition of the focus groups of professionals can be seen in Table 4. Also stated in this table is the age category in which they work.

TABLE 4. GROUP COMPOSITION OF FOCUS GROUPS. NUMBER OF PARTICIPANTS IS N.

Focus group composition	Focus group 1 N (total N=3)	Focus group 2 N (total N=3)	Focus group 3 N (total N=6)
Child health physicians:			
Age category 0-4	1	0	0
Age category 4-18	1	1	0
Child health nurses:			
Age category 0-4	1	0	1
Age category 4-18	0	1	0
Assistant:			
Age category 4-18	0	1	4
Quality officer	-	-	1

### 6.2 Transcription and encoding

Together with independent researcher AvA, the transcripts were read from the beginning and the codes were discussed. Both focus group 1 and 2 had 84 quotations that were selected and linked to codes. Of those 84 quotations in focus group 1, 10 quotations were interpreted in a different manner by researcher AS comparing to independent researcher AvA. A different code was designated to 3 quotations. In focus group 2, again 10 quotations were interpreted differently, but none of these codes received a code other than was initially designated. The encoded transcript of focus group 1 was also reviewed by supervisor SG. Of the 84 quotations, 10 quotations were interpreted in a different manner initially, but after discussion, only 2 of these quotations were designated with a different code. Quotations that received a different code than initially designated by researcher AS, remained in all cases in the same concept of the MIDI (innovation, user, organisation, socio-political context). The transcripts of recorded data and the encoded data can be provided by the first supervisor on personal request.

### 6.3 Results following the MIDI-framework

Of the 29 determinants of the MIDI, 22 determinants were mentioned either during focus groups or interviews. These determinants were identified as a facilitating factor, impeding factor, and/or as a recommendation. Each quotation linked to a determinant was counted according to being a facilitating or impeding factor, or as recommendation. An overview can be seen in Table 5 on page 29.

The determinants mentioned more than ten times were Completeness, Social support, Self-efficacy, Awareness of the content of the innovation, Material resources, Information accessible, and Legislation and regulation. Mentioned in every focus group and interview were the determinants Completeness and Awareness of the content of the innovation. Completeness was mentioned 59 times as an impeding factor and 82 times as a recommendation. Awareness of the content of the innovation was mentioned 74 times as a facilitating factor and 29 times as an impeding factor. There were no quotations that could not be linked with any of the MIDI-determinants.

An overview of the MIDI-concepts (innovation, user, organisation, and socio-political context) with their corresponding facilitating factors can be found in the Appendix 6. A comparable overview for the impeding factors of the MIDI-concepts can be found in Appendix 7. Finally, an overview of the recommendations of the MIDI-concepts can be found in Appendix 8.

From this point on, there is a description of the results per sub question. All quotes described in this chapter can be found in the transcripts, which are available on personal request via the first supervisor.

#### **6.4 MIDI-determinants associated with the innovation**

The first sub question is: What are facilitating and/or impeding factors regarding the protocol itself according to preventative child health professionals of the municipal health service Twente in their adherence towards the protocol used after child death, and which recommendations do they provide regarding this protocol?

##### Facilitating factors associated with the innovation

Facilitating factors of using the protocol were identified in the determinants Procedural clarity and Completeness. It was mentioned once that the protocol is clear. Client administration states that they use a script of their own, and that they think this script is sufficient for the client administration to perform their tasks properly. Another facilitating factor mentioned was the presence of evaluation of provided care after child death. Mentioned twice was that dossier analysis is done according to the protocol.

##### Impeding factors associated with the innovation

Of all impeding factors associated with the four MIDI-concepts, most impeding factors were mentioned in the concept Innovation, corresponding to determinants Procedural clarity and Completeness. Impeding factors for Procedural clarity were mostly that professionals think that the protocol is not sufficiently clear for them to work with. Mentioned four times in relation to the determinant Completeness was that professionals pointed out that they did not know what to do in different situations of child death. Also mentioned four times was that professionals found it difficult how to respond in situations where they receive notification of child death other than from the client administration. A quote that illustrates the opinion of a professional when notification is done via other ways than the GBA, can be seen below. Next to this impeding factor encoded under the MIDI-determinant Completeness, some professionals believe that they have missed an evaluation of provided care, even after "normal" cases of child death.

Lastly, concerning the determinant Relevance for the client, for one professional it was unknown why the grieving suitcase should return or why not.

---

*"Sometimes, I notice a child death via de media. Newspapers. And that it is not yet notified in the system. Thus, other ways of notification of a child death happen sometimes quicker, and to me that is peculiar. That should not be possible." (Focus group 2)*

---

##### Recommendations associated with the innovation

Recommendations mentioned concerning the innovation mostly corresponded to the determinant Procedural clarity and Completeness. Recommendations corresponding to the determinant Procedural clarity consisted of adding a description to the protocol, which include actions that need to be performed by other professionals. Additionally, a recommendation given for Procedural clarity was that one professional would like to see a centralization of the staff doctor in the protocol, while another professional likes that the team of child health professionals is central in this protocol.

TABLE 5. DETERMINANTS OF THE MIDI BY FLEUREN ET AL. (31) MENTIONED IN FOCUS GROUPS AND INTERVIEWS. OF THE 29 DETERMINANTS, 22 WERE MENTIONED EITHER AS FACILITATING OR IMPEDING FACTOR, OR A RECOMMENDATION WAS GIVEN.

Determinants mentioned of the MIDI-strategy	N times mentioned in focus groups and/or interviews		
	Facilitating factor (N)	Impeding factor (N)	Recommendation (N)
<b>Determinants associated with the innovation</b>			
1. Procedural clarity	3	4	7
2. Correctness	-	1	-
3. Completeness	4	59	82
4. Complexity	-	1	-
5. Compatibility	-	-	1
7. Relevance for client	1	1	-
<b>Determinants associated with the user</b>			
8. Personal benefits/drawbacks	-	2	1
10. Professional obligation	1	7	2
13. Social support	7	3	15
14. Descriptive norm	-	-	1
15. Subjective norm	2	-	2
16. Self-efficacy	18	1	-
17. Knowledge	3	4	2
18. Awareness of content of innovation	74	29	4
<b>Determinants associated with the organisation</b>			
19. Formal ratification by management	2	-	-
20. Replacement when staff leaves	4	2	2
21. Staff capacity	1	-	1
23. Time available	3	-	4
24. Material resources and facilities	-	2	14
27. Information accessible about the innovation	11	2	3
28. Performance feedback	-	1	-
<b>Determinant associated with the socio-political context</b>			
29. Legislation and regulations	14	4	14

In Paragraph 6.4.2, as an impeding factor for Completeness, professionals reported that they did not know what to do in situations that differ from “normal” deaths. A recommendations linked to this impeding factor was that professionals would like to see a description written in the protocol of how to act in different situations of child death. This was mentioned ten times and in every focus group and interview, except in the interview with the client administration. The quote below illustrates what was said about lack of description according to a participant.

Following the impeding factor for Completeness stated in Paragraph 6.4.2, evaluation of provided care, professionals suggested to include in the protocol that evaluation is a standard procedure in this protocol.

---

*“Some sort of role description, when I am deployed I would like to be able to fall back to a description of what needs to be done.” (Interview head of the child healthcare department)*

---

## **6.5 MIDI-determinants associated with the user**

The second sub question is: What are facilitating and/or impeding factors regarding the users according to child health professionals of the municipal health service Twente in their adherence towards the protocol used after child death, and which recommendations do they provide regarding the users?

### Facilitating factors associated with the user

Of all facilitating factors, most facilitating factors were identified with determinants involving the MIDI concept User. Professionals were generally positive about their own abilities. The facilitating factors were mostly linked to the determinants Self-efficacy, Knowledge and Awareness of the content of the protocol. Most professionals answered in such a way that it was interpreted that they know the protocol, know where to find it, believe they have sufficient knowledge about the protocol, and, whenever there are questions, know who to contact. This facilitating factor is illustrated by the quote below. Professionals are, in general, positive about which actions they need to take in order to support parents or to arrange all administrative documents in the organisation.

---

*“When I have questions, I contact the medical staff. Or maybe the quality officer. And otherwise, she will tell us where to find answers.” (focus group 1)*

---

### Impeding factors associated with the user

Professional obligation was a determinant that was mentioned by all assistants, because they believe that the protocol is not a personal obligation of theirs. When asked whether assistants should have tasks in situations of child death, there were mixed responses. Some professionals think they could be of value as they could monitor children’s behaviour in schools, being a tasks of the basic program of preventative child healthcare. Others do not know what to think of this suggestion or were negative about the suggestion. This is illustrated by the quote below.

---

*“As an assistant, you do not directly have an obligation of tasks in these situations.” (focus group 3)*

---

Impeding factors mentioned often were linked to the determinants Self-efficacy, Knowledge and Awareness of the content of the protocol. Some professionals were not aware that there is a protocol, or admitted to not knowing the protocol, not knowing the child healthcare guideline, or not knowing both. This is illustrated by the quote below. The reasons they gave for not knowing the content of the innovation, is because of the rareness of child deaths occurring or because professionals believe performing tasks in situations of child death is not a personal obligation. In addition to this, some professionals were wondering whether all who are supposed to work with this protocol, actually know what to do in situations of child death.

---

*"I have to admit that the protocol is not familiar to me. As I am sitting here, I realize that not knowing the protocol is a pity. I do not have to know the protocol by heart, but reading it once was a wise thing to do." (focus group 2)*

---

#### Recommendations associated with the user

As assistants stated above that an impeding factor is that they feel that they do not have professional obligations in these situations, some would like to do more towards schools.

The recommendation that was mentioned most falls under determinant Social support. Many professionals would like to receive emotional support, either from a team leader or from other professionals. They recommend that this is taken up in the protocol, or that contact information is present in the protocol. The quote below illustrates this recommendation.

A recommendation that is linked to the determinant Descriptive norm is that some professionals would like to have more and better contact with other instances, for instance the general practitioner, or with maternity organisations. Lastly, as a recommendation for the Awareness of the content of the protocol, some professionals think it could be useful to bring this protocol to attention in a team meeting or schooling.

---

*"There is need of the inclusion of social support for the professionals into the protocol". (interview team leader)*

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### **6.6 MIDI-determinants associated with the organisation**

The third sub question is: What are facilitating and/or impeding factors regarding the organisation according to child health professionals of the municipal health service Twente in their adherence towards the protocol used after child death, and which recommendations do they provide regarding the organisation?

#### Facilitating factors associated with the organisation

It was mentioned once that a professional did not believe that this protocol is being withheld by the organisation, and this was interpreted as a facilitating factor linked to the determinant Formal ratification by the management/organisation.

Furthermore, professionals think that these situations are prioritized above other situations and a facilitating factor for the determinant Time available is that professionals believe they are able to lay down their non-prioritized tasks. Most professionals are positive about where to find the protocol. This facilitator was linked to the determinant Information accessible about the protocol.

The determinant Staff capacity is mentioned as facilitator by multiple professionals and that they think that when someone is absent after child death, replacement of staff should not be a problem.

#### Impeding factors associated with the organisation

An impeding factor linked to the determinant Formal ratification by the management/organisation was that a professional believes using the protocol is not stimulated by the organisation. According to some professionals, impeding factors for the determinant Information accessible, were that some find it difficult to search for the protocol or cannot find the protocol. This is illustrated by the quote below. Another impeding factor mentioned linked to the determinant Material resources, was that some professionals searched for the grieving suitcase as it is present in the child healthcare guideline, and found out that it was not present at the municipal health service Twente.

---

*"Mavim (software used at the municipal health service Twente, red.) does not have an easy-to-use search query. You have to type the exact words "overlijden kind" or "routekaart" to find the protocol. But one has to know that." (Interview quality officer)*

---

### Recommendations associated with the organisation

Under the determinant Time available, some professionals gave the recommendation that they would like to be scheduled free from other tasks in situations of child death, so they can provide proper care to parents and do the administrative tasks as supposed.

Staff capacity as determinant is mentioned once, with the recommendation that the staff doctor prefers that there is another staff doctor present, as it would be convenient to divide tasks and, in times of absence, the other staff doctor is able to take over responsibilities.

