



# ADHD follow-up care; the professionals' perspective

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## ABSTRACT

### *Background*

Attention Deficit Hyperactivity Disorder (ADHD) is part of the so-called 'externalising mental disorders' with the estimated world-wide prevalence of 5.3 percent. After the diagnosis is made, treatment will be undertaken which needs to be evaluated and readjusted if necessary during the follow-up period. In the follow-up period, the follow-up care takes place whereby the child with ADHD is monitored regularly by a professional. However, little is known regarding the quality of the follow-up care in the Netherlands. Nevertheless, the available evidence indicates that there are shortcomings in the follow-up care provided by primary care in the Netherlands. Due to the uncertainty of the quality of care, the Health Council of the Netherlands recommends to investigate the quality of follow-up care and the compliance of the guidelines regarding this care. Therefore, it is important, besides investigating the children's, parents'- and policy's perspective, to examine the professionals' perspective. Ultimately, the gathered information might be used in the optimization of the follow-up care.

### *Objective*

The aim of this study is to gain insight in the quality of follow-up care for children with ADHD in the Netherlands and to gather information on how the quality of care can be improved to achieve better effectiveness of treatment, health outcomes, satisfaction and treatment adherence in children with ADHD.

### *Methods*

A qualitative approach using semi-structured interviews was conducted. The investigation was held in the region Twente in the Netherlands. Interviewees were nine professionals, including two general practitioners (GPs), two doctors working in youth health care, two schoolteachers, one internal tutor and one child psychiatrist. Open-coding thematic analysis was used to analyse the interviews. The identified main themes and subthemes were considered for answering the research questions.

### *Results*

Regarding the quality of follow-up care and the recommendations indicated by professionals, 17 themes were identified which reflect both topics. Some negative experiences towards the quality of follow-up care are the waiting lists, the scarcity in child psychiatrist, the differences in the provided care per region and the fact that the follow-up care does not always meet the requirements stated in the clinical guidelines. Also, parents do not always have the money for the medication, public transport or gasoline and children with poorer parents are at times affected by the insufficient budget of municipalities. GPs experience some barriers in the transmission from secondary- to primary care and the poor treatment adherence in children. One striking discovery of this investigation are the different experiences towards the knowledge and competence of GPs regarding ADHD. Some positive experiences are the freedom of choice and the fact that children and parents are being listened. It is the recommendation of some professionals to involve school and youth health care more within the follow-up care. Also, a telephonic consult, more homogeneity and refresh trainings were often indicated. Two GPs recommended a clear letter from secondary care in the transmission. And last, E-health could be used for the follow-up care in the future.

### *Conclusion*

Both positive- and negative experiences regarding the quality of follow-up care are identified by professionals, whereby more negative experiences were indicated. However, many recommendations are mentioned by the professionals which can be used in the optimization of the follow-up care in the Netherlands.

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# 1. Introduction

## 1.1 Background

ADHD is part of the so-called ‘externalising mental disorders’, whereby the disruptive effect on the environment occupies a central position. The diagnosis is made according to the classification system DSM-IV-TR.<sup>1</sup> The most important symptoms with regard to ADHD are inattention, impulsiveness and hyperactivity. These symptoms can occur separately or in combination in various forms.<sup>2</sup> The DSM-IV-TR has three subtypes, the inattentiveness type, the combined type and the hyperactive-impulsive type whereby the combined type is the most common. The inattention is the key thing regarding the inattentiveness type whereby the impulsiveness and the hyperactivity occurs in the hyperactive-impulsive type. The combined type consists of a combination of both the inattention and the hyperactivity/impulsiveness.<sup>1-3</sup>

The etiology of the disorder ‘ADHD’ is not known. What is clear from the Dutch national multidisciplinary guideline ‘ADHD in children and adolescents’ and the guideline issued by the Dutch College of General Practitioners ‘ADHD in children’ (NHG) is that hereditary factors play an important role.<sup>1,4</sup> A review of Cormier et al.<sup>5</sup> indicates that the hereditary explains 70 to 80 percent of the variance of ADHD. The clinical guidelines for ADHD likewise comment that there is evidence for anatomic differences, such as a smaller brain volume or a retarded maturation of the frontal cortex.<sup>1,4,6,7</sup> A considerable amount of research has been carried out regarding the relationship between environmental factors and the development of ADHD.<sup>5,8-11</sup> Likewise concerning the relationship between psychosocial factors and ADHD.<sup>8,9,12,13</sup> However, the overall conclusion of the NHG regarding these studies is that the relationship between these other potential causation factors and the development of ADHD is regularly uncertain.<sup>4</sup>

The exact prevalence of ADHD in the Netherlands is still unclear, according to the Dutch Health council. There are no recent Dutch studies or registrations that generate valid or reliable data with regard to the incidence or prevalence of ADHD in the Netherlands.<sup>14</sup> The estimated world-wide prevalence is 5.3 percent, based on a meta-analysis of Polanczyk et al.<sup>15</sup> Conform the foundation for pharmaceutical statistics (SFK), there is a significant increase in the number of prescriptions of ADHD medication in the Netherlands. It appears that the total number of prescriptions of ADHD medication (methylphenidate) for adolescents from 4 to 18 year in a period of 10 years (2003-2013) has quadrupled in the Netherlands.<sup>16</sup> Based on the estimations of the use of methylphenidate and the use of healthcare in primary and secondary care, the Dutch Health Council concluded that there is a growth in demand for help for ADHD in the Netherlands.<sup>14</sup>

The diagnosis is usually made from the age of 6 years.<sup>1,3,4</sup> This is because it is considered challenging at a young age (0 – 5 years) to distinguish between the symptoms of ADHD and normal development phenomena. Difficulties with the regulation of attention, distractibility, hyperactivity and impulsiveness are in certain developmental phases normal observations. Also, stressful and radical events can lead to behavioural traits which seem like symptoms of ADHD. However, these traits need to be separated from ADHD. The Dutch National Multidisciplinary Guideline indicates that the diagnosis must be performed by a health psychologist or a child- or youth psychiatrist.<sup>1</sup> Nevertheless, the NHG comments that the diagnosis can be made by a GP if certain conditions are fulfilled. Examples of those conditions are the presence of sufficient knowledge and expertise in ADHD and the sufficiency of effective treatment options at the general practice.<sup>4</sup>

After the diagnosis is made, treatment will be undertaken which will be evaluated and readjusted if necessary during the follow-up period. The treatment of ADHD can consist of pharmacotherapy, psycho-education and behavioural treatment.<sup>1,3</sup> The objective of treatment of a child with ADHD is to

diminish the symptoms of ADHD and/or any additional complexity (behavioural problems or problems at school), to restore or improve the social, emotional or educational functioning of the child and to increase the knowledge and insight regarding ADHD in the child.<sup>17</sup> During the follow-up period, the 'follow-up care' takes place whereby the child with ADHD will be regularly checked by a professional. During this check, attention will be paid to complaints (aggressive behaviour, tics, etc.), the effect of the medically assisted and drug-free treatment and side effects from pharmacotherapy.<sup>4</sup> Vitiello<sup>18</sup> comments that these regular visits of children with ADHD are essential for optimizing efficacy of treatment, evaluate the continuing need for medication and minimizing the adverse events. According to Gardner et al.<sup>19</sup>, the follow-up care permits adjustment of medication and it supports continuation of patients in treatment, including medical and/or psycho-social- or behavioural treatment. Likewise, it will lead to more improvement in the symptoms of ADHD when a child with ADHD is regularly checked.<sup>19</sup> The objective of the 'follow-up care' is to improve the effectiveness of treatment.<sup>14</sup> Professionals which are active within the follow-up care in the Netherlands according to clinical guidelines are the GPs and professionals working in the youth health care services.<sup>1,3,4</sup>

## 1.2 Problem definition

In an advice report called 'medication and society', it is stated that the Health Council of the Netherlands questions the quality of care for children with ADHD in the Netherlands.<sup>20</sup> There is evidence suggesting deficiencies in the quality of care for ADHD abroad, however little is known about this matter in the Netherlands.<sup>14,20</sup> Nevertheless, the available evidence indicates that there are shortcomings in the follow-up care provided by primary care in the Netherlands.<sup>21,22</sup> Although GPs write 61% of the repeat prescriptions of stimulant use of children with ADHD in the Netherlands, not enough attention is paid to the follow-up care since only 20 percent of those children actually receive the follow-up care.<sup>23,24</sup> This is a result of a study which investigated the current practices around initiation and follow-up care in the Netherlands whereby 924 children with ADHD were involved.<sup>23</sup> This indicates that GPs do not fully comply with the clinical guidelines which might be caused by the way the guidelines are implemented.<sup>25</sup> For the children, it may have an impact on the effectiveness of treatment and treatment adherence. Also, there might be a higher chance, of those who do not receive follow-up care, that children take in medicine with a wrong dose since no checks are made.<sup>18,19</sup> Faber et al.<sup>23</sup> comes to the conclusion that the follow-up care in the Netherlands appears to be poor and that there is a need for improvement. Also, it appears that GPs do not feel comfortable or competent enough to take over the medication treatment of children and adolescents with ADHD.<sup>22,24,26</sup> This may be caused by the fact that on average, GPs are involved with only 2-3 children with ADHD each year in the Netherlands.<sup>1</sup> As a consequence, special mental healthcare services often continue to provide the follow-up care which can lead to long waiting lists and expensive services.<sup>14</sup> In addition, deficiencies arise in the instructions of secondary- to primary care for monitoring ADHD, i.e. the follow-up care.<sup>24</sup>

Since January 1, 2015, municipalities in the Netherlands are responsible for the mental care for youth instead of the Dutch National government.<sup>27,28</sup> This transition is made since there were deficiencies in the previous system. Examples of this include the excessive pressure on specialised care and the medicalisation of abnormal behaviour.<sup>29</sup> One of the objectives of this decentralisation of care is to provide care closer to the citizens and to better organize care which is tailored to the needs, preferences and circumstances of the children and their families.<sup>30</sup> To be able to provide care closer to the children with ADHD, the care for the children needs to be provided nearby the environment of the children, e.g. at their school or general practice.<sup>14</sup> According to the clinical guidelines, the follow-up care should already be provided close to the children.<sup>1,3,4</sup> However, as mentioned previously, professionals of secondary care often take over the tasks of the follow-up care of the GPs. Therefore,

this provision of health care is not in line with the objective of the decentralisation.<sup>14</sup> This is because primary care is more accessible in comparison with secondary care; the care is provided nearby home, it requires little or no travel time and appointments can be made on short notice.<sup>31</sup>

Because of the uncertainty, the Health Council of the Netherlands recommends to investigate the quality of the follow-up care and the compliance of the guidelines regarding this care.<sup>14</sup> Therefore it is important, besides investigating the children's, parent's – and policy's perspective, to investigate the professionals' perspective. Although there is evidence from abroad with respect to professionals' experiences towards the provision of care for children with ADHD, little is known particularly regarding the experiences of those professionals towards the follow-up care and its quality.<sup>32-34</sup> With respect to the Netherlands, only the experiences of professionals active in a pilot project called 'Eureka' and a pilot called 'children and ADHD' are known towards the provision of care for children with ADHD.<sup>21,35</sup> The pilot Eureka was directed at achieving an integrated care program in which primary care professionals had a central role. GPs, a child psychiatrist, a primary care assistant practitioner (POH-GGZ) and a family therapist were active within this project.<sup>21</sup> The pilot 'children and ADHD' has been started with the aim to provide the care for children with ADHD particularly within primary care. GPs, POH-GGZ professionals, doctors' assistants and a paediatrician were active in this project.<sup>35</sup> The experiences of the involved professionals in both projects were largely positive. Nevertheless, one of the recommendations of both pilots was to involve school professionals in the provision of care. This is because they can provide extra information to the practitioner regarding the functioning of the child at school since they are more active in the child's environment than the practitioner itself. Although the experiences have been asked of the involved professionals within both pilots, there is no information gathered specifically regarding the experiences of the professionals towards the provision of the follow-up care and its quality.<sup>21,35</sup>

### 1.3 Aim of this study

The aim of this study is to gain insight in the quality of follow-up care for children with ADHD in the Netherlands and to obtain information on how the quality of care can be improved to achieve better effectiveness of treatment, health outcomes, satisfaction and treatment adherence in children with ADHD.<sup>36-38</sup>

To achieve the objective of this investigation, the professionals' perspective will be examined towards the quality of follow-up care for children with ADHD in the Netherlands. Ultimately, the gathered information will contribute to the existing knowledge regarding the current quality of follow-up care. Also, by asking professionals at school, it is known what their view is about the current follow-up care and whether they need to be more involved in the provision of follow-up care for children with ADHD.

## 2. Research question(s)

This study is directed to answer two main questions.

- 1) *‘What are the stakeholders’ experiences with the quality of follow-up care offered to children with ADHD in the Netherlands?’*
- 2) *‘Which recommendations do stakeholders give for the implementation of the follow-up care conform clinical guidelines to children with ADHD in the Netherlands?’*

The term ‘stakeholders’ comprises:

- 1) Health care professionals active in primary care and secondary care.
- 2) School professionals such as teachers and internal tutors.

This investigation was started on request of the Academic Collaborative Centre Youth in Twente. Because of this, health care professionals and school professionals working in the region Twente will be recruited for this investigation.

### 2.1 Thesis outline

The introduction of this thesis provided an overview of some general information regarding ADHD and the problem definition. The next chapter will provide information about the term ‘quality of care’ and the implementation of new care practices. Chapter 4 shows the methodology and the results of this investigation are outlined in chapter 5. Finally, the results will be discussed in chapter 6 and a conclusion will be presented.



### 3. Theoretical framework

This study investigates the experiences of professionals regarding the quality of the follow-care for children with ADHD. Also, recommendations are asked with regard to the implementation of the follow-up care. In this chapter, the term ‘quality of care’ will be further examined. Furthermore, academic literature will be undertaken regarding theories about implementation of new care practices conform clinical guidelines.

#### 3.1 Quality of care

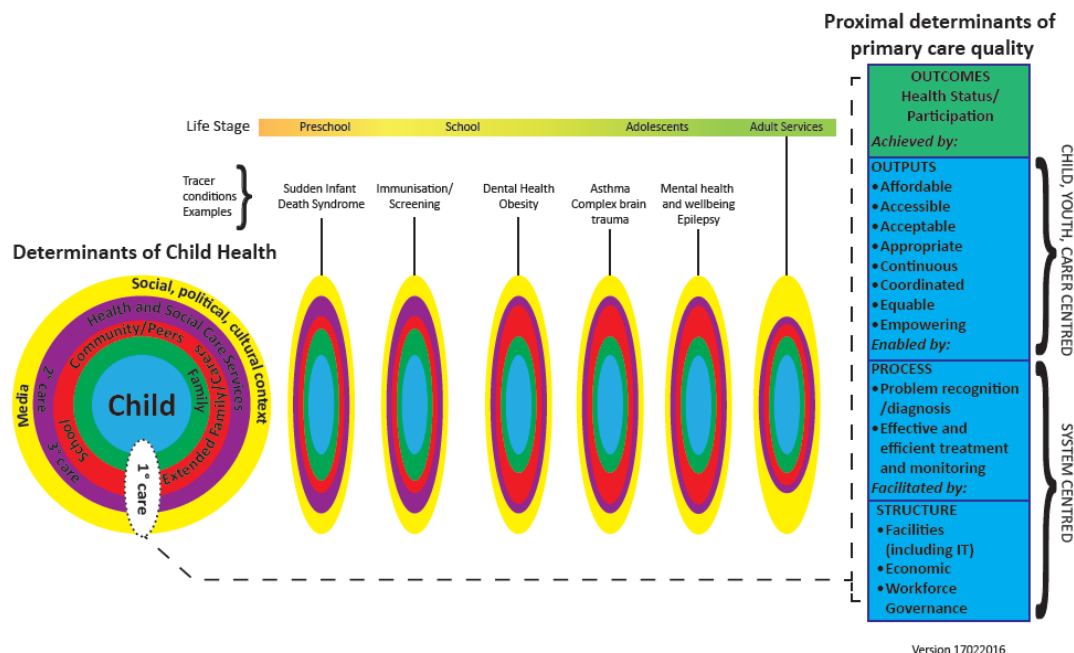
To be able to investigate the quality of the current follow-up care, it is of primary importance to understand what is meant by ‘quality of care’. Without this understanding, it would be infeasible to ultimately design interventions and measures used to improve results.<sup>39</sup> The World Health Organization’s (WHO) definition of quality of care is ‘the extent to which health care services provided to individuals and patient populations improve desired health outcomes’<sup>40</sup>. To achieve this, the WHO argued that it is important that the health care is safe, effective, timely, efficient, equitable and people-centred.<sup>40</sup> A definition of the Institute of Medicine (IOM) is quite similar to the definition of the WHO, namely ‘the degree to which health services for individuals and populations increase the likelihood of desired health outcomes and are consistent with current professional knowledge’<sup>41</sup>. Another definition stated by Donabedian<sup>42</sup>, a professor of medical care organization at the University of Michigan School of Public Health, is ‘the maximization of the benefits over risks of both technical and interpersonal aspects of patient care’. Donabedian likewise believes that before the quality of care will be evaluated, it is important to know which elements contribute to the quality of care.<sup>43,44</sup> He comments that there are different levels at which quality may be assessed, namely the performance of the care practitioners, the care implemented by patients and the care received by the community. The performance of the care practitioners can be divided into two elements, the technical- and interpersonal performance. The technical performance means the application of clinical medicine to a health problem which depends on the knowledge and skills of the care practitioner. With this technical performance, it is the aim to produce the greatest improvement in health.<sup>44</sup> The ‘inter-personal’ relationship refers to the interaction of the health care professionals and their patients.<sup>44,45</sup> Through this interpersonal relationship, important information can be exchanged which is necessary to make a diagnosis or select the most appropriate method for care. It is also vital, regarding the interpersonal relationship, to meet the social and individual expectations. In other words, the interpersonal relationship is expected to have the following virtues, privacy, empathy, informed choice, etc.<sup>44</sup> By assessing the quality of care, not only the performance of the care practitioners needs to be evaluated, likewise the ‘actual care’ received by patients and its family needs to be considered. It is important to note that not only the care practitioner is responsible for the success or failure of care, likewise the patient and its family. The last level of the quality assessment is the ‘care received by the community’. This level refers to the social distribution of levels of quality in the community. This depends on for instance the access to care and who receives greater or lesser qualities of care. The performance of care practitioners plays a part in this, nevertheless, the quality of the care received in the community is likewise influenced by many other factors.<sup>44</sup>

There are several frameworks to assess quality of care. An example of such a framework is the framework of Donabedian which considers three categories, namely the ‘structure’, ‘process’ and ‘outcome’.<sup>44</sup> This framework was introduced in his article called ‘Evaluating the Quality of Medical Care’ in 1966. Later on, this article became one of the most frequently cited public health articles of the next 50 years.<sup>43,46</sup> The organisation factors that define the health system under which care is provided refers to the ‘structure’. The ‘process’ is the actual delivery and receipt of care and the

‘outcomes’ are the consequences of care.<sup>36,43,45,46</sup> Another framework which is used to ensure quality improvement in health care organizations is a framework made by the IOM. This framework considers six domains which can be translated into aims. The IOM believes that the health care should be ‘safe’, ‘effective’, ‘patient-centred’, ‘timely’, ‘efficient’ and ‘equitable’. To assist the improvements, the IOM has set up 10 rules to guide the redesign of the health care.<sup>47</sup>

However, the criteria that are used to evaluate the quality of care for adults cannot be translated to children.<sup>36</sup> This is because according to Rigby et al.<sup>48</sup>, health determinants, disease patterns, preventive and therapeutic health services and data sources are different for children and adults. When the quality of care for children is considered, several challenges could be identified. Those challenges can be seen on several fields, namely the development of the child, the dependency on their caregivers and the different epidemiology and demographic patterns of the children.<sup>36</sup> It is for example considered challenging to measure the quality of care when a child’s functioning generally improves with age. This is because in that case their health care utilisation changes periodically as well as the health care they require.<sup>36</sup> In conclusion, the framework of Donabedian and the IOM might not be suitable to use within this investigation. Furthermore, the framework of Donabedian fails to consider pre-existing characteristics, e.g. biological characteristics and environmental factors. These factors are, conform Mitchel et al.<sup>49</sup> and the Agency for Healthcare Research and quality (AHRQ)<sup>50</sup>, important determinants in the evaluation of the quality of care.