A question present in the question matrix was whether the grieving suitcase should return, and why. Professionals mentioned five times that they would like to see the grieving suitcase return to the municipal health service Twente. And if this cannot be made available, then some professionals would like to see the grieving suitcase being removed from the child healthcare guideline. These statements were interpreted as recommendations and were linked to the determinant Material resources. The quote below illustrates this recommendation also in cases of deceased parents.

A practical recommendation given by professionals that was linked to the determinant Information accessible about the protocol is that it can be convenient to link the roadmap to the child healthcare guideline. According to this professional, this should make searching for the roadmap or guideline easier, and when one finds one, the other is automatically found as well.

---

*"I think the grieving suitcase needs to return. I had a case of a deceased parent, and the mother wanted support for the child. And then you read in the guideline that there is a grieving suitcase, but that it is not present at the municipal health service. I had to figure out myself how to support this child." (focus group 2)*

---

## **6.7 MIDI-determinants associated with the socio-political context**

The fourth sub question is: What are facilitating and/or impeding factors regarding the socio-political context according to child health professionals of the municipal health service Twente in their adherence towards the protocol used after child death, and which recommendations do they provide regarding the socio-political context?

### Facilitating factors associated with the socio-political context

There were two facilitators identified under the concept Socio-political context, which only includes the determinant Legislation and regulation. Professionals have stated that they believe that they have enough knowledge about medical confidentiality. This was interpreted as a facilitating factor that falls under the determinant Legislation and regulation, and under the determinant Knowledge (which falls under the concept User of the MIDI). Another facilitating factor that was provided and that was linked to both concepts Socio-political context and User, was that some professionals believe that, if they have questions, that they know who to contact. This facilitating factor was linked to the two determinants Legislation and regulation, and Self-efficiency.

### Impeding factors associated with the socio-political context

There were three impeding factors mentioned that fall under Socio-political context. One child healthcare professional mentioned not being familiar with law and regulation around child death. There was also mentioned that one professional does not know what to do in some situations of Legislation and regulation. This impeding factor is illustrated by the quote below and falls under two determinants: Legislation and regulation, and Self-efficiency. The last impeding factor was mentioned by the staff doctor. This professional believed that one disadvantage of health professionals consulting many others in situations of not knowing about law and regulation, is that many different opinions and advices can be given.

---

*"There have been situations where I did not know what to do. In these situations, I have asked others from the organisation."*  
*(interview team leader)*

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### Recommendations associated with the socio-political context

The only recommendation given in the concept Socio-political context of the MIDI was mentioned five times in focus groups and interviews. Many professionals would like to have written down in the protocol what can and cannot be done in situations that involve police or forensic doctors, for instance. This recommendation falls under Completeness (MIDI-concept Innovation) as well as under Legislation and regulation. This is illustrated by a quote and can be seen below.

---

*"It can be a suggestion to include a description of 'how to handle in situations that involve legislation and regulation'."*  
(interview staff doctor)

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Recapitulating, this chapter discussed the results from the focus groups and interviews. First, the focus group composition was presented, and subsequently, translation and encoding was explained. The largest part of this chapter were answers to the sub questions. Factors towards adherence were identified under the MIDI-concepts Innovation, User, Organisation, and Socio-political context. In the next chapter, these results will be brought to a broader perspective and there will be discussed what the impact of these results.

## 7 CONCLUSION & DISCUSSION

At first, a general conclusion about present research is provided in this chapter. Based on the results of this study, an answer is given per sub question. After the conclusion in Paragraph 7.1, the discussion is started, which first consists of a discussion about outcomes of present research according to the MIDI-framework. After discussing the MIDI-framework, the present research is placed in a broader perspective. A link is made between outcomes of present research and what is presented in literature on outcomes of other evaluations performed with the MIDI, evaluation of other bereavement programmes, and adherence to guidelines in general. The final chapter of this thesis is ended with recommendations for future research.

### 7.1 Conclusion

The goal of this research was to identify the facilitating and/or impeding factors according to child health professionals of the municipal health service Twente in their adherence towards the protocol used after child death, and, according to these professionals, what the possible ways were of improving the care provided to parents around child death. According to the participants of this research, 22 of the 29 determinants of the MIDI were mentioned either as facilitating factor, impeding factor, and/or recommendation. However, not all determinants were mentioned as often as others, and a distinction can be made between the four concepts of the MIDI. Determinants associated with the MIDI concepts innovation and user were mentioned most frequently, where determinants associated with the MIDI concepts organisation and socio-political context were mentioned least.

In general, it can be concluded that professionals believe that the protocol is not complete and not clear, as they state that it is unknown which actions need to be done in situations that differ from 'normal' situations, or with notifications other than from the GBA. These impeding factors towards adherence led to recommendations to improve and complete the protocol by writing down a description of roles and tasks to perform by the professionals.

Regarding the user of the protocol, professionals were in general positive about their own abilities (MIDI-determinants Self-efficacy, Knowledge, and Awareness of the content of the innovation), which was identified as a facilitating factor of adherence towards the protocol. However, there were still some participants that were not aware of the content of the protocol, which can be concluded as an impediment to adherence of the protocol. A recommendation for this is that some think it could be an idea to discuss this protocol in a team meeting or schooling. Another recommendation given regarding the user of the protocol, was that many professionals believe it would be convenient to include in the protocol where to find emotional support.

Organisation-related facilitating factors towards adherence of the protocol were that professionals prioritize actions in situation of child death above all other actions. It can be concluded that professionals believe that providing proper care to the family of the deceased child is of importance. Professionals report that the protocol and guideline can be difficult to find, which is an impediment to adhere to the protocol. Most recommendations given regarding the organisation include that information accessible can be improved when the grieving suitcase returns to the municipal health service Twente.

Most professionals believe to have sufficient knowledge about medical confidentiality. However, some professionals do not know what to do in some situations of child death, concerning Legislation and regulation (MIDI-determinant). This corresponds to the recommendation that is provided concerning Socio-political context, where many professionals recommend to have written down in the protocol what to do with Legislation and regulation in different situations of child death.

## **7.2 MIDI-framework**

The MIDI-strategy by Fleuren et al. (31) was chosen as the framework of this research. Fleuren et al. described that the MIDI is not yet a validated instrument and that it is unknown whether the MIDI can be used in other settings than in preventative child healthcare settings.

In present research, 22 of the 29 determinants were mentioned either as facilitating or impeding factor, or as recommendation. The seven determinants that were not mentioned include: Observability, Outcome expectations, Client satisfaction, Client cooperation, Financial resources, Coordinator, and Unsettled organisation. It seems logical why the first four of these seven determinants were not mentioned by participants, as this research did not include opinions of clients (parents) about the protocol. Financial resources and Coordinator not being mentioned as determinants can be explained by the fact that this protocol is already implemented. Financial resources and a Coordinator for implementation are therefore not applicable, and after implementation, this protocol is not dependent on financial resources.

## **7.3 Past literature**

Equal to the research of Konijnendijk et al. (32), the MIDI-framework proved to be a valuable framework in collecting structured data for answering the research question in present research. Unlike the research of Konijnendijk et al., in this research there was no need for adding determinants in addition to the 29 determinants of the MIDI. Konijnendijk et al. identified an additional five determinants that were not included in the 29 determinants of the MIDI. These determinants include Feasibility, Concreteness, Attitudes, Routine, and Inter-agency cooperation. By comparing the value of these extra determinants to present research, it is believed that one of these determinants was applicable for present research. The determinant Routine was mentioned as an impeding factor in the research of Konijnendijk et al., because the guideline used in the prevention of child abuse is not integrated in daily practice. In present research, this is mentioned as well. However, quotes regarding Routine were encoded under "Awareness of the content of the innovation", as the reason why awareness of the content of the innovation was insufficient. Rogers et al. (30) mentioned too in their study that quick diffusion of protocol is hindered when it is not used often. Therefore, Routine is a determinant that should be included in the list of MIDI-determinants. This is explained more in detail later on.

When further comparing the results of present research to the results of Konijnendijk et al. (32), similarities and differences can be found. Konijnendijk et al. performed research into the factors of adherence towards child abuse prevention guidelines in preventative child healthcare setting. The first difference between both studies is that Konijnendijk et al. found that most factors of (non-)adherence were identified with the MIDI-concept user, where present research found most factors of (non-)adherence were identified in the MIDI-concept innovation. As in present research, participants of the research of Konijnendijk et al. believe that the protocol is rather important. Noteworthy, this resulted in comparable results corresponding to the awareness of the content of the protocol of the professionals. In both studies, the majority of the professionals are aware of the existence of the protocol/guidelines, but when asked about details of the protocol/guidelines, many professionals confess not knowing the content in detail or not having read the entire content. Furthermore, in both studies professionals mention multiple times that the protocol/guideline is not clear and complete. In situations of child death or child abuse, or other situations with a large impact to members of a community, actions need to be performed concise and in a certain time span, and therefore it is no surprise that during evaluation, obscurities and uncertainties are often mentioned as impeding factors.

Gijzen et al. (41) used the SWOT-method to identify factors of influence on the implementation of the CDR (Child Death Review). The conclusions of this research were that insufficient time and finances, and lack of statutory basis were weaknesses and threats. The acceptance of the CDR by professionals and the statutory base were the most important preconditions for the implementation of the CDR. Many strengths, weaknesses, opportunities, and threats mentioned in the study of

Gijzen et al. are similar to the determinants included in the MIDI, such as time and finances, expertise/knowledge, presence of a coordinator, colleagues using the innovation, and whether the user and client experience benefits with using the innovation. This reaffirms that the determinants included in the MIDI are well-chosen and compatible, being mentioned often as key-factors of an implementation.

#### Past literature about bereavement programmes

Looking at the research of O'Malley et al. (40), who wrote a technical report without evaluation of professionals' opinions on the provision of care in the Emergency Department, there are two similarities in the baseline-care they provide compared to the protocol in present study. O'Malley et al. state that when a child dies in the emergency department, this needs to be communicated thoroughly with other out-of-hospital care providers, as otherwise reminders for visits or immunizations could continue. In present research, this is mentioned frequently by the professionals. They mention to experience often that the notification of a child death happens through other information channels, such as via social media, resulting in confusion among the professionals, as they often do not know what has been done or needs to be done in these situations.

Another similarity found in the research of O'Malley et al. is that they conclude it is important to provide care to the care providers. In present research, support to professionals themselves was also mentioned by professionals several times as impeding factor and recommendation towards adherence of the protocol. O'Malley state that this can be done with an evaluation or a brief closing ritual and this can help in understanding emotional responses of all who are involved. They have included this in their baseline-care. Looking at the protocol of the municipal health service Twente, this could be included in the dossier analysis, which should be done after every child death.

DeCinque et al. (39) performed research on bereavement support programmes in oncological hospital-settings. A noteworthy result they found is the fact that none of the nine oncological hospital departments screen families on risk for the development of complicated or pathological grieving-processes, even though there are valuable predictors (age, gender, cause of death) for developing pathological grieving-processes. The action 'screening for families with a high-risk of developing impaired grieving-processes' is also not included in the protocol of municipal health service Twente. It can be rather interesting to screen for valuable predictors of pathological grieving-processes, for instance when a child healthcare nurse visits a family at home. When there is screened for high-risk of developing pathological grieving, parents could, on beforehand, receive more personalized care or be referred to more specialized care by child health professionals of the municipal health service Twente.

A similarity with the research of DeCinque et al. comparing to present research, is that formally evaluating bereavement programmes is not done automatically. As mentioned in the Introduction of this thesis, Love et al. (28) and Sonnichsen et al. (29) already stated that internal evaluation can result in positive change, organisational learning, and with this, organisation's performance.

#### Past literature about adherence to guidelines/protocols in general

Rogers et al. (30) stated that the relative advantage, compatibility, complexity, trial-ability, and observability are of influence to the rate of adoption of an innovation in a community. Reflecting on these five factors in relation to the protocol used at the municipal health service Twente, we can make assumptions on whether the outcomes of present research are surprising. Most professionals have said that this protocol is rather important; professionals prioritize tasks that need to be done after child deaths above other tasks. The relative advantage of utilizing this protocol can thus be seen as high. The protocol is compatible with the tasks of the child health professionals as this protocol is made by the municipal health service Twente. However, assistants do not believe to have personal obligations in situations of child death.