The ‘MOCHA conceptual framework’ might be a suitable framework to use within this investigation because it is a model which can be used to measure the quality of care specially intended for children. In this model, several factors are considered which can be measured to acquire information about the quality of care for children.<sup>36,51</sup> The framework and the factors are shown in figure 1 below.



Figuur 1 MOCHA conceptual framework

The MOCHA conceptual framework is based on three theoretical frameworks, namely the Bronfenbrenner’s ecological model of determinants of health, the model of Kringos which presents the determinants of quality of primary care and a life course epidemiological framework of childhood health and disease. The ecological circle on the left of the model presents the Bronfenbrenner’s model whereby the right hand block presents the model of Kringos. The horizontal axis outlines the

life course epidemiological framework. The ecological circle is focused on the environmental factors which can influence the development of the children's health. In conclusion, the aspects which are missing in the framework of Donabedian, e.g. the biological characteristics and environmental factors, are included in the MOCHA conceptual framework by including Bronfenbrenner's model. The variation in the colour scheme in the horizontal axis outlines how the determinants are weighted over time. For instance, in the early years, there is a larger influence of parents and family and there is a greater influence of school when the children grow older.<sup>51</sup> The proximal determinants of primary care quality for children are affordable, accessible, acceptable, appropriate, continuous, coordinated, equable and empowering. The first determinant 'affordable' is defined by Kringos as *"financial barriers patients experience to receive primary care services, such as co-payments and cost sharing arrangements"*<sup>52</sup>. The determinant 'accessible' is defined by Evans et al. as *"the availability of good health services within reasonable reach of those who need them and of opening hours, appointment systems and other aspects of service organization and delivery that allow people to obtain the services when they need them"*<sup>53</sup>. The determinant accessible is further operationalized by using the attributes 'availability', 'geographic accessibility' and the 'accommodation of accessibility' of Kringos et al.<sup>54</sup> The determinant 'acceptability of care' is defined by Evans as *"people's willingness to seek services, based on their judgement of effectiveness of the service and whether or not they are treated with dignity and respect"*<sup>53</sup>. The determinant 'appropriate' is divided into two types, namely the 'appropriateness of a service' and 'appropriateness of the setting in which care is provided'. The appropriate of service is defined by Lavis as *"a service that is expected to do more good than harm for a patient with a given indication or set of indications"*<sup>55</sup>. Appropriateness of setting is defined by Lavis as *"whether the patient's clinical characteristics, and the services required for his or her care, match the setting in which the care is provided"*<sup>55</sup>. The determinant 'continuity of care' is defined by Gulliford from the patient perspective as *"the patient's experience of a continuous caring relationship with an identified health care professional"* and from the provider perspective as *"the delivery of a seamless service through integration, coordination and the sharing of information between different providers"*<sup>56</sup>. The determinant 'coordinated care' is defined by Kringos as *"the ability of primary care providers to coordinate use of other levels of health care"*<sup>54</sup>. The determinant 'equable care' is defined by Kringos as *"the absence of systematic and potentially remediable differences in health status across population groups"*<sup>54</sup>. The final determinant 'empowerment care' is defined by the WHO as *"a process in which patients understand their role, are given the knowledge and skills by their health-care provider to perform a task in an environment that recognizes community and cultural differences and encourages patient participation"*<sup>57</sup>. The determinants with each subdomain and definition are outlined in table 1 below.

Table 1 Proximal determinants of primary care quality

Factor	Subdomain	Definition
<b>affordable</b>	Affordability of PC	Financial barriers to receive primary care services, such as co-payments and cost-sharing arrangements <sup>54</sup> .
<b>accessible</b>	Availability of PC	The volume and type of primary care services relative to population needs <sup>54</sup> .
	Geographic accessibility of PC	Remoteness of services in terms of travel distance for patients <sup>54</sup> .
	Accommodation of accessibility	The manner in which resources are organized to accommodate access (e.g. appointment system, after-hours care arrangements, home visits) <sup>54</sup> .

<b>acceptable</b>	Acceptability of PC	people's willingness to seek services, based on their judgement of effectiveness of the service and whether or not they are treated with dignity and respect <sup>53</sup> .
<b>appropriate</b>	Appropriateness of service	A service that is expected to do more good than harm for a patient with a given indication or set of indications <sup>55</sup> .
	Appropriateness of setting	Whether the patient's clinical characteristics, and the services required for his or her care, match the setting in which the care is provided <sup>55</sup> .
<b>continuous</b>	Longitudinal continuity of care	Having a long-term relationship between primary care providers and their patients in their practice beyond specific episodes of illness or disease <sup>54</sup> .
	Informational continuity of care	An organized collection of each patient's medical information readily available to any health care provider caring for the patient <sup>54</sup> .
	Relational continuity of care	The quality of the longitudinal relationship between primary care providers and patients, in terms of accommodation of patient's needs and preferences, such as communication and respect for patients <sup>54</sup> .
<b>coordinated</b>	Gatekeeping system	The level of direct access for patients to health care providers without a referral from a primary care provider <sup>54</sup> .
	Primary care practice and team structure	The extent to which practices are shared, team size and tenure <sup>54</sup> .
	Skill-mix of primary care providers	Diversification and substitution of primary care providers <sup>54</sup> .
	Integration of primary care-secondary care	Care integration can be achieved through specialist outreach models and clinical protocols facilitating shared care <sup>54</sup> .
	Integration of primary care and public health	The extent to which primary care providers collaborate with practitioners from the public health sector to provide services that influence health <sup>54</sup> .
<b>equable</b>	Equality in access	The extent to which access to primary care services is provided on the basis of health needs, without systematic differences on the basis of individual or social characteristics <sup>54</sup> .

### 3.2 Implementation of new care practices

Clinical guidelines, interventions or programs can be seen as 'innovations'.<sup>58</sup> Fleuren et al.<sup>59</sup> and Weingart et al.<sup>60</sup> take the view that the introduction of innovations in healthcare for improving health outcomes is considered as challenging. Evidence shows that the use of clinical guidelines can help improve health care processes, outcomes and costs.<sup>25</sup> Regarding the healthcare for children with ADHD, clinical guidelines have a positive influence on the quality of diagnosis and treatment.<sup>20</sup> The perceived benefits of the implementation of such clinical guidelines is the reduction of inappropriate care, better awareness and control of health care spending and an improved clinical efficiency. However, it frequently appears that in practice patients receive treatment which differs from recommended best practice.<sup>61</sup> This lack of compliance with the clinical guidelines might be caused by the way the guidelines are implemented.<sup>25</sup>

A generic framework which is used for the introduction and evaluation of innovations in healthcare is shown in figure 2.<sup>59</sup>

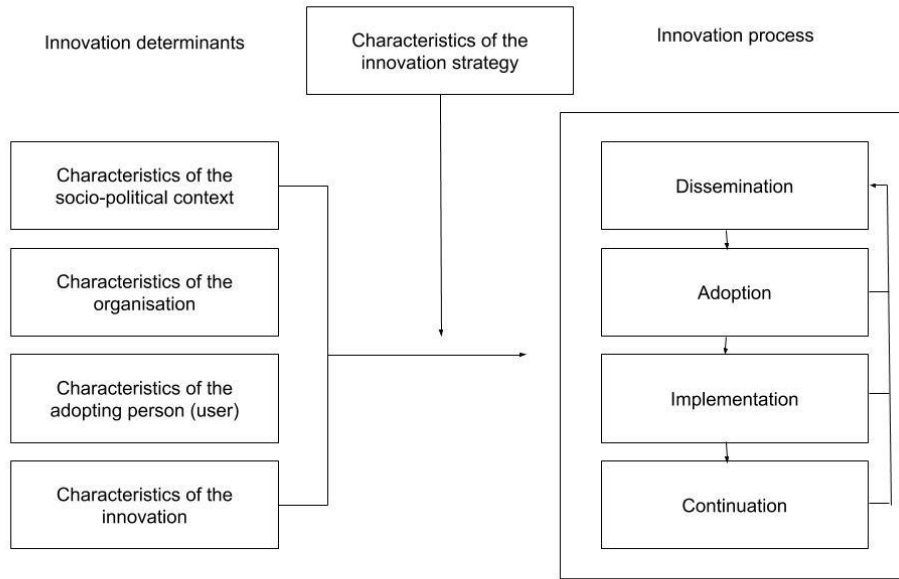


Figure 2 Framework indicating the innovation process and related determinants

The stages described on the right side of the framework can be seen as a critical phase whereby the desired change may or may not occur. Each transition to another process (dissemination, adoption, implementation and continuation) can be positively or negatively affected by several determinants. These determinants can be associated with the clinical guidelines, the user of the guideline (professional), the organisation and the socio-political context. By understanding these determinants, it can guide the process of designing innovation strategies which will have the potential to ultimately produce real change.<sup>59</sup> In a study of Fleuren et al.<sup>59</sup>, those determinants are examined which has led to an instrument called ‘the measurement instrument for determinants of innovation’ (MIDI). This instrument can be used either before or after the introduction of an innovation. The MIDI consists of 29 determinants which can be measured to gain information about the importance of the determinants to ultimately plan innovation strategies. The determinants can be associated with the innovation itself, the adopter, the organisation and finally, the socio-political context.<sup>59,62</sup> Table 2 below shows an overview of the 29 determinants with each definition derived from a report of Fleuren et al.<sup>62</sup>

Table 2 29 determinants of the MIDI

Determinants associated with the innovation	
<b>1. Procedural clarity</b>	The extent to which the innovation is described in clear steps / procedures <sup>62</sup> .
<b>2. Correctness</b>	Degree to which the innovation is based on factually correct knowledge <sup>62</sup> .
<b>3. Completeness</b>	Degree to which the activities described in the innovation are complete <sup>62</sup> .
<b>4. Complexity</b>	Degree to which implementation of the innovation is complex <sup>62</sup> .
<b>5. Compatibility</b>	Degree to which the innovation is compatible with the values and working method in place <sup>62</sup> .

<b>5. Observability</b>	Visibility of the outcomes for the user, for example whether the outcomes of a particular treatment are clear to the user <sup>62</sup> .
<b>7. Relevance for client</b>	Degree to which the user believes the innovation is relevant for his/her client <sup>62</sup> .
<b>Determinants associated with the adopting person (user)</b>	
<b>8. Personal benefits/drawbacks</b>	Degree to which using the innovation has advantages or disadvantages for the users themselves <sup>62</sup> .
<b>9. Outcome expectations</b>	Perceived probability and importance of achieving the client objectives as intended by the innovation <sup>62</sup> .
<b>10. Professional obligation</b>	Degree to which the innovation fits in with the tasks for which the user feels responsible when doing his/her work <sup>62</sup> .
<b>11. Client/patient satisfaction</b>	Degree to which the user expects clients to be satisfied with the innovation <sup>62</sup> .
<b>12. Client/patient cooperation</b>	Degree to which the user expects clients to cooperate with the innovation <sup>62</sup> .
<b>13. Social support</b>	Support experienced or expected by the user from important social referents relating to the use of the innovation (for example from colleagues, other professionals they work with, heads of department or management) <sup>62</sup> .
<b>14. Descriptive norm</b>	Colleagues' observed behaviour; degree to which colleagues use the innovation <sup>62</sup> .
<b>15. Subjective norm</b>	The influence if important others on the use of the innovation <sup>62</sup> .
<b>16. Self-efficacy</b>	Degree to which the user believes he or she is able to implement the activities involved in the innovation <sup>62</sup> .
<b>17. Knowledge</b>	Degree to which the user has the knowledge needed to use the innovation <sup>62</sup> .
<b>18. Awareness of content of innovation</b>	Degree to which the user has learnt about the content of the innovation <sup>62</sup> .
<b>Determinants associated with the organisation</b>	
<b>19. Formal ratification by management</b>	Formal ratification of the innovation by management, for example by including the use of the innovation in policy documents <sup>62</sup> .
<b>20. Replacement when staff leave</b>	Replacement of staff leaving the organisation <sup>62</sup> .
<b>21. Staff capacity</b>	Adequate staffing in the department or in the organisation where the innovation is being used <sup>62</sup> .
<b>22. Financial resources</b>	Availability of financial resources needed to use the innovation <sup>62</sup> .
<b>23. Time available</b>	Amount of time available to use the innovation <sup>62</sup> .
<b>24. Material resources and facilities</b>	Presence of materials and other resources of facilities necessary for the use of the innovation as intended (such as equipment, materials or space) <sup>62</sup> .

<b>25. Coordinator</b>	The presence of one or more persons responsible for coordinating the implementation of the innovation in the organisation <sup>62</sup> .
<b>26. Unsettled organisation</b>	Degree to which there are other changes in progress (organisational or otherwise) that represent obstacles to the process of implementing the innovation, such as re-organisations, mergers, cuts, staffing changes or the simultaneous implementation of different innovations <sup>62</sup> .
<b>27. Information accessible about use of innovation</b>	Accessibility of information about the use of the innovation <sup>62</sup> .
<b>28. Performance feedback</b>	Feedback to the user about progress with the innovation process <sup>62</sup> .
<b>Determinants associated with the socio-political context</b>	
<b>29. Legislation and regulations</b>	Degree to which the innovation fits in with existing legislation and regulations established by the competent authorities (examples being financial structures, or substantive legislation and supervision from the Dutch Health Care inspectorate or the Dutch Care Authority).

### 3.3 Conclusion

Since guidelines can positively influence the health care processes, the outcomes and costs, one could say that guidelines improve the quality of care.<sup>39,45,51</sup> In the MOCHA conceptual framework, proximal determinants of primary care quality are adopted. By investigating those eight domains regarding the follow-up care, a clear vision could be gathered of the quality of follow-up care. However, those domains are determinants of primary care quality. Besides investigating the experiences of professionals in youth health care and general practitioners (primary care), likewise experiences will be gathered of a child psychiatrist which is working in secondary care. However the interface between primary- and secondary care is integrated in the model.<sup>51</sup> Also, by asking the same domains about the follow-up care provided in secondary care, a clear vision could be gathered regarding potential differences between the follow-up care provided in primary- or secondary care. By using the MIDI, facilitating factors or barriers which positively or negatively contribute to the existing follow-up care could be gathered. If those facilitating factors or barriers are clear, recommendations could be assigned regarding the implementation of the follow-up care conform clinical guidelines. Chapter 4 (methods) describes information of how both models can be used within this investigation. Chapter 6 (discussion) describes whether these 2 models were suitable to use in obtaining data regarding both research questions.



## 4. Methods

### 4.1 Research design

Within this study, a qualitative approach is used. It is the aim of the current study to investigate the subject matter in greater depth rather than obtaining some general information about the view of the involved professionals. This leads to the conclusion that a qualitative approach was most suitable for this study.<sup>63</sup> Furthermore, it is the aim of this study to understand the perspective of the professionals and explore their opinion about the current organization of the follow-up care which makes a qualitative approach more appropriate instead of a quantitative approach or mixed methods.<sup>64</sup>

### 4.2 Method

The method which is used for this study is individual semi-structured interviews. The main reason for choosing individual interviews instead of group interviews is the fact that the topics which were identified might have been sensitive for the professionals. The involved professionals had to talk about the current organization of the follow-up care and what is needed to make it work. In other words, the professionals might have had some comments on their own provision of healthcare or to their colleagues' provision. Because the interviews were held individually, the involved professionals might have been more willing to talk openly about their own or each other's provision of care than when the interview was held in a group.<sup>63-65</sup>

The interviews were 'semi-structured' since it increases the chance that most of the topics are addressed during an interview to obtain as much information as possible about the topics.<sup>63</sup> Also, given the fact that the opinion of the involved professionals were asked, semi-structured interviews provide space for the interviewee to determine the kind of information produced about the topics.<sup>64</sup>

The interviews were held face to face. The advantages of this method is that a lot of subjects can be discussed which is the case within this study. Also, a face to face interview creates a high degree of flexibility and it is the aim of this investigation to go in greater depth and that is not possible with a written interview.<sup>63</sup>

### 4.3 Study population

#### 4.3.1 The sample/sample size

The investigation was performed in the region Twente. Professionals which are active in the follow-care in the Netherlands were involved, such as GPs and professionals working in the youth health care.<sup>1,3,4</sup> Since professionals in the second line frequently take over the tasks of the follow-up care of the GPs, likewise professionals of the second line were involved within this investigation.<sup>14</sup> Also, professionals at school such as schoolteachers or an internal tutor were included within this investigation. The semi-structured interviews are performed with nine professionals. The source of the problem mentioned in the problem definition occurs in the first line, i.e. at the general practices. Therefore, it is efficient to interview more GPs than for instance professionals of the second line. Therefore three GPs and only one professional of the second line were interviewed within this investigation. Furthermore, two schoolteachers and one internal tutors were interviewed. Finally, two professionals working in youth health care were interviewed. By interviewing these professionals, a clear view is obtained of the follow-up care considering the fact that all the chain partners active in the follow-up care are involved in this investigation. In table 3 below shows the actual quantity of each professional within this investigation.



*Table 3 Characteristics of the sample*

Professional	Quantity
GPs	3
Child psychiatrist	1
School teachers	2
Internal tutor	1
Professionals working in youth health care	2
<b>Total</b>	<b>9</b>

#### 4.3.2 Inclusion- and exclusion criteria

The inclusion and exclusion criteria of the sample for this study are stated in table 4. For this investigation, there were no exclusion criteria.

*Table 4 Inclusion- and exclusion criteria of the respondents*

Respondents	Inclusion criteria	Exclusion criteria
<ul style="list-style-type: none"> <li>• GPs</li> <li>• Schoolteachers</li> <li>• Internal tutors</li> <li>• Professionals working in youth health care</li> <li>• Child psychiatrists</li> </ul>	<ul style="list-style-type: none"> <li>• Experience in his/her work field with children with ADHD in the last 3 years</li> <li>• Operating in the region Twente</li> <li>• Speak Dutch</li> </ul>	-

#### 4.3.3 Recruitment of respondents

The professionals were gathered through convenience sampling. Several institutes were therefore contacted such as the University of Twente, GGD Twente and 'Oudervereniging Balans Twente'. Ultimately, potential participants were approached by email to cooperate in this investigation. Within this email, the study was clearly introduced to make sure that the professionals were more willing to cooperate within this study. This was done by the attached personal information form (PIF)(appendix A). In this PIF, several topics are described. For instance, the objective of the study, the relevance of the study and the publication of the results.<sup>63</sup>

#### 4.3 Proceeding of the interviews

The nine interviews were held at a place which was considered as private and practical for the interviewees. The interviews with the GPs were held at their general practice. The interviews with the schoolteachers and internal tutor were held at school where they work. The interviews with the two professionals of youth health care were conducted at the GGD Twente and finally, the interview with the child psychiatrist was held at Karakter.