Health professionals have mentioned that the protocol is not complete, some professionals do not know what their task is in different situations of child death, and some confessed not knowing about the existence of the protocol or not using it. Adherence of professionals to this protocol is influenced by the awareness of this protocol, and depends on the reasons to use it. Professionals need to

believe that the protocol is beneficial to them or to the client (in this case families of a deceased child). Luckily, all participants understand and realize the importance of high-quality support towards parents. This fastens the diffusion rate of the protocol. Fastening the diffusion rate more can too be done by including a detailed description of roles and tasks to the protocol, as this would make the protocol less complex.

The low trial-ability of the implementation causes a slower diffusion of the implementation, as there is no process of "trial and error", continued by improvement of the error. Providing care to parents cannot be trialled, as bereavement of parents could become pathological when the provision of care is not of high quality.

The observability of the impact of the protocol can be viewed in two different ways: The administrative actions and communication with the parents can immediately be observed, which makes diffusion of this implementation quicker. On the other side, the impact of these actions regarding to the bereavement process of the parents is more difficult to observe. There can be multiple instances that support parents and siblings of the deceased child, and sometimes it is not possible to prevent pathological bereavement processes. The death of a child is acknowledged to be one of the most traumatic events one can ever experience (52). Therefore, using the protocol improperly does not directly result in pathological bereavement of parents, it is merely a component of the bereavement process of parents. For the contrary, this also applies: proper use of the protocol does not directly result in a smooth bereavement process. This is what DeCinque et al. (39) tried to explain with their recommendation to screen for valuable predictors in developing impaired grieving processes. Child health professionals being unable to see what the result are of using the protocol causes a slower diffusion of the implementation.

Quick diffusion of the innovation is withheld most by the fact that, luckily, child death is a rare phenomenon. Child death is not experienced often by child health professionals from the municipal health service, as can be seen in the child mortality rates of the region Twente, which involves around 65 cases of child death annually. Circa half of this number involves stillbirths, which remain unnoticed in many cases by municipal health services. Some professionals may never experience situations that involve child death in their career, while others have already experienced it several times in a few years. Because of the rarity of the event and because the protocol is only implemented since November 2016, it could be very possible that many professionals did not have the opportunity to work with this protocol yet. All in all, this causes the diffusion rate of an implementation to be slower. Most protocols present in the municipal health service Twente are used more frequently and are therefore better known by health professionals. Presumably and, (most of all) hopefully, the rate of diffusion does not improve, as this means that there would be more cases of child death.

Looking back at the five factors of Rogers et al. (30) that influence the diffusion rate of an implementation, complexity is presumably the only factor that can be easily improved. Relative advantage and compatibility already cause a higher diffusion rate, as professionals in general believe that the protocol is important to use and that the tasks are compatible with their working abilities. Trial-ability and observability cause a slower diffusion rate, but remain difficult to modify in situations of child death, as the protocol cannot be trialled and results of using the protocol are not directly observable by child health professionals.

#### **7.4 Strengths and weaknesses**

The results and conclusion of present research must be interpreted with caution. At first, the focus groups did not include the aimed number of participants. Having larger and more focus groups can be more representative to reality. However, to reject this weakness, it seemed that after only three focus groups, saturation of answers was reached and therefore, it was chosen to not execute more focus groups. The quick saturation could be a result of the group composition, being heterogeneous in all focus groups, which is a strength. Additionally, another strength is that the small focus groups gave participants more time and space to answer questions thoroughly than they would have had with larger focus groups.

Naturally in focus groups, participants could be restrained to a certain extent in giving honest opinions when colleagues are present (53). This phenomenon was strengthened by the fact that in

every focus group, there was an attention officer child abuse and/or staff doctor present, who were the supervisors of the focus groups. In some situations of child death, the attention officer and staff doctor act as overseers, and review whether the professionals delivered proper care and executed their tasks according to the law and regulation. In the focus groups, this may have resulted in social desirable answers.

It is tried to be as open as possible about the decision-making process throughout the research. The focus groups were held with one interview-matrix and the interview were only adjusted to make questions sensible according to the profession that was interviewed. Especially for the focus groups, there was a time indication for every MIDI-concept, in order to give all concepts approximately equal amounts of time. Time indication and openness about the decision-making process are strengths for the generalizability of this research.

An important limitation is that with conducting qualitative research, as Plochg et al. (51) already mentioned, there will always be bias to a certain extent. This is because there is always a form of subjectivity present in the results, being monitored by the researcher. That is not different in this research and it was aimed to reduce the threats that could influence validity and reliability as much as possible. Editing raw data to clear results is rather susceptible to reporting bias. It is tried to prevent this as much as possible. However, this reporting bias can be seen as the heaviest weighing-limitation of this research. After encoding of transcriptions, two of the encoded transcripts were checked by independent researcher, and one of these two encoded transcripts was checked by supervisor. This was done to prevent reporting bias as much as possible. Because of time, it was unfortunately not possible to let the independent researcher check all encoded transcripts. Even though there were no major differences in encoding in the two transcripts that were checked (codes remained in the same MIDI-concept), there is always a possibility that there are differences in interpretation in the other six transcripts.

Additionally, another limitation is that there is also a presumable amount of confirmation bias. At the beginning of this research, and this was also the practical reason to start this research in the first place, there were informal opinions about the protocol not functioning properly. This led to an expectation outcome in advance by the researcher and supervisors. This could have led to a question matrix for focus groups and interviews that was more targeted on confirming those informal opinions. In addition to this, the researcher's supervisor was at the same time an interviewee. Thus, the supervisor was not completely unbiased and this again could have led to confirmation bias.

Recapitulating, present research has considerable weaknesses, but it is possible to interpret the results by keeping those weaknesses in mind. The most important weaknesses are the reporting bias and the confirmation bias. The most important strength is the openness of the research, which causes a high generalizability.

## **7.5 Recommendations**

Child health professionals have provided many recommendations. Reviewing all given recommendations, the majority can be summarized into six advices: Detailed description, Evaluation, Questions, Support from organisation, Grieving suitcase, and Search-strategy. Giving a detailed description of roles and tasks should be relatively easy to add to this protocol, for instance in an appendix. Providing general descriptions per situation of child death should already help child health professionals in their handling. A description of roles and tasks that are expected from health professionals should at least be included of situations that involve an external cause of death, cot death, forensic doctors, the NODOK-procedure, and (social) media.

In order to monitor and manage the quality of care that is provided by child health professionals, it is necessary to have a moment of evaluation after every case of a child death. Dossier/file analysis is standard in situations that led to turmoil in and/or outside the organisation. Nonetheless, it is possible to learn from every situation of child death, even in relatively 'normal' situations of child death.

Many health professionals stated that they did not know what to do or who to call when there are questions. Interviewees recommend contact information when there are questions about police or

inspection being involved, when there are medical questions, but also who to contact when there are general questions.

There has to be support from the organisation by giving health professionals time and space for their own grieving-process. Additionally, it must be known to every employee where one could find emotional support. It was recommended to add to the protocol where emotional support can be found, and to instruct team leaders that they monitor behaviour of health professionals more closely after situations of child death, and offering emotional support, even when someone has not yet asked for this.

Health professionals mentioned missing the grieving suitcase, as it is present in the child healthcare guideline, but absent at the municipal health service Twente. They have also mentioned that they prefer different types of grieving suitcases, depending on the targeted audience (schools, preschools, familial setting).

The roadmap should be linked to the child healthcare guideline in the software used at the municipal health service Twente, so that when someone finds one of the two documents, the other document is found immediately as well. This should help in finding both documents.

Lastly, the results of present research can be applicable to other municipal health services. The protocol after child death is a self-made protocol, but many municipal health services have similar organisational roles and tasks.

#### Recommendations for future research

In present research, there were many facilitating and impeding factors, and recommendations provided by child health professionals towards adherence of the protocol used after child death. Future research should focus on performing similar research on a larger scale, for instance in other municipal health services of the Netherlands. This could contribute in the process of making a general working method for, for instance, all municipal health services in the Netherlands, but also in other countries.

Subsequently, follow-up research should consist of assessments of obtained outcomes and whether they can be modified easily. This accompanies the decision-making process of (re-) implementation-strategies. After re-implementation, a new evaluation needs to take place to test whether adjustments were beneficial to the provision of care by the child health professionals.

## REFERENCES

1. Baumer JH, Wadsworth J, Taylor B. Family recovery after death of a child. *Arch Dis Child*. England; 1988 Aug;63(8):942–7.
2. Rogers CH, Floyd FJ, Seltzer MM, Greenberg J, Hong J. Long-term effects of the death of a child on parents' adjustment in midlife. *J Fam Psychol*. United States; 2008 Apr;22(2):203–11.
3. WHO. 100 Core Health Indicators. 2015; Available from: <http://www.who.int/healthinfo/indicators/2015/en/>
4. WHO. Infant mortality definition. 2017; Available from: [http://www.who.int/gho/child\\_health/mortality/neonatal\\_infant\\_text/en/](http://www.who.int/gho/child_health/mortality/neonatal_infant_text/en/)
5. WHO. Definition stillbirth [Internet]. 2017. Available from: [http://www.who.int/maternal\\_child\\_adolescent/epidemiology/stillbirth/en/](http://www.who.int/maternal_child_adolescent/epidemiology/stillbirth/en/)
6. WHO | Under-five mortality. WHO [Internet]. World Health Organization; 2016 [cited 2017 Mar 14]; Available from: [http://www.who.int/gho/child\\_health/mortality/mortality\\_under\\_five/en/#.WMfMGsaFF8M.mendeley&title=Under-five mortality](http://www.who.int/gho/child_health/mortality/mortality_under_five/en/#.WMfMGsaFF8M.mendeley&title=Under-five mortality)
7. UNICEF, WHO. Levels & Trends in Child Mortality. Rep 2015 [Internet]. 2015;1–34. Available from: [http://www.who.int/maternal\\_child\\_adolescent/documents/levels\\_trends\\_child\\_mortality\\_2015/en/](http://www.who.int/maternal_child_adolescent/documents/levels_trends_child_mortality_2015/en/)
8. United Nations. Goal 4: reduce child mortality [Internet]. Available from: <http://www.un.org/millenniumgoals/childhealth.shtml>
9. WHO. MDG 4: reduce child mortality [Internet]. Available from: [http://www.who.int/topics/millennium\\_development\\_goals/child\\_mortality/en/](http://www.who.int/topics/millennium_development_goals/child_mortality/en/)
10. van Wijhe M, McDonald SA, de Melker HE, Postma MJ, Wallinga J. Effect of vaccination programmes on mortality burden among children and young adults in the Netherlands during the 20th century: a historical analysis. *Lancet Infect Dis*. United States; 2016 May;16(5):592–8.
11. CBS. Minder kinderen overleden aan kanker [Internet]. 2016. Available from: <https://www.cbs.nl/nl-nl/nieuws/2016/35/minder-kinderen-overleden-aan-kanker>
12. CBS. Begrippenlijst [Internet]. Available from: <https://www.cbs.nl/nl-nl/onze-diensten/methoden/begrippen?tab=k#id=kindersterfte>
13. Nibud. Uw kind wordt volwassen [Internet]. Available from: <https://www.nibud.nl/consumenten/uw-kind-wordt-18-jaar/>
14. perined. Zwangerschap en geboorte. 2014;2012–4. Available from: <https://www.perined.nl/producten/publicaties/jaarboeken>
15. HealthyChildren.org. Congenital Abnormalities [Internet]. 2015. Available from: <https://www.healthychildren.org/English/health-issues/conditions/developmental-disabilities/Pages/Congenital-Abnormalities.aspx>
16. FOMAT. Procedure na overlijden [Internet]. 2016. Available from: <http://www.fomat.nl/proc-overlijden.html>
17. CBS-statline. Doodsoorzaken; niet-natuurlijke dood (inwoners), div. kenmerken, 1996-2011 [Internet]. 2014. Available from: <http://statline.cbs.nl/StatWeb/publication/?VW=T&DM=sInl&PA=37683>
18. CBS-statline. Zelfdoding onder jongeren. 2016; Available from: [http://statline.cbs.nl/Statweb/publication/?VW=T&DM=SLNL&PA=7052\\_95&D1=88&D2=a&D3=3-6&D4=59-64&HD=150709-0917&HDR=G2%2CG1%2CG3&STB=T](http://statline.cbs.nl/Statweb/publication/?VW=T&DM=SLNL&PA=7052_95&D1=88&D2=a&D3=3-6&D4=59-64&HD=150709-0917&HDR=G2%2CG1%2CG3&STB=T)
19. CBS-statline. Doodsoorzaak kinderen per leeftijd [Internet]. 2016. Available from: <http://statline.cbs.nl/Statweb/publication/?DM=SLNL&PA=7233&D1=0-1,173,311,346,420,499,568,616,641,719,784,857,930,1010,1093,1169,1229,1317,1408&>