Before the interview took place, permission was asked of the involved professionals by means of the 'informed consent'. By the informed consent (appendix B), respondents were informed about the information of the investigation which is relevant for the respondents to know.<sup>63,64</sup> The interviews were recorded with a digital recorder. Besides the audiotape, the interviewer made use of handwritten notes to improve the reliability. For instance, aspects regarding the follow-up care which have a need for improvement conform the professionals were noted. The length of the interviews were between 20 and 60 minutes with an average of 38 minutes.

#### 4.4 Interview protocol

The semi-structured interviews were guided by means of a topic guide (appendix C, in Dutch). Both models were integrated in the topic guide. An introduction was set up in the first part of the interview. Within this introduction, the interviewer and interviewee introduced each other. Thereafter the aim and the duration of the interview were appointed. It is particularly important that the informed consent was signed before the actual interview took place. To make sure that the professionals felt at their ease, the interview started with 4 simple questions, such as how long the professional is already functioning as for instance a GP or schoolteacher.

During the second part of the interview, the term ‘follow-up care’ was discussed. It was asked whether the professional recognizes the term or not. If not, the term was explained and by doing so, it was clear for the professionals what the interviewer meant by this term.

In the third part, the experiences of the professionals towards the follow-up care were requested. The first question was open, so that the professional could tell his or her story. Later on, additional aspects which were not mentioned before by the professional were explored regarding the MIDI. In other words, the experiences regarding the 4 domains (e.g. determinants associated with the innovation, user, organisation and of the socio-political context) of the MIDI were requested. An example of such a question was as follows:

*‘What is your experience regarding the clinical guidelines? With this I mean for instance the completeness or complexity of the clinical guidelines?’*

During the fourth part, the experiences of the professionals towards the quality of the follow-up care were asked. Likewise, the third part started with an open question. Later on, experiences were asked regarding each factor of the MOCHA conceptual framework. By doing so, a clear vision was obtained regarding the quality of follow-up care conform the professionals. An example of such a question was as follows:

*‘What is your opinion regarding the accessibility of the follow-up care which you provide for children with ADHD?’*

Throughout the fifth part, recommendations were asked regarding the follow-up care. Firstly, the parts of the follow-up care which need improvement conform the professional were repeated by the interviewer. Later on, it was asked what their recommendations are in line with the parts which need improvement.

#### 4.5 Ethics

##### 4.5.1 Ethical approval

Approval for proceeding this investigation has been granted by the ethical committee of the Faculty of Behavioural, Management and Social Sciences of the University of Twente under file number BCE18220.

#### 4.6 Data analysis

##### 4.6.1 Data management

The topics showed in table 5 indicate the management plan for this investigation.<sup>64</sup>

Table 5 Data management plan

Topics	Explanation
<b>Type of data</b>	<ul style="list-style-type: none"> <li>• Fieldnotes of nine interviews</li> <li>• Interview transcripts of nine interviews</li> </ul>
<b>Storage</b>	<ul style="list-style-type: none"> <li>• The gained data is stored at the laptop of the interviewer</li> <li>• There is a backup on google drive of the account of the interviewer</li> <li>• The gained data is secure and confidential since only the interviewer can have access to his/her laptop and account on google drive</li> <li>• Only the interviewer and its supervisors have access to the data</li> </ul>
<b>Data cataloguing and discovery</b>	<ul style="list-style-type: none"> <li>• The field notes and transcripts are labelled with code numbers for the respondents</li> </ul>
<b>Archiving and deposit</b>	<ul style="list-style-type: none"> <li>• At the end of the study, the anonymous data will be stored at the University of Twente</li> </ul>

#### 4.6.2 Analysing the obtained data

The recorded audios were transcribed by means of the program '*Express scribe transcription*' and '*Microsoft word*'. The interviews were transcribed word for word. To ensure confidentiality, any identifier (names/specific location/etc.) was removed.<sup>64</sup>

The transcripts were analysed by using an open coding thematic analysis with the program '*Atlas.ti*'. Open coding was chosen because of the small sample size and to open up all potential avenues of enquiry. The intention was to generate as much codes as possible.<sup>64</sup> The six steps of Braun & Clarke<sup>66</sup> were used for the analysis including; familiarising with the data, generating initial codes, searching for themes, reviewing themes, defining and naming themes and producing the report.

The first two transcripts were coded by two assessors, including the researcher and a colleague researcher. First of all, the researcher selected text fragments of the two transcripts and coded these fragments. Later on, the colleague researcher received both transcripts with the text fragments and a list of codes which were used so that the colleague researcher could find out which code belongs to which text fragment. To ultimately measure the agreement of both of the observers (researcher & colleague researcher), the kappa statistic has been carried out.<sup>67</sup> The Cohen's kappa of the first- and second interview were 0,950 and 0,804 which indicates almost perfect agreement.<sup>67</sup> Therefore, the researcher coded the rest of the transcripts without involvement of a colleague researcher.

After all the codes have been drawn up, the themes were established. The final themes are fully based on the codes which have been conducted. The final themes were used to give answers to both of the research questions. In chapter 6, 'discussion', there will be figured out whether those themes fit with the domains of the MOCHA conceptual framework and the MIDI.

## 5. Results

Within this chapter, the results of this investigation are presented. First of all, the characteristics of the professionals are outlined in table 6, followed by the results of the thematic content analysis. Thereafter, data segments will be presented to be able to give answers to both research questions.

### 5.1 Characteristics of the professionals

Table 6 describes the characteristics of the professionals. A total of nine professionals were interviewed for this investigation whereby the interviews were held at their workplace. Most of the professionals have sufficient work experience as their profession. The average is 15 years. The work experience of professional E is unclear. It is known that she works as a doctor since she was 26, however it is unknown what her age is right now.

Table 6 Characteristics of the professionals

Participants	Gender	Profession	Work experience	Place of interview
Professional A	Male	GP	29 years	General practice
Professional B	Male	GP	27 years	General practice
Professional C	Female	GP	20 years	General practice
Professional D	Female	Doctor working in youth health care	17 years	GGD Twente
Professional E	Female	Doctor working in youth health care	Unclear	GGD Twente
Professional F	Female	Child psychiatrist	16 years	Karakter
Professional G	Male	Schoolteacher	3 years	Primary school
Professional H	Female	Schoolteacher	2 years	Primary school
Professional I	Female	Internal tutor	3 years	Primary school

### 5.2 Results of the thematic content analysis

After the thematic content analysis was executed, a total number of 217 codes were composed, including 136 codes for the quality of follow-up care and 81 codes for the recommendations. These 217 codes were grouped in 17 themes and 46 subthemes by using the six steps of Braun & Clarke.<sup>66</sup> Table 7 describes the themes and subthemes of the quality of follow-up care whereby each theme represents an aspect of the quality of care and each subtheme describes an important aspect of such a theme. However, the theme 'positive freedom of choice' does not include a subtheme since only 1 code can be linked with this theme. Table 8 shows the themes and subthemes regarding the recommendations of the follow-up care.

Table 7 Themes and subthemes of the quality of care

Quality of follow-up care	
Theme	Subthemes
Accessibility of follow-up care	<ul style="list-style-type: none"> <li>Waiting lists in secondary care are experienced as annoying, irritating and unacceptable</li> <li>Positive- and negative experiences regarding the travel distance of secondary care</li> <li>General practice is easily accessible by phone</li> </ul>
Availability of follow-up care	<ul style="list-style-type: none"> <li>The quantity of health care providers is sometimes not experienced as pleasant</li> <li>Significant scarcity in child psychiatrists</li> </ul>

<b>Knowledge/competence of professionals</b>	<ul style="list-style-type: none"> <li>• Adequate knowledge/competence regarding ADHD (own experience)</li> <li>• Inadequate knowledge/competence regarding ADHD (hearing of)</li> </ul>
<b>Continuity of follow-up care</b>	<ul style="list-style-type: none"> <li>• Provided follow-up care does not meet the requirements stated in clinical guidelines</li> <li>• Different attitudes of professionals towards ADHD</li> <li>• The differences in health care per region is experienced as 'difficult' and 'not right'</li> <li>• Professionals who provide the follow-up care have a long-term relationship with the children</li> <li>• Comments on the provision of secondary care regarding the diagnosis and treatment of ADHD</li> </ul>
<b>Financial barriers</b>	<ul style="list-style-type: none"> <li>• Parents sometimes have no money for medication and/or public transport and gasoline to reach the location of secondary care</li> <li>• There are financial barriers to provide the follow-up care</li> </ul>
<b>Transmission of information/cooperation between stakeholders</b>	<ul style="list-style-type: none"> <li>• There is a lack of a good exchange of information from secondary- to primary care</li> <li>• Experienced insufficient treatment adherence in children and their parents</li> <li>• Professionals cannot easily reach each other by phone</li> <li>• Doctors working in youth health care act as intermediaries in the follow-up care because of the privacy rules</li> <li>• Parents do not always provide the same information to different stakeholders</li> <li>• Schools are not fully involved in the follow-up care which is experienced as 'regrettable'</li> <li>• GGZ-institutions are more open to receive feedback from school in comparison with GPs</li> <li>• Social district teams are positively experienced.</li> <li>• Children are heard by their practitioner</li> <li>• Workload is sometimes too much for schoolteachers</li> </ul>
<b>Clinical guidelines</b>	<ul style="list-style-type: none"> <li>• NHG guideline is a manageable and complete directive conform GPs</li> <li>• Other professionals do miss some items regarding the clinical guidelines</li> </ul>
<b>Equity/equality of follow-up care</b>	<ul style="list-style-type: none"> <li>• Children originating in different socioeconomic status/ethnicity are treated the same</li> <li>• Children with poorer parents are at times affected by the financial barriers</li> </ul>
<b>Freedom of choice</b>	<ul style="list-style-type: none"> <li>• Children and their parents are able to choose by whom they want to be treated with</li> </ul>

Table 8 Themes and subthemes of the recommendations of follow-up care

Recommendations follow – up care	
Theme	Subtheme
Financials	<ul style="list-style-type: none"> <li>• Appointments with municipalities for the financials should be made</li> <li>• Budget for consultations between professionals is needed</li> </ul>

<b>Transmission of information/cooperation stakeholders</b>	<ul style="list-style-type: none"> <li>• <i>Clear letter from secondary- to primary care</i></li> <li>• <i>Good instructions for children and parents in the transfer from secondary- to primary care</i></li> <li>• <i>Telephonic consult of secondary care</i></li> <li>• <i>More guidance for schools</i></li> </ul>
<b>Knowledge professionals</b>	<ul style="list-style-type: none"> <li>• <i>Refresh trainings for professionals</i></li> </ul>
<b>Clinical guidelines</b>	<ul style="list-style-type: none"> <li>• <i>Renewal of the JGZ-directive is needed</i></li> </ul>
<b>E-health</b>	<ul style="list-style-type: none"> <li>• <i>Trusted websites for professionals</i></li> <li>• <i>Follow-up care through E-health</i></li> </ul>
<b>Staff capacity</b>	<ul style="list-style-type: none"> <li>• <i>Reinforcement of professionals</i></li> </ul>
<b>Continuity</b>	<ul style="list-style-type: none"> <li>• <i>More homogeneity in the care</i></li> </ul>
<b>Task/roles in follow-up care</b>	<ul style="list-style-type: none"> <li>• <i>Conflicting recommendations of the involvement of school professionals in the follow-up care</i></li> <li>• <i>Conflicting recommendations of the role of youth health care in the follow-up care</i></li> <li>• <i>Conflicting recommendations of the role of POH-GGZ</i></li> <li>• <i>Task division</i></li> </ul>

### 5.2.1 Quality of follow-up care

In the next paragraphs, themes regarding the quality of the follow-up care are clarified. In appendix D, the original Dutch fragments are shown. In addition, after each quote, it is shown which professional has said it.

#### Accessibility of follow-up care

The theme ‘accessibility of follow-up care’ is about whether the follow-up care is accessible for the children and their parents.

#### Waiting lists in secondary care are experienced as annoying, irritating and unacceptable

In almost every interview, professionals addressed that there are significant waiting lists in secondary care. These waiting lists are experienced when a possible diagnosis has to be ensured or during the follow-up care, when the care is getting too complex for primary care.

*‘But it is irritating that the waiting lists in secondary care are growing tremendously. That is really annoying.’ – (transcript line number 4-50 – child psychiatrist)*

*‘The waiting time between referral and intake is, yes, unacceptably long. Yes sometimes 3 months. And at the time that parents come with their child with behaviour problems, the situation is highly critical. Because it has been around for a while.’ – (transcript line number 9-39 - GP)*

As the quotations show, the waiting lists are experienced by the child psychiatrist as irritating and annoying. One GP believes that the waiting lists are unacceptably long.

#### Positive- and negative experiences regarding the travel distance of secondary care

A GP indicated that the children and their parents need to travel longer to arrive at the location of secondary care in comparison with primary care and commented that when the follow-up care is provided in primary care, it would be more pleasant for the children and their parents. Likewise, the child psychiatrist indicated that the travel distance is sometimes too long for the children and their parents.

*‘But they have to travel through more time to be able to finally reach the location. Yes, and well in the beginning, for some visitors, that isn’t really a problem, for a lot of people though if they are treated well. But*

*you can imagine that when the child has received treatment for several years, it would be more pleasant when a child is stabilised, that it can be treated in the general practice.’ - (transcript line number 1-98 - GP)*

However, many other professionals had the opposite opinion. They believe that secondary care is accessible for the children and their parents, because there are a lot of health care providers at a short distance.

#### General practice is easily accessible by phone

Regarding the accessibility of primary care, one of the GPs who provides the follow-up care in his general practice indicated that in his opinion, the accessibility for the children and their parents is good.

*‘Well, we are good accessible. We are available by telephone from 8 till 17. And they have the opportunity, when they need it, to visit the general practice within 1 or 2 days.’ - (transcript line number 9-20 - GP)*

#### Availability of follow-up care

The ‘availability of follow-up care’ implies for instance the staff capacity and the amount of health care providers for children with ADHD.

#### The quantity of health care providers is sometimes not experienced as pleasant

Regarding the availability of care, certain professionals talked about the fact that there are many health care providers for children with ADHD in the Netherlands. The internal tutor indicated that she noticed that it sometimes creates some unclarity among providers due to the quantity of the providers.

*‘There are sometimes to many providers or different people involved with the family, in which one of the contact points no longer has an complete overview. Sometimes, it is too much. But yes, this point sometimes reduces clarity.’ - (transcript line number 11-34 – internal tutor)*

A doctor working in youth health care also asserted that she finds it difficult that there are many health care providers and she believes that it would be more pleasant for the children and their parents to be treated by only one provider through the whole process.

#### Significant scarcity in child psychiatrists

The child psychiatrist and a doctor working in youth health care both indicated that there is a significant scarcity in child psychiatrists. The significant scarcity in child psychiatrists can be a limitation for GPs when they notice, during the follow-up care, that a referral to secondary care is needed.

*‘We can do the check-ups when the children are stabilised. However, in my opinion, we need to be able to send them back easily to secondary care when it is not going well with the child.’ – ‘And why can’t you them back easily?’ – ‘Waiting lists, scarcity in child psychiatrists’ - (transcript line number 9-40 - GP)*

#### Knowledge and competence of professionals

This theme implies whether professionals have sufficient knowledge and competence regarding the disorder ‘ADHD’.

#### Adequate knowledge/competence regarding ADHD (own experience)

Two GPs and the child psychiatrist of the sample provide follow-up care in their practice and consider themselves competent enough to provide the follow-up care. Likewise, in their opinion, they have sufficient knowledge regarding ADHD. In addition, the child psychiatrist believes that the follow-up care provided in secondary care is of good quality because of the knowledge of the professionals.



*'Yes In my opinion, the follow-up care which we provide as Karakter, is simply good. Because we have good practitioners, high educated people. We have integrated care pathways, so there are people in the health care, which are specialised in ADHD. But on the other hand do not take a blindered view. So they also have a view on the other psychopathology which children can have. And the follow-up care, we try to structure the care as smart and efficient as possible with a high educated professional with knowledge.'* - (transcript line number 4-37 – child psychiatrist)

#### Inadequate knowledge/competence regarding ADHD (hearing of)

However, some other professionals expressed some critical comments on the knowledge of GPs regarding ADHD in their work experience.

*'Well, what I notice is that GPs not always have enough knowledge. Which I can imagine because they only have a few patients with ADHD in their practice.'* - (transcript line number 4-21 – child psychiatrist)

*'So I am wondering, whether the GP have sufficient knowledge, of all the environments.'* - (transcript line number 2-21 – doctor working in youth health care)

A doctor working in youth health care also notes that there is a difference in the follow-up care provided by secondary- and primary care, caused by the differences in the knowledge of the professionals. In addition, a doctor working in youth health care notes that children with ADHD which are stabilised, cannot be sent from secondary to primary care because some GPs have the opinion that it is too complex for them to provide the follow-up care. Also, another doctor working in youth health care notes that some GPs shift the responsibility of the care for children with ADHD to their POH-GGZ. This doctor believes that GPs shift the responsibility because of the knowledge of the GPs. Regarding the knowledge of the schoolteachers, the doctor working in youth health care notes that some schoolteachers do not have sufficient knowledge of methylphenidate.

#### Continuity of follow-up care

This theme implies the continuity of the provided care and the continuity among professionals.

#### Provided follow-up care does not meet the requirements stated in the clinical guidelines

During the interviews, it became clear that the provided follow-up care is not always in line with the requirements stated in the clinical guidelines. For instance, the internal tutor indicated that she notes that follow-up care is only provided shortly after the diagnosis is made. In addition, it is more on the initiative of school that a follow-up is provided.

*'We notice that the follow-up care is provided when a child is recently diagnosed with ADHD. However, after a while not anymore.'* - (transcript line number 11-3 – internal tutor)

In addition, one of the doctors working in youth health care notes that some GPs are only taking care for repeat prescriptions during the follow-up care.

*'Or yes, I only need to deliver a prescription and the child is not considered for length, weight and blood pressure. So, I have that experience. And then I am thinking, that is not right.'* - (transcript line number 2-4 – doctor working in youth health care)

#### Different attitudes of professionals towards ADHD

Through the interviews, it became clear that there are some different attitudes experienced towards ADHD. For instance, a doctor working in youth health care has the experience that there is a difference in young GPs and older GPs considering the fact that young GPs show a greater tendency to treat the children with ADHD. In addition, one GP notes that some GPs are working in an old-fashioned way solo. In addition, the child psychiatrist notes that it is different per GP whether they have an affinity for ADHD.



*'Because the GPs, who especially like it, who have a feeling with it and dare to provide the care, it is really different per GP.'* - (transcript line number 4-17 – child psychiatrist)

Furthermore, there are some perceived differences regarding the attitude of schoolteachers towards ADHD. For instance, it is experienced that teachers with a lot of work experience are having more trouble in teaching a class with children with several disorders (including ADHD) in comparison with teachers who just finished their education.

The differences in health care per region is experienced as 'difficult' and 'not right'

The child psychiatrist and a schoolteacher had a comment during the interviews regarding the difference in the way health care is provided per region. They regard this fact as difficult and not right.

*'But you know, I find it difficult that not every region in Netherland is organised in the same manner'. – (transcript line number 4-1 – child psychiatrist)*

*'But what I notice is that there is a huge difference regarding the team here in Enschede and the team in Hengelo. And then I am thinking, that cannot be right. For people in Hengelo, it is a disadvantage.'* – (transcript line number 3-65 - schoolteacher)

Professionals who provide the follow-up care have a long-term relationship with the children

What became clear from the interviews, held with the three professionals who actually provide the follow-up care, is that they see the children on the long-term during the follow-up care.

Comments on the provision of secondary care regarding the diagnosis and treatment of ADHD

Regarding the diagnosis of ADHD, a schoolteacher and a GP commented that they do have the opinion that at times, the diagnosis is too easily being made in secondary care.