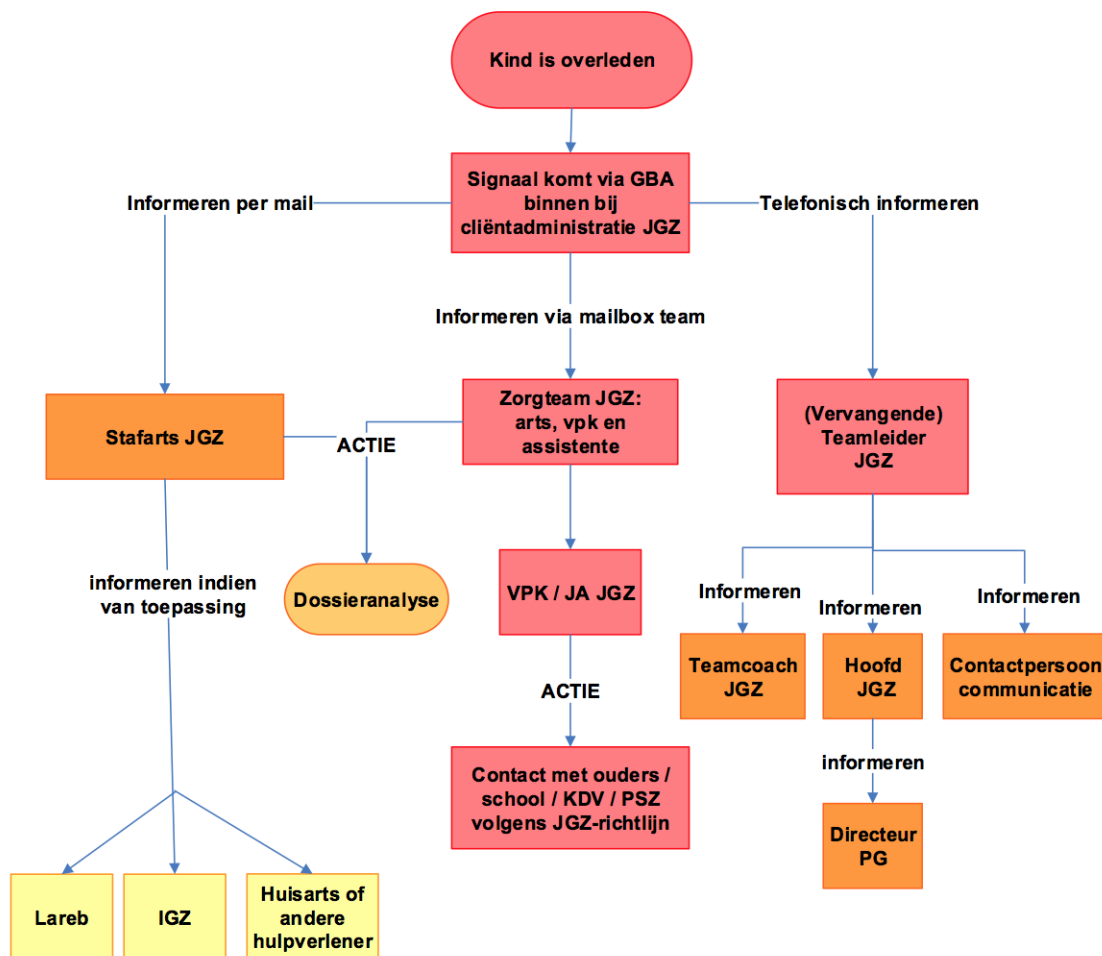


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20. Monasta L, Istituto FIRCCS, Ca N. Child Health in the European Union. 2012;(January).
  21. GGD/GHOR. Over GGD/GHOR [Internet]. Available from: <http://www.ggdghor.nl/organisatie/over-ggd-ghor/>
  22. Twente G. GGD Twente [Internet]. Available from: <https://www.ggdtwente.nl>
  23. Twente G. GGD Twente - kind en jongeren [Internet]. Available from: <https://www.ggdtwente.nl/home/kinderen/wat-doen-we-voor-je>
  24. NJC. Preventie wiegendood [Internet]. 2016. Available from: <https://www.ncj.nl/preventie-wiegendood/adviezen-veilig-slapen/>
  25. NJC. Richtlijn: Begeleiding gezin bij overlijden kind (2009) [Internet]. 2009. Available from: <https://www.ncj.nl/aanbod/richtlijnen/jgzrichtlijnenwebsite/details-richtlijn/?richtlijn=6&rlpag=574>
  26. Dijk AE Van, Dijs-elsinga J, Miranda E De, Perined B, Blaauw JH, Klumper FJCM, et al. Perinatale Zorg in Nederland 2015 . Utrecht : Perined , 2016. 2016;
  27. Databank. Geboortecijfers Twente [Internet]. 2010. Available from: <http://www.databanktwente.nl/demografie-geboortecijfers.html>
  28. Love AJ. Internal evaluation: Building organizations from within. Vol. 24. Sage; 1991.
  29. Sonnichsen RC. High impact internal evaluation: A practitioner's guide to evaluating and consulting inside organizations. Sage Publications; 1999.
  30. Rogers EM. Diffusion of preventive innovations. *Addict Behav.* England; 2002;27(6):989–93.
  31. Fleuren MAH, Paulussen TGWM, Van Dommelen P, Van Buuren S. Measurement Instrument for Determinants of Innovations (MIDI). TNO. 2014;
  32. Konijnendijk AAJ, Boere-boonekamp MM, Haasnoot-smallegange RME, Need A. A qualitative exploration of factors that facilitate and impede adherence to child abuse prevention guidelines in Dutch preventive child health care. 2014;20:417–24.
  33. Overheid.nl. Wet op lijkbezorging [Internet]. 2017. Available from: <http://wetten.overheid.nl/BWBR0005009/2015-07-01>
  34. NVK. NODOK procedure per 1 augustus van start [Internet]. 2016. Available from: <https://www.nvk.nl/Nieuws/tabid/606/articleType/ArticleView/articleId/1700/NODOK-procedure-per-1-augustus-van-start.aspx>
  35. Achterberg PW, Volksgezondheid C, Verkenningen T. Recente perinatale sterftetrends in Nederland : 2007;2000–5.
  36. RIVM. Volksgezondheidszorg.info [Internet]. 2017. Available from: <https://www.volksgezondheidszorg.info/onderwerp/sterfte-naar-doodsoorzaak/cijfers-context/huidige-situatie#node-doodsoorzaken-naar-leeftijd>
  37. Wetboek B. Levenloos geboren kind: akte en naamskeuze. :1–2.
  38. Gijzen S, L'Hoir MP, Boere-Boonekamp MM, Need A. How do parents experience support after the death of their child? *BMC Pediatr.* England; 2016 Dec;16(1):204.
  39. deCinque N, Monterosso L, Dadd G, Sidhu R, Lucas R. Bereavement support for families following the death of a child from cancer: practice characteristics of Australian and New Zealand paediatric oncology units. *J Paediatr Child Health.* Australia; 2004 Mar;40(3):131–5.
  40. O'Malley PJ, Barata IA, Snow SK. Death of a child in the emergency department. *J Emerg Nurs.* United States; 2014 Jul;40(4):301–4.
  41. Gijzen S, Hilhorst MI, L'Hoir MP, Boere-Boonekamp MM, Need A. Implementation of Child Death Review in the Netherlands: results of a pilot study. *BMC Health Serv Res.* England; 2016 Jul;16:235.
  42. May C, Finch T. Implementing, Embedding, and Integrating Practices: An Outline of Normalization Process Theory. *Sociology* [Internet]. SAGE Publications; 2009 Jun 1;43(3):535–54. Available from: <http://dx.doi.org/10.1177/0038038509103208>
  43. Fine LG. The SWOT Analysis.
  44. London IC. Stakeholder analysis.
  45. Olander S, Landin A. Evaluation of stakeholder influence in the implementation of

- construction projects. *Int J Proj Manag*. Elsevier; 2005;23(4):321–8.
46. Mitchell RK, Agle BR, Wood DJ. Toward a Theory of Stakeholder Identification and Salience: Defining the Principle of Who and What Really Counts. *Acad Manag Rev* [Internet]. Academy of Management; 1997;22(4):853–86. Available from: <http://www.jstor.org/stable/259247>
  47. Mitchell RK, Wood DJ. Toward a Theory of Stakeholder Identification and Salience : Defining the Principle of Who and What Really Counts Author ( s ): Ronald K . Mitchell , Bradley R . Agle and Donna J . Wood Source : The Academy of Management Review , Vol . 22 , No . 4 ( Oct . , 1997 ) , pp . 853-886 Published by : Academy of Management Stable URL : <http://www.jstor.org/stable/259247> TOWARD A THEORY OF STAKEHOLDER IDENTIFICATION AND SALIENCE : DEFINING THE PRINCIPLE OF WHO AND WHAT REALLY COUNTS. 2017;22(4):853–86.
  48. Mark MM, Shotland RL. Stakeholder based evalaution. 1985;9(5):605–26.
  49. Gill P, Stewart K, Treasure E, Chadwick B. Methods of data collection in qualitative research: interviews and focus groups. *Br Dent J* [Internet]. Nature Publishing Group; 2008 Mar 22;204(6):291–5. Available from: <http://dx.doi.org/10.1038/bdj.2008.192>
  50. TranscriptionJobsHQ. Different types of transcription [Internet]. 2016. Available from: <http://transcriptionjobshq.com/different-types-transcription/>
  51. Zwieten MCB Van. Kwalitatief onderzoek. 2005;
  52. Johnson LC, Rincon B, Gober C, Rexin D. The development of a comprehensive bereavement program to assist families experiencing pediatric loss. *J Pediatr Nurs Nurs Care Child Fam* [Internet]. Elsevier; 1993 Jun 4;8(3):142–6. Available from: [http://www.pediatricnursing.org/article/0882-5963\(93\)90071-R/abstract](http://www.pediatricnursing.org/article/0882-5963(93)90071-R/abstract)
  53. Acocella I. The focus groups in social research: advantages and disadvantages. *Qual Quant* [Internet]. 2012;46(4):1125–36. Available from: <http://dx.doi.org/10.1007/s11135-011-9600-4>

## APPENDIX 1 – ROADMAP

### ROUTEKAART INFORMATIE INTERN BIJ OVERLIJDEN KIND



#### Opmerkingen:

- Teamleider maakt inschatting of het proces Psychosociale Hulpverlening bij incidenten (PSHi) moet worden ingeschakeld.
- Indien eigen teamleider niet aanwezig is wordt collega-teamleider geïnformeerd. Indien er geen teamleiders aanwezig zijn, dan wordt het hoofd JGZ geïnformeerd.
- Wanneer in het gezin meerdere kinderen aanwezig zijn, het overlijden van het betreffende kind in hun dossiers vermelden. De Cliëntadministratie stelt de betreffende teams hiervan op de hoogte.
- Voordat je een huisbezoek gaat afleggen, altijd eerst in het DD JGZ van het kind kijken.
- In vakantieperiode wordt de dienstdoende jeugdarts gebeld.

## **Routekaart informatie intern bij overlijden kind**

*Deze routekaart is gemaakt als handvat voor medewerkers JGZ. Wanneer een medewerker signaleert dat een kind is overleden, geeft hij dat door aan zijn teamleider. De teamleider bepaalt het vervolg, zoals aangegeven in de routekaart. Hiermee wordt beoogd dat medewerkers tijdig op de hoogte zijn en bijv. ouders kunnen benaderen. Bovendien geeft deze werkwijze de mogelijkheid om in te spelen op mogelijke onrust in het werkgebied. Daarnaast wordt een analyse gedaan door de stafarts, om na te gaan of er verbetering in de kwaliteit van zorg mogelijk is.*

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**Lareb** is het Nederlands bijwerkingen centrum.