*'It went a bit weird I think. I do not believe that you can diagnose a child like that. I believe that more is needed. I had the feeling that it was being done too easily'. - (transcript line number 3-3 - schoolteacher)*

In addition, the internal tutor sometimes notices that the diagnosis is being made without involving the school in the process. In certain situations, the internal tutor doubts whether that is reliable. One of the GPs indicated that he has his doubts whether the medication is being prescribed too easily in secondary care.

### Financial barriers

This theme implies experienced financial barriers during the provision of follow-up care or for the children and parents itself.

Parents sometimes have no money for medication and/or public transport and gasoline to reach the location of secondary care

The child psychiatrist and two GPs commented during the interviews that not all the medication for the children is reimbursed and for that reason, some of the parents are not able to purchase the medication. This is experienced as a big problem by the child psychiatrist. A GP believes that it is a shame that long-action methylphenidate is not reimbursed because long-action methylphenidate ensures less fluctuations in the behaviour of the child.

*'And what I consider as a big problem, well okay, I am focusing again on medication. That not all medication is reimbursed by the health insurer. And that not all parents, slash a lot of parents, do not have the money to buy the medication by themselves.'* – (transcript line number 4-27 – child psychiatrist)

*'And when you provide long- action methylphenidate, than it is of course much more stable. But likewise very expensive. That is a shame right? That a health insurer does not think to just reimburse it.'* – (transcript line number 9-7 – GP)

In addition, the child psychiatrist notes that at times, parents lack financial resources to pay for public transport or gasoline to reach the location of secondary care.

#### There are financial barriers to provide the follow-up care

During the interviews, there have been many discussions about the financial barriers which the professionals experience during the provision of care. Some professionals indicated that the budget is insufficient and the financial resources are limited. Because of that, the child psychiatrist notes a division of care. The children with richer parents are able to buy the care by themselves and the children with poorer parents are the ones which are the most affected by the financial problems.

*'There are at certain moments parents who say; listen, I do not want to have anything to do with the social district teams. The budget of the municipalities is limited. I have enough money, I will go to a private psychologist. Because that is what you experience. And you know, that is of course very pleasant for those parents who can pay it for their child. However, there are enough parents who cannot afford that. And the result is a division in the health care. And that is something wat concerns me.'* – (transcript line number 4-58 – child psychiatrist)

Also, one GP indicated that he is very motivated to provide the follow-up care in his general practice. However, because there is no budget for that care, he cannot provide that care. Nevertheless, what he notes is that, apart from the fact that there is not a budget, some GPs still provide that care in their practice.

#### Exchange of information and cooperation between stakeholders

The theme 'exchange of information and cooperation between stakeholders' is about the experiences of professionals regarding these two aspects.

#### There is a lack of a good exchange of information from secondary- to primary care

It is the experience of both GPs who provide the follow-up care that there are shortcomings in the exchange of information from secondary care to primary care. In their opinion, insufficient 'good exchanges' are done from secondary care to primary care. In addition, it is the opinion of one GP that the quality of the follow-up care provided in primary care also depends on a 'good exchange' from secondary care. If GPs want to experiment with the dosage of the medication, and this is already done in secondary care but not transferred to primary care, a duplication of effort might be provided.

*'But everything depends of a 'warm transmission' from secondary care to primary care. And that is what is lacking at the moment in my opinion.'* - (transcript line number 5-29 - GP)

#### Experienced insufficient treatment adherence in children

One of the GPs notes that during the follow-up care, some children and their parents do not show up for a 'follow-up'. It is the experience of one GP that the adherence depends on the wellbeing of the children. When the ADHD is getting unmanageable, they do show up for a follow-up because in such a situation, care is needed. Likewise, the child psychiatrist notes that when the follow-up care is provided in primary care, children and parents do not always show up. This situation is experienced by the child psychiatrist as challenging. However, in the opinion of the GP and the psychiatrist, it is the responsibility of the children and their parents to show up at the follow-up. Also, both GPs who provide the follow-up care encounter problems regarding the medication intake of the children.

*'So they take the medication irregularly and sometimes they only take the medication when they go to school and not when they are at home because, apparently, the system of the child can handle it more than when a child is at school. So the medication does play a big role, the medication compliance. So we come across that from time to time.'* - (transcript line number 5-7 - GP)

### Professionals cannot easily reach each other by phone

In almost every interview, the professionals talked about the fact that they can hardly reach each other by phone which is experienced as unpractical by a doctor working in youth health care.

*'Yes, well in my opinion, that is not feasible if I have to call them. Because you never reach the schoolteachers.'* - (transcript line number 9-34 - GP)

*'Yes. Or you called the GP back. Well, then they are in a consult again. You can hardly consult each other and that is just unpractical.'* - (transcript line number 12-15 – doctor working in youth health care)

*'But what my experience is through the years, is that when I offer education to GPs, they always tell me that we, as secondary care, are never accessible.'* - (transcript line number 4-49 – child psychiatrist)

### Doctors working in youth health care act as intermediaries in the follow-up care because of the privacy rules

Both of the youth health doctors are only involved in the follow-up care on initiative of school or parents and they act solely as intermediaries between school and the practitioners. This is because schoolteachers cannot reach practitioners itself due to the privacy rules.

### Parents do not always provide the same information to different stakeholders

The internal tutor sometimes experiences that parents tell a different story to the school and their GP and she believes this is due to fear or insecurity of the parents.

*'For instance at school, they can lay down the care. Of or, go along in which the schoolteacher says. While they can moderate a bit at the GP. And in that case, another story is told to the GP whereby another conclusion will be made.'* - (transcript line number 11-18 – internal tutor)

### Schools are not fully involved in the follow-up care which is experienced as 'regrettable'.

The internal tutor experiences that at school, they do not hear a lot about the follow-up care and she finds that regrettable. Likewise, both school teachers indicated that they do not hear anything about the follow-up care and they have the opinion that it would be better when they are involved within the follow-up care.

*'Yes I find that regrettable, because especially those short lines are very important because you just do not easily provide medication. You also want to measure the effects of the psycho – education.'* - (transcript line number 11-7 – internal tutor)

### GGZ-institutions are more open to receive feedback from school in comparison with GPs

The internal tutor indicated during the interview that she experiences that GGZ-institutions are more open to receive feedback from the school in comparison with GPs. In her opinion, that is because of the shorter lines between school and GGZ institutions.

*'That is due the fact that GGZ-institutions visit the school and take a look at the schools. For instance Karakter, or Mediant, yes, they all have some processes whereby they visit the school to provide some guidance and at that moment, they can see that school can also detect or whether school has things in place and a GP is yet at a more distance so that makes it difficult I guess.'* - (transcript line number 11-14 – internal tutor)

### Social district teams are positively experienced.

The child psychiatrist and the internal tutor are both satisfied about the social district teams because they are deeply involved with the schools.

*'What I consider as good nowadays is that in the transition, a lot of district teams, social district teams cooperate closely with the schools. Primary schools and secondary schools.'* - (transcript line number 4-10 – child psychiatrist)

#### Children are being heard by their practitioner

All three professionals who provide the follow-up care commented that they try to listen to the child and give them freedom to talk about their situation, needs and preferences. The other professionals indicated that they also do experience and believe that professionals who provide the follow-up care listen to the child.

*'I try to come in contact with the child, depending on the age of course. But certainly, when the child is able to say something about it, I'm trying to ask what the experiences are of the child. Later on, I check the given information with the parents of the child. But some children can indicate very well like 'I'm a much calmer person'. That is really funny, but they can indicate it well.'* - (transcript line number 9-23 - GP)

#### Workload is sometimes too much for schoolteachers

The workload of the schoolteachers has been addressed several times during the interviews with both schoolteachers and the internal tutor. One schoolteacher and the internal tutor indicated that they notice that it is sometimes too much for themselves or their colleagues. The other schoolteacher does not experience a certain pressure regarding his work, but likewise notes it in his environment.

#### Clinical guidelines

This theme implies the experiences of professionals towards the clinical guidelines used for the provision of follow-up care.

#### NHG is a manageable/complete directive conform GPs

Both of the GPs, who actually provide the follow-up care, have the opinion that the NHG directive is manageable and complete for the provision of the follow-up care.

#### Other professionals do miss some items regarding the clinical guidelines

However, some professionals have comments on the clinical guidelines for the care for children with ADHD. Items which professionals miss are the division of tasks in the directive of youth health care services, the network and the fact that secondary care is accessible for other stakeholders for sharing thoughts and experiences.

*'And I believe that for instance the fact that the GGZ is accessible for GPs, paediatricians, doctors working in youth health care and social district teams to share thoughts can be added in the clinical guidelines.'* - (transcript line number 4-16 – child psychiatrist)

#### Equality/equity of follow-up care

The theme 'equality/equity of follow-up care' is about whether children with ADHD are treated the same by professionals.

#### Children originating in different socioeconomic status/ethnicity are treated the same by professionals

From the interviews with all the professionals, it became clear that children and their parents originating in different socioeconomic statuses or ethnicity are treated the same.

*'And I do believe that, we do not treat the children differently. Likewise, I do not believe that in health care institutions, they also do not treat those children differently.'* - (transcript line number 5-26 -GP)

#### Children with poorer parents are at times affected by the financial barriers

However, as mentioned previously, children with poorer parents are sometimes affected by shortcomings in financial resources to finance the care.

### Freedom of choice

This theme is about whether children and their parents have the opportunity to decide where and by whom they want to be treated with.

Children and their parents are able to choose by whom they want to be treated with

All professionals indicated during the interviews that the children and parents have the opportunity to share their knowledge and to specify where and by whom they want to be treated with.

*'And that GPs also listen right, if parents say I want to be treated over there or there. That that also happens. Yes, that is what I hear.'* - (transcript line number 4-43 – child psychiatrist)

## 5.2.2 Recommendations follow-up care

In the next paragraphs, themes are identified which reflect the identified recommendations.