Bijwerkingen na een vaccinatie kunnen hier gemeld worden, door ouders/jongeren en door zorgprofessionals. Als JGZ medewerker kun je gebruik maken van een online meldformulier. Bij onrust na overlijden van een kind zal de stafarts telefonisch contact opnemen voor overleg, bijv. wanneer vaccin als mogelijke oorzaak van het overlijden wordt overwogen.

**IGZ:** Inspectie Gezondheidszorg.

Zorgaanbieders in Nederland zijn wettelijk verplicht om binnen 6 weken zelf gedegen onderzoek te doen en eventuele calamiteit, binnen drie werkdagen, te melden bij de inspectie. De inspectie houdt hierop nauwlettend toezicht en grijpt in als een zorgaanbieder zich niet aan de regels houdt. Zie: [leidraad melding IGZ](#) Na melding moet de JGZ een rapport opstellen, volgens de richtlijnen van de Inspectie.

Incidenten, misstanden en structurele tekortkomingen die bij de IGZ worden gemeld zijn belangrijk voor het toezicht van de inspectie. Naar aanleiding van sommige meldingen neemt de inspectie handhavingsmaatregelen. Daarnaast zijn meldingen een belangrijke bron van informatie over de kwaliteit van de zorg. In bijzondere gevallen verricht de inspectie zelf onderzoek naar aanleiding van een melding.

### **Procesbeschrijving Psychosociale Hulpverlening bij incidenten (PSHi)**

De procesbeschrijving Psychosociale Hulpverlening bij incidenten (PSHi) is ontwikkeld ter ondersteuning van het coördinatieproces van GGD Twente. In de procesbeschrijving wordt beschreven hoe in het geval van een incident dient te worden gehandeld teneinde deze te voorkomen, dan wel te komen tot een doelmatige bestrijding van de gevolgen van de gebeurtenis ten aanzien van de psychosociale hulpverlening.

Het doel van de PSHi is om door middel van samenwerking en coördinatie van de psychosociale hulpverlening bij incidenten een bijdrage te leveren aan vermindering en/of voorkoming van de maatschappelijke onrust en van de met het incident samenhangende psychosociale klachten en/of gezondheidsproblemen.

## APPENDIX 2 – DESIGN FOCUS GROUPS

### Agenda for focus groups

Date:

Time: 16.00

Location: GGD

### *Goal*

- To gain insight on the opinions of child health professionals of the care they provide to parents who have lost a child.
- To assess what improvements can be made in the protocol around a child death at the GGD Twente.

### *Phases*

- Phase 1: Introduction of subject etc.
- Phase 2: Identifying the extent of use of the protocol around child death
- Phase 3: Identifying the care child health professionals provide to parents who have lost their child.
- Phase 4: Evaluating the care child health professionals provide to parents who have lost their child.
- Phase 5: Evaluation of experiences from child health professionals towards regulation and legislation

### *Materials*

- *GarageBand®*
- *Informed consents*
- *Roadmap*
- *Pens*

### *Attendees (6-8 persons)*

- *Child health physicians, child health nurses, assistants, and quality officer.*

### *Moderator (AS)*

- Leads discussion
- Listens attentively, is able to think at the same time and asks sub questions
- Is objective about the subject

### *Assistant-moderator (RH and/or SG)*

- Listens attentively
- Participate in discussion whenever needed

<b><i>Time schedule (total duration of ±60 minutes)</i></b>	<b><i>Phase</i></b>	<b><i>What</i></b>	<b><i>Explanation</i></b>
<i>0-10 minutes (total of 10 minutes)</i>	1	<i>Welcome/ introduction</i>	<i>Introduction of moderator and recorder, introduction of subject, informed consent</i>
<i>10-25 minutes (total of 15 minutes)</i>	2	<i>Identifying extent of use of protocol</i>	<i>Asking questions such as: Do you know the protocol around a child death? Are you using this protocol and to what extent?</i>
<i>25-40 minutes (total of 15 minutes)</i>	3	<i>Identifying care that child health professionals provide to parents</i>	<i>Asking questions such as: What care do you provide to parents? What are situations where parents ask for your care?</i>
<i>40-50 minutes (total of 10 minutes)</i>	4	<i>Evaluating the care that is provided by child health professionals</i>	<i>Asking questions such as: what can be improved about the protocol? Do you know situations where you did not know what to do?</i>
<i>50-55 minutes (total of 5 minutes)</i>	5	<i>Evaluating the opinions of child health professionals towards regulation and legislation</i>	<i>Asking questions such as: what are the experiences with regulation and legislation? Are there any difficulties?</i>
<i>55-60 minutes (total of 5 minutes)</i>	<i>Ending phase</i>	<i>Summarizing focus group</i>	<i>Give a summary of the session and explain what is next in the research.</i>

## APPENDIX 3 – QUESTION MATRIX

### Fase 1: Introductie

Duur: 10 minuten

#### Introductie

- Doelstelling

Samen met Riet Haasnoot en Sandra Gijzen doe ik onderzoek naar de zorg die JGZ-professionals leveren aan ouders en kinderen, rondom het overlijden van een kind. Wij willen graag inzicht hebben hoe jullie, de professionals, de zorg evalueren die jullie leveren. Deze evaluatie wordt gedaan met behulp van focusgroepen en interviews. Een focusgroep is een sessie waarbij mensen van verschillende disciplines met elkaar in discussie gaan om vragen te beantwoorden. Uiteindelijk zal dit leiden tot een kwaliteitsverbetering van de zorg die de JGZ levert.

- Recorder

Deze gehele focusgroep wordt opgenomen met een voice-recorder. De data die hiermee wordt verzameld, wordt alleen voor onderzoek gebruikt. Jullie kunnen op elk moment stoppen met dit onderzoek.

- Moderator

De focusgroep wordt geleid door Anne.

- Informed consent

Wij vragen jullie om informed consent te tekenen. Hiermee verklaren jullie dat jullie voldoende zijn ingelicht over de doelen van dit onderzoek, dat jullie akkoord gaan met het feit dat deze focusgroep vocaal wordt opgenomen en dat jullie vrijwillig mee willen doen aan dit onderzoek.

- Regels

Niet door elkaar spreken. Vooral luid en duidelijk spreken. Over antwoorden wordt geen oordeel geveld.

### Fase 2: Algemeen/Innovatie

Duur: 20 minuten

*Allereerst zou ik jullie willen vragen of jullie je naam en beroep/werkzaamheden zouden willen vertellen, zodat ik een idee heb hoe jullie stemmen klinken op de recorder.*

1. Welke zorg leveren jullie rondom overlijden? Dit kan zijn:

Emotionele zorg: vragen hoe het met ouders gaat, monitoren van ontwikkeling kind, thuisbezoeken voor vaccinaties

Instrumentale zorg: bijv. extra oproepen of de “rouwkoffer”

Informatie verlenen: (mail)adressen geven waar ouders terecht kunnen, medische informatie geven wanneer ouders onzeker zijn over zwanger worden of opvoeden. Welke acties worden er door jullie uitgezet? Dit kunnen acties binnen de eigen organisatie zijn of naar de ouders en overige betrokkenen toe.

Denk hierbij ook aan verschillen in overlijden; is hierbij de zorg die jullie verlenen of de acties die jullie uitzetten nog verschillend?

- a. Natuurlijk overlijden
  - i. Verwacht overlijden door ziekte
- b. Niet-natuurlijk overlijden
  - i. Transport
  - ii. Rondom het huis
  - iii. Suïcide
  - iv. Moord en doodslag

2. Binnen onze organisatie bestaat het protocol “routekaart bij overlijden kind”. Zijn jullie bekend met het protocol binnen de GGD? Zo ja; in hoeverre zijn jullie hiermee bekend? Zo nee: wat is de reden dat jullie hiermee niet bekend zijn?

3. Wat vinden jullie noodzakelijke onderdelen die het protocol moet bezitten?

- a. Vinden jullie dat het evalueren van zorg een noodzakelijk onderdeel moet zijn van het protocol? Wordt dit momenteel ook gedaan?
- b. Zijn er nog aanpassingen nodig voor het protocol? Vinden jullie het protocol duidelijk?

### Fase 3: User

Duur: 15 minuten

- 4. Volgen jullie het protocol binnen de GGD wanneer een kind is overleden? Waarom wel? Indien niet gebruik: wat is er voor jullie nodig om dit protocol te kunnen gebruiken?
- 5. Aan dit protocol zit de JGZ-richtlijn "Rouwbegeleiding gezin bij overlijden kind", kennen jullie deze? Volgen jullie de richtlijn? Zo ja; welke onderdelen van de richtlijn gebruiken jullie? Zo nee; wat zijn voor jullie redenen van niet gebruiken van de richtlijn?

### Fase 4: Organisatie

Duur: 10 minuten

- 6. Worden jullie gesteund vanuit de organisatie om dit protocol te gebruiken? Zo ja; op welke wijze worden jullie gesteund? Zo nee; wat zouden hiervoor de redenen kunnen zijn?
  - a. En wat is er nodig, vanuit de organisatie, om volgens protocol te kunnen werken?

### Fase 5: Socio-political perspectief

Duur: 10 minuten

- 7. Onder socio-political context valt wet- en regelgeving. Hierbij kan gedacht worden aan de wettelijke kaders, waaronder het medische beroepsgeheim of de verplichting om te melden bij de inspectie. Wat gaat hierin goed? Ervaren jullie hierin belemmeringen?
  - a. Wat is er nodig, vanuit socio-political perspectief, om volgens protocol te kunnen werken?



## Interview matrix client administration

Fase 1: Introductie

Duur: 10 minuten

Introductie

- **Doelstelling**

Samen met Riet Haasnoot en Sandra Gijzen doe ik onderzoek naar de zorg die JGZ-professionals leveren aan ouders en kinderen, rondom het overlijden van een kind. Wij willen graag inzicht hebben hoe jullie, de professionals, de zorg evalueren die jullie leveren. Deze evaluatie wordt gedaan met behulp van focusgroepen en interviews. Een focusgroep is een sessie waarbij mensen van verschillende disciplines met elkaar in discussie gaan om vragen te beantwoorden. Uiteindelijk zal dit leiden tot een kwaliteitsverbetering van de zorg die de JGZ levert.

- **Recorder**

Deze gehele focusgroep wordt opgenomen met een voice-recorder. De data die hiermee wordt verzameld, wordt alleen voor onderzoek gebruikt. Jullie kunnen op elk moment stoppen met dit onderzoek.

- **Moderator**

De focusgroep wordt geleid door Sandra/Riet.

- **Assistent-moderator**

Notities en opnames worden gemaakt door Anne.

- **Informed consent**

Wij vragen jullie om informed consent te tekenen. Hiermee verklaren jullie dat jullie voldoende zijn ingelicht over de doelen van dit onderzoek, dat jullie akkoord gaan met het feit dat deze focusgroep vocaal wordt opgenomen en dat jullie vrijwillig mee willen doen aan dit onderzoek.

Fase 2: Algemeen/Innovatie

Duur: 20 minuten

Zouden jullie allereerst jullie naam en beroep willen omschrijven? Zo krijg ik een idee van hoe jullie praten, met welke intonatie en zo is het makkelijker voor mij om jullie stemmen terug te herkennen.

1. Kunnen jullie beschrijving wat er precies gebeurd vanaf het moment dat jullie een melding krijgen dat er een kindje is overleden? Zijn er ook al acties die uitgevoerd worden, m.b.t. overlijden van een kind, voordat het kind is overleden?

a. Gaat er ook nog iets fout in jullie acties?

2. Blijkbaar krijgen jullie niet alleen meldingen via het GBA, maar ook via het RIVM. Zijn er nog andere manieren om een melding binnen te krijgen?

a. Verschillen hierin jullie vervolgacties bij?

3. Welke acties worden er door jullie uitgezet? Is dit nog verschillend voor een natuurlijk overlijden of een niet-natuurlijk overlijden?

a. Natuurlijk overlijden

i. Verwacht overlijden door ziekte

b. Niet-natuurlijk overlijden

i. Transport

ii. Rondom het huis

iii. Suïcide

iv. Moord en doodslag

4. Binnen onze organisatie bestaat het protocol "routekaart bij overlijden kind". Zijn jullie bekend met het protocol binnen de GGD? Zo ja; in hoeverre zijn jullie hiermee bekend? Zo nee: wat is de reden dat jullie hiermee niet bekend zijn?

5. Wat vinden jullie noodzakelijke onderdelen, voor jullie zelf om te gebruiken, die het protocol moet bezitten?

a.Vinden jullie dat het evalueren van zorg een noodzakelijk onderdeel moet zijn van het protocol? Wordt dit momenteel ook gedaan?

Fase 2: User

Duur: 15 minuten

6.Volgen jullie het protocol binnen de GGD wanneer een kind is overleden? Waarom wel? Indien niet gebruik: wat is er voor jullie nodig om dit protocol te kunnen gebruiken?

a.Zouden jullie meer informatie willen in het protocol m.b.t. jullie handelen?

Fase 3: Organisatie

Duur: 10 minuten

7.Worden jullie gesteund vanuit de organisatie om dit protocol te gebruiken? Zo ja; op welke wijze worden jullie gesteund? Zo nee; wat zouden hiervoor de redenen kunnen zijn?

a.En wat is er nodig, vanuit de organisatie, om volgens protocol te kunnen werken? Bijvoorbeeld dat het protocol op jullie kamer aanwezig is.

Fase 4: Socio-political perspectief

Duur: 10 minuten

8.Wordt jullie handelen nog bepaald door bepaalde regels of wetgeving? Hebben jullie geheimhoudingsplicht?

a.Ervaren jullie hier nog problemen mee?

Fase 5: Eindfase

Duur: 5 minuten

Samenvatten en afsluiten van focusgroep

## Interview matrix team leader

Fase 1: Introductie

Duur: 10 minuten

### Introductie

- Doelstelling

Samen met Riet Haasnoot en Sandra Gijzen doe ik onderzoek naar de zorg die JGZ-professionals leveren aan ouders en kinderen, rondom het overlijden van een kind. Wij willen graag inzicht hebben hoe jullie, de professionals, de zorg evalueren die jullie leveren. Deze evaluatie wordt gedaan met behulp van focusgroepen en interviews. Een focusgroep is een sessie waarbij mensen van verschillende disciplines met elkaar in discussie gaan om vragen te beantwoorden. Uiteindelijk zal dit leiden tot een kwaliteitsverbetering van de zorg die de JGZ levert.

- Recorder

Deze gehele focusgroep wordt opgenomen met een voice-recorder. De data die hiermee wordt verzameld, wordt alleen voor onderzoek gebruikt. Jullie kunnen op elk moment stoppen met dit onderzoek.

- Moderator

De focusgroep wordt geleid door Anne.

- Informed consent

Wij vragen jullie om informed consent te tekenen. Hiermee verklaren jullie dat jullie voldoende zijn ingelicht over de doelen van dit onderzoek, dat jullie akkoord gaan met het feit dat deze focusgroep vocaal wordt opgenomen en dat jullie vrijwillig mee willen doen aan dit onderzoek.

- Regels

Niet door elkaar spreken. Vooral luid en duidelijk spreken. Over antwoorden wordt geen oordeel geveld.

### Fase 2: Algemeen/Innovatie

Duur: 20 minuten

8. Zou jij kunnen beschrijven wat er precies gebeurt vanaf het moment dat jij een melding krijgt dat er een kindje is overleden? Welke acties voer jij hierna uit?

Denk hierbij ook aan verschillen in overlijden; zijn de acties die een teamleider uitvoert nog verschillend m.b.t. het soort overlijden?

- c. Natuurlijk overlijden
    - i. Verwacht overlijden door ziekte
  - d. Niet-natuurlijk overlijden
    - i. Transport
    - ii. Rondom het huis
    - iii. Suïcide
    - iv. Moord en doodslag
2. Gaan hierin nog acties verkeerd? Bijvoorbeeld miscommunicatie of dergelijke? Kan dit voorkomen worden?
  9. Binnen onze organisatie bestaat het protocol "routekaart bij overlijden kind". Ben jij bekend met het protocol binnen de GGD? Zo ja; in hoeverre ben jij hiermee bekend? Zo nee: wat is de reden dat jij hiermee niet bekend bent?
  10. Wat vinden jij noodzakelijke onderdelen die het protocol moet bezitten?
    - a. Vind jij dat het evalueren van zorg een noodzakelijk onderdeel moet zijn van het protocol? Wordt dit momenteel ook gedaan?
    - b. Zijn er nog aanpassingen nodig voor het protocol? Vinden jij het protocol duidelijk?

### Fase 2: User

Duur: 15 minuten

11. Volg jij het protocol binnen de GGD wanneer een kind is overleden? Waarom wel? Indien niet gebruik: wat is er voor nodig om dit protocol te kunnen gebruiken?
12. Aan dit protocol zit de JGZ-richtlijn "Rouwbegeleiding gezin bij overlijden kind", kennen jullie deze?
  - a. Onderdeel van de richtlijn is het rouwkoffertje. Deze is nu niet beschikbaar bij de GGD. Zou deze beschikbaar moeten zijn?

#### Fase 3: Organisatie

Duur: 10 minuten

13. Wordt jij gesteund vanuit de organisatie om dit protocol te gebruiken? Zo ja; op welke wijze worden jullie gesteund? Zo nee; wat zouden hiervoor de redenen kunnen zijn?
  - a. En wat is er nodig, vanuit de organisatie, om volgens protocol te kunnen werken?

#### Fase 4: Socio-political perspectief

Duur: 10 minuten

14. Als teamleider heb je ook te maken met wet- en regelgeving. Bijvoorbeeld het medische beroepsgeheim of de verplichting om te melden bij de inspectie. Wat gaat hierin goed? Ervaren jullie hierin belemmeringen?
  - a. Wat is er nodig, vanuit socio-political perspectief, om volgens protocol te kunnen werken?

## Interview head of the child healthcare department

Fase 1: Introductie

Duur: 10 minuten

### Introductie

- Doelstelling

Samen met Riet Haasnoot en Sandra Gijzen doe ik onderzoek naar de zorg die JGZ-professionals leveren aan ouders en kinderen, rondom het overlijden van een kind. Wij willen graag inzicht hebben hoe jullie, de professionals, de zorg evalueren die jullie leveren. Deze evaluatie wordt gedaan met behulp van focusgroepen en interviews. Een focusgroep is een sessie waarbij mensen van verschillende disciplines met elkaar in discussie gaan om vragen te beantwoorden. Uiteindelijk zal dit leiden tot een kwaliteitsverbetering van de zorg die de JGZ levert.

- Recorder

Deze gehele focusgroep wordt opgenomen met een voice-recorder. De data die hiermee wordt verzameld, wordt alleen voor onderzoek gebruikt. Jullie kunnen op elk moment stoppen met dit onderzoek.

- Moderator

De focusgroep wordt geleid door Anne.

- Informed consent

Wij vragen jullie om informed consent te tekenen. Hiermee verklaren jullie dat jullie voldoende zijn ingelicht over de doelen van dit onderzoek, dat jullie akkoord gaan met het feit dat deze focusgroep vocaal wordt opgenomen en dat jullie vrijwillig mee willen doen aan dit onderzoek.

### Fase 2: Algemeen/Innovatie

Duur: 20 minuten

15. Via welke weg krijg jij binnen dat er een kindje overleden is? Door wie word jij ingelicht dat er een kindje is overleden? In welke omstandigheden krijg jij een melding van een overleden kind? Zou jij kunnen beschrijven wat er precies gebeurt vanaf het moment dat jij een melding krijgt dat er een kindje is overleden? Welke acties voer jij hierna uit?
3. Gaan hierin nog wat verkeerd? Bijvoorbeeld door miscommunicatie of dergelijke? Kan dit voorkomen worden?
16. Binnen onze organisatie bestaat het protocol "routekaart bij overlijden kind". Ben jij bekend met het protocol binnen de GGD? Zo ja; in hoeverre ben jij hiermee bekend? Zo nee: wat is de reden dat jij hiermee niet bekend bent?

*Zo nee; deze routekaart wordt gevolgd door JGZ-professionals als een leidraad en hierin staat wie moet informeren en welke acties er moeten worden uitgevoerd.*

17. Wat vinden jij noodzakelijke onderdelen die het protocol moet bezitten?
  - a. Vind jij dat het evalueren van geleverde zorg een noodzakelijk onderdeel moet zijn van het protocol? Wordt dit momenteel ook gedaan? Of een beschrijving waar professionals terecht kunnen voor vragen of emotionele steun?
  - b. Zijn er nog aanpassingen nodig voor het protocol? Vind jij het protocol duidelijk?

### Fase 2: User

Duur: 15 minuten

18. Volg jij het protocol binnen de GGD wanneer een kind is overleden? Waarom wel? Indien niet gebruik: wat is er voor nodig om dit protocol te kunnen gebruiken?
19. Aan dit protocol zit de JGZ-richtlijn "Rouwbegeleiding gezin bij overlijden kind", hierin staat hoe professionals ouders kunnen ondersteunen.
  - a. Onderdeel van de richtlijn is het rouwkoffertje, hierin kunnen boekjes, folders contactgegevens en dergelijke staan voor het rouwproces. Als er hulp nodig is dan kunnen zij hieruit informatie halen. Dit rouwkoffertje kan gegeven worden aan ouders,

maar ook aan bijvoorbeeld scholen. Deze is nu niet beschikbaar bij de GGD. Zou deze beschikbaar moeten zijn?

#### Fase 3: Organisatie

Duur: 10 minuten

20. Wat denk jij; wat is er nodig, vanuit de organisatie, voor iedereen die op dit protocol staat, om volgens dit protocol te kunnen werken? Denk je dat er scholing nodig is? Of wellicht bespreking tijdens ITO-gesprekken?

#### Fase 4: Socio-political perspectief

Duur: 10 minuten

21. Als hoofd JGZ heb je ook te maken met wet- en regelgeving. Bijvoorbeeld het medische beroepsgeheim. Weet jij wat je moet doen als je met zulke kwesties te maken hebt? Wat gaat hierin goed? Ervaren jullie hierin belemmeringen?

## Interview matrix quality officer

Fase 1: Introductie

Duur: 10 minuten

### Introductie

- Doelstelling

Samen met Riet Haasnoot en Sandra Gijzen doe ik onderzoek naar de zorg die JGZ-professionals leveren aan ouders en kinderen, rondom het overlijden van een kind. Wij willen graag inzicht hebben hoe jullie, de professionals, de zorg evalueren die jullie leveren. Deze evaluatie wordt gedaan met behulp van focusgroepen en interviews. Een focusgroep is een sessie waarbij mensen van verschillende disciplines met elkaar in discussie gaan om vragen te beantwoorden. Uiteindelijk zal dit leiden tot een kwaliteitsverbetering van de zorg die de JGZ levert.

- Recorder

Deze gehele focusgroep wordt opgenomen met een voice-recorder. De data die hiermee wordt verzameld, wordt alleen voor onderzoek gebruikt. Jullie kunnen op elk moment stoppen met dit onderzoek.

- Moderator

De focusgroep wordt geleid door Anne.

- Informed consent

Wij vragen jullie om informed consent te tekenen. Hiermee verklaren jullie dat jullie voldoende zijn ingelicht over de doelen van dit onderzoek, dat jullie akkoord gaan met het feit dat deze focusgroep vocaal wordt opgenomen en dat jullie vrijwillig mee willen doen aan dit onderzoek.

### Fase 2: Algemeen/Innovatie

Duur: 20 minuten

4. Zou jij kunnen beschrijven; wat is jouw rol m.b.t. de zorg rondom overlijden kind?
5. Wat merk jij van de uitvoering? Merk jij het als alles goed gaat, merk jij het als er vragen zijn of als er acties verkeerd gaan? Bijvoorbeeld miscommunicatie of dergelijke? Kan dit voorkomen worden? En hoe wordt dit opgelost?
6. Binnen onze organisatie bestaat het protocol "routekaart bij overlijden kind". Wat is jouw rol m.b.t. dit protocol? Heb jij dit protocol gemaakt of ben jij toezichthouder?
7. Wat vind jij noodzakelijke onderdelen die het protocol moet bezitten?
  - a. Vind jij dat het evalueren van zorg een noodzakelijk onderdeel moet zijn van het protocol? Wordt dit momenteel ook gedaan?
  - b. Zijn er nog aanpassingen nodig voor het protocol? Vinden jij het protocol duidelijk?

### Fase 2: User

Duur: 15 minuten

8. Jij maakt zelf geen gebruik van het protocol, maar denk jij dat dit protocol gebruikt moet worden door de uitvoerende mensen? En zo ja; wat denk ik wat er voor de gebruikers nodig is om dit protocol wel goed te gebruiken?
9. Aan dit protocol zit de JGZ-richtlijn "Rouwbegeleiding gezin bij overlijden kind", kennen jullie deze?
  - a. Onderdeel van de richtlijn is het rouwkoffertje. Deze is nu niet beschikbaar bij de GGD. Zou deze beschikbaar moeten zijn? En waarom wel/niet

### Fase 3: Organisatie

Duur: 10 minuten

10. Is er genoeg steun vanuit de organisatie om dit protocol te gebruiken, denk jij? Zo ja; op welke wijze worden jullie gesteund? Zo nee; wat zouden hiervoor de redenen kunnen zijn?
  - a. En wat is er nodig, vanuit de organisatie, om volgens protocol te kunnen werken?

#### Fase 4: Socio-political perspectief

Duur: 10 minuten

11. Als kwaliteitsfunctionaris; heb je te maken met wet- en regelgeving? Bijvoorbeeld het medische beroepsgeheim of de verplichting om te melden bij de inspectie. Wat gaat hierin goed en fout?
  - a. Wat merk jij van de uitvoering hiervan? En wat zijn hun ervaringen? Wat gaat hierin goed? Ervaren jullie hierin belemmeringen?
12. Als laatste, heb jij nog aanvulling op wat er net allemaal is verteld, of op het protocol. Verbeteringen of dergelijke?



## Interview matrix staff doctor

Fase 1: Introductie

Duur: 10 minuten

### Introductie

- Doelstelling

Samen met Riet Haasnoot en Sandra Gijzen doe ik onderzoek naar de zorg die JGZ-professionals leveren aan ouders en kinderen, rondom het overlijden van een kind. Wij willen graag inzicht hebben hoe jullie, de professionals, de zorg evalueren die jullie leveren. Deze evaluatie wordt gedaan met behulp van focusgroepen en interviews. Een focusgroep is een sessie waarbij mensen van verschillende disciplines met elkaar in discussie gaan om vragen te beantwoorden. Uiteindelijk zal dit leiden tot een kwaliteitsverbetering van de zorg die de JGZ levert.

- Recorder

Deze gehele focusgroep wordt opgenomen met een voice-recorder. De data die hiermee wordt verzameld, wordt alleen voor onderzoek gebruikt. Jullie kunnen op elk moment stoppen met dit onderzoek.

- Moderator

De focusgroep wordt geleid door Anne.

- Informed consent

Wij vragen jullie om informed consent te tekenen. Hiermee verklaren jullie dat jullie voldoende zijn ingelicht over de doelen van dit onderzoek, dat jullie akkoord gaan met het feit dat deze focusgroep vocaal wordt opgenomen en dat jullie vrijwillig mee willen doen aan dit onderzoek.

### Fase 2: Algemeen/Innovatie

Duur: 20 minuten

13. Zou jij kunnen beschrijven; wat is jouw rol m.b.t. de zorg rondom overlijden kind?
14. Wat merk jij van de uitvoering? Merk jij het als alles goed gaat, merk jij het als er vragen zijn of als er acties verkeerd gaan? Bijvoorbeeld miscommunicatie of dergelijke? Kan dit voorkomen worden? En hoe wordt dit opgelost?
15. Binnen onze organisatie bestaat het protocol "routekaart bij overlijden kind". Gebruik jij zelf dit protocol? Ik kan me voorstellen dat er vanuit jou veel meer lijntjes moeten komen. Maar die staan hier nu niet in. Hoe zit dat met de teamleider?
16. Wat vind jij noodzakelijke onderdelen die het protocol moet bezitten?
  - a. Vind jij dat het evalueren van zorg een noodzakelijk onderdeel moet zijn van het protocol? Wordt dit momenteel ook gedaan?
  - b. Zijn er nog aanpassingen nodig voor het protocol? Vinden jij het protocol duidelijk? Zou jij voor jezelf een checklist willen hebben met de acties die jij moet uitvoeren?

### Fase 2: User

Duur: 15 minuten

17. Jij maakt zelf geen gebruik van het protocol, maar denk jij dat dit protocol gebruikt moet worden door de uitvoerende mensen? En zo ja; wat denk ik wat er voor de gebruikers nodig is om dit protocol wel goed te gebruiken?
18. Aan dit protocol zit de JGZ-richtlijn "Rouwbegeleiding gezin bij overlijden kind", kennen jullie deze?
  - a. Onderdeel van de richtlijn is het rouwkoffertje. Deze is nu niet beschikbaar bij de GGD. Zou deze beschikbaar moeten zijn? En waarom wel/niet

### Fase 3: Organisatie

Duur: 10 minuten

19. Is er genoeg steun vanuit de organisatie om dit protocol te gebruiken, denk jij? Zo ja; op welke wijze worden jullie gesteund? Zo nee; wat zouden hiervoor de redenen kunnen zijn?
  - a. En wat is er nodig, vanuit de organisatie, om volgens protocol te kunnen werken?

Fase 4: Socio-political perspectief

Duur: 10 minuten

20. Als kwaliteitsfunctionaris; heb je te maken met wet- en regelgeving? Bijvoorbeeld het medische beroepsgeheim of de verplichting om te melden bij de inspectie. Wat gaat hierin goed en fout? Heb jij zelf hier nog vragen in, in sommige situaties? Wat doe je dan?
  - a. Wat merk jij van de uitvoering hiervan? En wat zijn hun ervaringen? Wat gaat hierin goed? Ervaren jullie hierin belemmeringen?
21. Als laatste, heb jij nog aanvulling op wat er net allemaal is verteld, of op het protocol. Verbeteringen of dergelijke?

## APPENDIX 4 – CODEBOOK

Coding with MIDI (Determinants of Fleuren et al.)	Short explanation	Codes		
		Facilitating	Impeding	Recommendation
Determinants associated with the innovation				
1.Procedural clarity	Is the innovation described in clear steps?	1F	1I	1R
2.Correctness	Is the innovation based on factually correct knowledge?	2F	2I	2R
3.Completeness	Are the activities described in the innovation complete?	3F	3I	3R
4.Complexity	Is the innovation complex?	4F	4I	4R
5.Compatibility	Is the innovation compatible with the values and working method in place?	5F	5I	5R
6.Observability	Are the outcomes of using the innovation clearly observable?	6F	6I	6R
7.Relevance for client	Is the innovation relevant for the client? (not user)	7F	7I	7R
Determinants associated with the user				
8.Personal benefits/drawbacks	Is using the innovation advantageous or disadvantageous of the user?	8F	8I	8R
9.Outcome expectations	What is the probability and importance of achieving the client objectives as intended by the innovation?	9F	9I	9R
10.Professional obligation	Does the innovation fit within the tasks of the user?	10F	10I	10R
11.Client satisfaction	Does the user expect the client to be satisfied with the innovation?	11F	11I	11R
12.Client/patient cooperation	Does the user expect the cooperation of clients with the innovation?	12F	12I	12R
13.Social support	Does the user expect social support from social referents by using the innovation?	13F	13I	13R
14.Descriptive norm	Do colleagues use the innovation?	14F	14I	14R
15.Subjective norm	What is the influence of important others with using the innovation?	15F	15I	15R
16.Self-efficacy	Does the user believe that he or she is able to implement the activities involved in the innovation?	16F	16I	16R
17.Knowledge	Does the user have the knowledge to use the innovation?	17F	17I	17R
18.Awareness of content of innovation	Does the user have learned about the content of the innovation?	18F	18I	18R
Determinant associated with the organisation				

19. Formal ratification by management	<i>Is the innovation formally ratified by the organisation/ management?</i>	19F	19I	19R
20. Replacement when staff leaves	<i>Is there replacement of staff when they leave the organisation?</i>	20F	20I	20R
21. Staff capacity	<i>Is there adequate staffing in the organisation when using the innovation?</i>	21F	21I	21R
22. Financial resources	<i>Are the financial resources available when using the innovation?</i>	22F	22I	22R
23. Time available	<i>Is there sufficient time available when using the innovation?</i>	23F	23I	23R
24. Material resources and facilities	<i>Are there sufficient material resources and facilities when using the innovation?</i>	24F	24I	24R
25. Coordinator	<i>Is a coordinator present for implementation of the innovation?</i>	25F	25I	25R
26. Unsettled organisation	<i>Are there changes in progress that could represent obstacles in the process of implementation of the innovation?</i>	26F	26I	26R
27. Information accessible about the innovation	<i>Is information accessible and available about the use of the innovation?</i>	27F	27I	27R
28. Performance feedback	<i>Is there feedback available for the user about progress with the innovation process?</i>	28F	28I	28R
<i>Determinants associated with the socio-political context</i>				
29. Legislation and regulations	<i>Does the innovation fit in with existing legislation and regulations?</i>	29F	29I	29R

## APPENDIX 5 – INFORMED CONSENT

### **Toestemmingsverklaringformulier (informed consent)**

**Titel onderzoek: Zorg vanuit de JGZ rondom kindersterfte**  
**Verantwoordelijk onderzoeker: Anne M. Siers**

#### ***In te vullen door de deelnemer***

Ik verklaar op een voor mij duidelijke wijze te zijn ingelicht over de aard, methode, doel en belasting van het onderzoek. Ik weet dat de gegevens en resultaten van het onderzoek alleen anoniem en vertrouwelijk aan derden bekend gemaakt zullen worden. Mijn vragen zijn naar tevredenheid beantwoord.

Ik begrijp dat film- en videomateriaal of bewerking daarvan uitsluitend voor analyse en/of wetenschappelijke presentaties zal worden gebruikt.

Ik stem geheel vrijwillig in met deelname aan dit onderzoek. Ik behoud me daarbij het recht voor om op elk moment zonder opgaaf van redenen mijn deelname aan dit onderzoek te beëindigen.

Naam deelnemer: .....

Datum: ..... Handtekening deelnemer: .....

#### ***In te vullen door de uitvoerende onderzoeker***

Ik heb een mondelinge en schriftelijke toelichting gegeven op het onderzoek. Ik zal resterende vragen over het onderzoek naar vermogen beantwoorden. De deelnemer zal van een eventuele voortijdige beëindiging van deelname aan dit onderzoek geen nadelige gevolgen ondervinden.

Naam onderzoeker: .....

Datum: ..... Handtekening onderzoeker: .....

## APPENDIX 6 – OVERVIEW OF FACILITATING FACTORS

Determinant	Facilitator	N mentioned
Innovation	<i>I think the protocol is clear.</i>	2
	<i>Evaluating provided care is being done anyway, with or without it being written down in the protocol.</i>	2
	<i>Dossier analysis is done when there is a reason to do this. This does not happen in all cases. Staff doctor and team of child health professionals will then analyse a child's dossier.</i>	2
	<i>We, as client administration, use our own script, and that is sufficient to act properly.</i>	1
	<i>Care customized to parents is helpful.</i>	2
User	<i>Emotional support can be provided by the team leader, staff doctor, or the team itself</i>	2
	<i>I will search for the protocol when it is necessary.</i>	4
	<i>The protocol and guideline are handles for me in order to know what to do and where to think of.</i>	3
	<i>If I have questions, I will contact the team leader or staff doctor.</i>	5
	<i>If I have questions, I will contact the quality officer.</i>	2
	<i>I think I have sufficient knowledge to carry out the actions properly.</i>	2
	<i>The client administration checks for mutations in the GBA, then "removes the child from healthcare". An email is sent to the team of child health professionals and CC is sent to the staff doctor. The team leader is called by telephone. When siblings are involved, an extra email is sent the same or different team of child health professionals of those siblings. Our script is evaluated every year.</i>	1
	<i>I receive the notification via email or telephone by the client administration.</i>	3
	<i>I will contact the parents and ask in what ways they are in need of support. Then, customized care is provided.</i>	5
	<i>I will contact other health professionals and discuss what already is being done and what needs to be done in the support of parents.</i>	2
	<i>On behalf of the team of child health professionals, a postcard is sent to parents.</i>	3
	<i>It has to be made impossible for parents to receive invitations for appointments at the municipal health service.</i>	1
	<i>Appointments are made for home visits.</i>	3
	<i>I think I am going to discuss with the team of child health professionals about what we can do.</i>	1
	<i>I notice that if it concerns an unnatural death, that I am a bit more active about the evaluation of provided care.</i>	1
	<i>Maternity care can provide a checklist to us, which could be of ease when a child has died.</i>	1

	<i>As a team leader, after a child death, my first appraisal is whether this death raises questions or turmoil. When this causes trouble in some way, the staff doctor, inspection, or the director of the child health department is contacted.</i>	1
<b>Organisation</b>	<i>These situations are prioritized above other situations.</i>	2
	<i>I would search in MAVIM. This is convenient, because you can look it up at home.</i>	2
	<i>I know there are physical folders of the child healthcare guideline laying in our cabinet.</i>	1
	<i>When a physician is not present, an attending physician is called.</i>	1
	<i>It should not be a problem when the staff doctor is absent, because in most cases, dossier analysis is not acute and can wait until the staff doctor has returned. When matters are urgent, another capable doctor will do the tasks of the staff doctor.</i>	1
	<i>When the client administration is not present during a situation with child death, there are others who are able to perform the tasks of the client administration.</i>	1
	<i>I do not have the idea that the organisation withholds professionals to use this protocol.</i>	1
<b>Socio-political context</b>	<i>There is sufficient known about medical confidentiality.</i>	3
	<i>If I have questions about medical issues, I will contact the staff doctor. When I have questions about juridical issues, I will contact the juridical advisor.</i>	2

## APPENDIX 7 – OVERVIEW OF IMPEDING FACTORS

Determinant	Impeding factor	N mentioned
Innovation	<i>As a quality officer, I can imagine this protocol not being clear. Some people may not be capable of working with only a process scheme. We did not explain this scheme in written text.</i>	1
	<i>In recent situation, I [doctor] contacted Lareb, and not the staff doctor.</i>	1
	<i>There is no line between the team leader and staff doctor. In situations that differ from “normal” deaths, I most definitely have contact with the staff doctor.</i>	1
	<i>The forensic doctor contacted us, but this scenario is not present in the protocol.</i>	1
	<i>I would like to consult with the team leader.</i>	1
	<i>Evaluation afterwards would be useful, as I too had questions and I did not know with whom to evaluate.</i>	2
	<i>Evaluation of provided care is useful in every case of child death</i>	3
	<i>I have negative experiences of home visits done by myself without a colleague.</i>	1
	<i>I do not know in which timespan some actions need to be performed.</i>	1
	<i>I do not know what everyone does in different situations of child death.</i>	4
	<i>This protocol helps you to act in the right direction, but there are matters of which you do not think about.</i>	1
	<i>The client administration uses its own script in situations of child death. This is not included in the protocol and is only present at the client administration.</i>	1
	<i>I do not know who to contact when I have questions.</i>	2
	<i>What happens when nobody is available to do a certain task is not written down in this protocol.</i>	1
	<i>I do not know what needs to be done in situations that involve suicides. What needs to be done towards schools? This is not included in the child healthcare guideline.</i>	1
	<i>What needs to be done in situations that involve the NODOK-procedure? Or with suspected child abuse?</i>	1
	<i>There were questions from a preschool, to tell about bereavement. This is not according to the protocol, but this is rather important.</i>	1
	<i>When there is turmoil, there is not included in the protocol what needs to be done.</i>	1



	<i>A mother did not know she could request a copy of the closed file of her child. This is not included as a task.</i>	1
	<i>A psychosocial worker is not included in the protocol.</i>	1
	<i>Contact with a municipality is not included in the protocol.</i>	1
	<i>Sometimes, other information systems inform the client administration or other professionals earlier than the GBA. This could be via the RIVM, obstetricians, or (social) media. It is not known what needs to be done in these situations, as is could be that the team of child health professionals is notified by these information systems without the client administration knowing this.</i>	4
	<i>It is possible that police ask questions to child health nurses or child health physicians, that this is the first notification for the team of child health professionals of the child death.</i>	1
	<i>It is possible that the client administration does not receive a notification of a stillborn baby or a baby that died during pregnancy, because its parents did not request a birth and/or death certificate. It is then not notified by us [client administration] or the team of child health professionals.</i>	1
	<i>As staff doctor, I support the team of child health professionals when there are questions from police or when death involves around vaccination. This is not written down in the protocol.</i>	1
	<i>I may look into dossiers/files as staff doctor, but I hesitate to do this as it is not yet written down as an official task of mine and health professionals may think that I check whether they have done their job properly.</i>	1
	<i>In “normal” situations of child death, I [head of child department] do not expect and do not want to be informed, only in situations where I am needed.</i>	1
	<i>As head of the child department, I am informed by the team leader when there are is an escalation in some form. There is, however, another route of which I am informed. This can be via de crisis organisation of the municipal health service.</i>	1
	<i>I do not know whether and why the grieving suitcase should return at the municipal health service.</i>	1
<b>User</b>	<i>I do not believe this protocol could be of help</i>	1
	<i>I would like schooling about the way of which conversation is conducted.</i>	2
	<i>Social support is what I have missed. This could be provided by the team leader. This is not present in the protocol</i>	3
	<i>As an assistant, I am not very familiar with the protocol and guideline, because these are tasks of child health physicians and child health nurses have to perform. We do monitor behaviour of siblings and other children at school.</i>	4
	<i>The amount of contact with parents is much more in the age category of 0-4 than in the 4-18 age category.</i>	3

	<i>When we do not know the parents yet, because it involves a firstborn child or because the child switches from team of child health professionals, then it can be very difficult to make contact with the parents.</i>	2
	<i>I am not aware of the tasks of the staff doctor and team leader. Apparently, the staff doctor contacts the general practitioner. I notice that I only know what I have to do.</i>	1
	<i>I have to admit that I do not know this protocol.</i>	2
	<i>I do not know this guideline.</i>	2
	<i>I have to admit that I do not know this protocol and guideline, but as head of the child department I should have been informed, because professionals expect you to handle in such situations.</i>	1
	<i>Is the mailbox of the team of child health professionals safe?</i>	1
	<i>Does the client administration process the child death in the dossiers?</i>	1
	<i>I did not know that the head of the department is only involved in situations that involve turmoil.</i>	1
	<i>I am wondering whether all health professionals know what tasks he or she needs to perform in these situations.</i>	3
	<i>I was wondering whether the guideline has included that professionals can contact parents again after four weeks.</i>	1
	<i>I have had the feeling that I could have done more towards parents.</i>	1
	<i>I do not search for this protocol and I do not use this protocol in these situations. The only task I perform is to contact the parents and ask whether they would like a home visit.</i>	1
	<i>I know that there is a guideline, but I have not yet used it in situations of a child death.</i>	1
	<i>I have never heard of the grieving suitcase</i>	2
	<i>I do not know if the grieving suitcase is being missed.</i>	1
	<i>I think I receive a notification of a child's death by the municipality.</i>	1
<b>Organisation</b>	<i>As a team leader, I do not only want to have contact with the team coach, but I want to have contact with the whole team and naturally, that is what I do. Because, when the team coach is absent that day or period, the team of child health professionals needs to perform their tasks.</i>	1
	<i>I do not have the feeling that the organisation stimulates me to use this protocol</i>	1
	<i>I find it difficult to search in MAVIM, there are so many protocols.</i>	2
	<i>The grieving suitcase is present in the guideline, but is absent in the municipal health service Twente.</i>	1
	<i>As a quality officer, I do not know whether health professionals know this protocol.</i>	1
<b>Socio-</b>	<i>There are situations where I do not know what to do.</i>	1

<b>political context</b>	<i>I am not familiar with the law and regulation around child death.</i>	1
	<i>The disadvantage of health professionals consulting others is that they can receive many different opinions and advices.</i>	1

## APPENDIX 8 – OVERVIEW OF RECOMMENDATIONS

Determinant	Recommendation	N mentioned
Innovation	<i>It should be made clear in the protocol how to handle in situations that differ from “normal” child deaths, for instance; -External causes of death; -Cod death; -When forensic doctors are involved; -NODOK-procedures (“further investigation cause of child death”, in Dutch: “Nader Onderzoek DoodsOorzaak Kind”). -When (social) media is involved.</i>	>5
	<i>I, quality officer, plead for a centralisation of the staff doctor.</i>	1
	<i>As a staff doctor, I think that the team of child health professionals should remain centralized in this protocol.</i>	1
	<i>I would like to have a moment afterwards to evaluate the care given to parents and children, also in times where it does not involve a special case of child death, because professionals often remain with some questions.</i>	>5
	<i>I think it is very important to mention in the protocol what actions need to be done in which period of time.</i>	1
	<i>It is important to know what actions are performed by other professionals involved in a child death.</i>	5
	<i>I would like to know who needs to be contacted when I have questions, this should be written down in a protocol.</i>	5
	<i>Home visits should be done with two professionals, and not alone.</i>	2
	<i>I miss the decision making part in this protocol, when a normal situation deviates in an escalation. These are tasks of the team leader and staff doctor, but is not mentioned in the protocol.</i>	1
	<i>I would like to receive an email, next to the “task” that is set up in the digital system. It could be useful to put a reminder in the email, such as “pay attention, there is a protocol that could be useful in these situations”.</i>	1
	<i>A checklist could be useful, because then it is possible to see what actions you have missed and what needs to be done.</i>	3
	<i>After a child is “removed from care”, it is not possible for professionals to look into their files/dossier. That is why the whole team should be kept informed what happens after a child death. A notification in mICAS in files of siblings could be of help.</i>	1
	<i>The professionals of the age category 0-4 and 4-18 should communicate thoroughly when a child dies at the age of 4 or 5, because sometimes, the child is not yet seen by the 4-18 professionals. This is also important when a child dies in one age category and siblings are in the other age category. All professionals that have contact with this family should know what is going on.</i>	3

	<i>As a team leader, when I receive a notification of a child death, I do not want contact with only the team coach, but with the whole team.</i>	1
	<i>It is important that the professionals that have to work with this protocol, experience themselves why this protocol is useful and important. This could be done with focus groups, what we are doing now.</i>	1
<b>User</b>	<i>I would like to receive emotional support from my team leader.</i>	>5
	<i>The protocol should include where to find emotional support.</i>	3
	<i>Maybe we could do more towards schools, as assistants, even though at this moment, we play a limited role in child death.</i>	1
	<i>As a staff doctor, I would like to have permission to look into dossiers/files. This is not yet written down as a task of mine, but I would like to see this happening.</i>	1
	<i>I would like to know from other organisations, mainly from maternity organisations, when couples are pregnant. Otherwise, we do not know whether or not there has been a miscarriage or a still born baby.</i>	1
	<i>Support from the staff, and specifically the staff doctor, should be utilized more.</i>	1
	<i>I think it is useful to review this protocol again.</i>	1
	<i>Maybe this protocol can be part of an schooling, or maybe in a team meeting.</i>	2
	<i>This protocol should be brought to attention once and thoroughly.</i>	1
<b>Organisation</b>	<i>I would like to be scheduled free when I have to deal with child death, because it is also tough for us as professionals.</i>	3
	<i>I would like to have a "grieving suitcase" available, both for parents and for schools, which contains information, websites, a local map of instances which provide help, and game material for kids. If, for some reason, this cannot be made available, it should be removed from the guideline.</i>	5
	<i>It is helpful to have two staff doctors. If one cannot function properly or is absent, the other could easily take over some tasks.</i>	1
	<i>Everybody should know how to search protocols and other material on MAVIM, as MAVIM could be difficult with their search terms.</i>	1
	<i>Helpful could be to attach the guideline to the protocol, in MAVIM. In this way, when one finds the guideline, you immediately find the protocol too, and vice versa.</i>	1