### Financials

This theme implies recommendations about the financials for the follow-up care for children with ADHD.

Appointments with municipalities for the financials should be made

Several professionals commented during the interviews that they have the opinion that it is needed to make some appointments with municipalities regarding the financials. One of the GPs commented that it is needed because he can only provide follow-up care in his general practice when there is a budget available. Also, he indicated that it would create some motivation under the GPs to retrain themselves regarding ADHD when there is a budget available.

*'But appointments should be made, in this case with the municipalities, to ensure the financials of that care in the general practice. However, it gets jammed on that aspect nowadays because that is not there yet.'* - (transcript line number 1-6 - GP)

Budget for consultations between professionals is needed

The child psychiatrist indicated during the interview that she believes that it is needed that there is a budget available for the consultation between professionals.

*'Because what you notice, half an hour with a GP on the phone, all right that is totally fine. It is actually great. To adjust some information. To share some knowledge. Yes that is really nice, I always love to do it. But then I am thinking, it needs to be paid. So I have the opinion that budgets are needed from the municipalities, for those consultations.'* - (transcript line number 4-18 – child psychiatrist)

### Exchange of information and cooperation between stakeholders

This theme implies recommendations to strengthen the cooperation between stakeholders and to make sure that a 'good exchange' will be ensured in the future from secondary- to primary care.

Clear letter from secondary- to primary care

The two GPs, who provide the follow-up care, believe that a clear letter from secondary care to primary care would be a solution for the insufficient exchange of information. That letter should include a summary of what is provided in secondary care and a proposal regarding the medication wherein the child is marked as stable.

*'Than it would be pleasant that we receive a clear letter, where, wherein a summary is stated of what is done. Wherein a proposal of the medication is indicated wherein the child is marked as stable.'* - (transcript line number 5-28 – GP)

#### Good instructions for children and parents in the transfer from secondary- to primary care

A GP had the opinion that it is needed that children and parents are well instructed in the transfer from secondary- to primary care. By doing so, it will be clear for the parents when they have the first check-up regarding the follow-up care.

#### Telephonic consult of secondary care

The internal tutor indicated during the interview that she believes that a telephonic consult of secondary care would be a good idea. In that case, school professionals can, by courtesy of parents, talk with secondary care to share thoughts and ask questions.

*'Maybe they need to do something with a telephonic consultation. Wherein for instance the school, by courtesy of the parents of course, that we can call them to adjust some information. How we think it is going, problems we encounter, think with us. They do not have to visit our place, but just that we can negotiate.'* - (transcript line number 11-43 – internal tutor)

#### More guidance for schools

A schoolteacher suggested during the interview that he believes that it would be a good idea that schools receive more guidance from practitioners to know how to treat a child with ADHD in the classroom.

*'Well more, I believe that they, that schools need to receive some guidance to guide the children. Because the children are at school most of the day. And I believe that it is good, that it is thought through how we can adjust things on school.'* - (transcript line number 3-67 –schoolteacher)

#### Knowledge professionals

The theme 'knowledge of professionals' is about recommendations to strengthen the knowledge of professionals regarding the disorder ADHD.

#### Refresh trainings for professionals

One doctor working in youth health care suggested that schoolteachers need to be educated about the administration regarding the medication. Therefore, she indicated that doctors working in youth health care could educate the schoolteachers. In addition, the child psychiatrist and the two doctors working in youth health care commented that some GPs need to be retrained to be able to provide the follow-up care. However, that was not the opinion of the GPs who actually provide the follow-up care. The GP who is restricted by the financials to be able to provide the follow-up care also suggested that when they have the financials, they need to retrain themselves. In addition, all the professionals, except for the GPs, suggested that it would be a good idea for doctors working in youth health care to provide the follow-up care instead of GPs. However, the doctors working in youth health care commented that it is in that case needed to retrain themselves to be able to provide the follow-up care.

*'With the right training, because that is, than the knowledge needs to be jacked up. So training about, about the medication itself but also where you need to pay attention to.'* - (transcript line number 2-91 –doctor working in youth health care)

#### Clinical guidelines

This theme implies recommendations for the clinical guidelines used for the provision of follow-up care.

#### Renewal of the JGZ – directive is needed

A doctor working in youth health care indicated that the directive of youth health care needs to be updated with regard to the division of tasks. In addition, she commented that when doctors working

in youth health care provide the follow-up care in the future, the directive of youth health care needs to be updated regarding the provision of the follow-up care.

*'Because in that case the JGZ-directive, because than you talk about, well yes the adjustment of the medication and so on. Then, it has to be absorbed in the JGZ-directive.'* - (transcript line number 2-30 –doctor working in youth health care)

## E-health

This theme implies recommendations regarding E-health for the follow-up care.

### Trusted websites for professionals

The child psychiatrist suggested that a website, in which the social chart is indicated, would be a great idea. She also suggested that it would be good idea to have some trusted websites for professionals to visit. By doing so, it could provide some knowledge for them.

### Follow-up care through E-health

The child psychiatrist likewise suggested that the follow-up care could be provided through E-health in the future. In that case, the children and their parents do not have to visit the location of secondary care and they can easily stay at home. However, they still have to visit a practitioner, for instance a GP or doctor working in youth health care for the measures regarding blood pressure, length and weight.

*'In that case Skype or Facetime would be a possibility. The parents are just staying at home with the child or for instance at school and through Facetime, contact can be established. But you still need to measure the blood pressure, length and weight. But that can be established at for instance the general practice. Or the doctor of youth health care of course. Those things could be developed.'* - (transcript line number 4-59 – child psychiatrist)

## Staff capacity

The theme 'staff capacity' is about whether more staff is needed regarding the follow-up care.

### Reinforcement of professionals

A doctor working in youth health care suggested that it would be an idea to reinforce secondary care because there is a significant scarcity in child psychiatrists. The GP who is restricted by the financials to be able to provide the follow-up care suggested that more assistants could be deployed in the general practice who can play a part in the follow-up care.

*'I can ensure that more assistants are being deployed who could provide some controls at the child. However, they need to be educated.'* - (transcript line number 1-76 – GP)

## Continuity

This theme implies recommendations to improve the continuity of care.

### More homogeneity in the care

One of the GPs indicated that it is needed that there is homogeneity among the GPs. In addition, he believes that the same agreements have to be made with the municipalities among the GPs. To ensure homogeneity under the GPs, the GP suggested that a health care group, for instance the company for GPs in Twente (THOON), could be an idea. One schoolteacher considers it important that the follow-up care is provided the same in each region because he believes that the differences in the provision of health care is not right.

*'And for the follow-up care, I do believe that it good that the same things are being done. Because I experience a huge difference in the district team here in Enschede and the district team in Hengelo.'* - (transcript line number 3-64 – Schoolteacher)



In addition, he suggested that arrangements regarding the requirements of the follow-up care should be made to be able to strengthen the follow-up care and to make sure that the provided follow-up care is the same in every region.

### Task and/or roles of professionals in the follow-up care

This theme implies recommendations about who should provide the follow-up care and who should be involved.

#### Conflicting recommendations of the involvement of school professionals in the follow-up care

Some professionals suggested during the interviews that school could be more involved regarding the follow-up care. Of these professionals, the internal tutor, the child psychiatrists, the doctors working in youth health care and both schoolteachers share this opinion. The GPs did not share this thought and believe it is the responsibility of the parents to share the information of school.

*‘But they simply just have short lines with the child itself, they see the children every day. So I believe that something is needed, like what is the part of the care which they can deliver.’ - (transcript line number 2-100 – doctor working in youth health care)*

The internal tutor believes that when school professionals are more involved in the follow-up care in the future, a telephonic arrangement must be achieved when for instance a GP provides the follow-up care. In such a situation, school professionals and the GPs are able to exchange information through the phone.

#### Conflicting recommendations of the role of youth health care in the follow-up care

It has been addressed several times that doctors working in youth health care could provide the follow-up care.

*‘And I do believe that doctors working in youth health care could have a bigger role within the follow-up care for children with ADHD. Likewise with autism or with a depression. Because they are more educated than people working in a social district team.’ - (transcript line number 4-11 – child psychiatrist)*

However, the two GPs who provide the follow-up care do not share this thought. Also, a doctor working in youth health care questions whether doctors working in youth health care should provide the follow-up care. This is because they cannot prescribe medications. She likewise believes that it might be ‘too much’ for the doctors working in youth health care.

#### Conflicting recommendations of the role of the POH-GGZ

Also, different opinions were shared regarding the involvement or role of the POH-GGZ within the follow-up care. One GP suggested that the POH-GGZ could play a part in the follow-up care when it is provided in primary care. However, another GP did not share this thought.

*‘I do believe that the follow-up care has to be provided by a doctor and not by a POH-GGZ. They cannot prescribe medication. They cannot say like ‘take a pill more or less’. And a POH-GGZ takes more than half an hour and sometimes an hour in which I think, I am done within 10 minutes.’ - (transcript line number 5-14 – GP)*

#### Task division

A GP and a doctor working in youth health care both indicated that a task division might work when the follow-up care is provided in the general practice or youth health care.

*‘You can imagine that one of us takes the responsibility and acquires the required knowledge. We have already such a task division.’ - (transcript line number 1-36 – GP)*



## 6. Conclusion and discussion

The aim of this study was to gain insight in the quality of follow-up care for children with ADHD in the Netherlands and to gather information on how the quality of care can be improved to achieve better effectiveness of treatment, health outcomes, satisfaction and treatment adherence in children with ADHD.

### 6.1 Conclusion

#### 6.1.1 Quality of follow-up care

Both positive and negative experiences were indicated by the professionals regarding the quality of follow-up care. Some negative experiences are the waiting lists and scarcity in child psychiatrists. In addition, the provided follow-up care does not always meet the requirements stated in the clinical guidelines. Regarding the financials, parents do not always have the money to purchase the medication and/or public transport and gasoline to reach the location of secondary care. Children with poorer parents are at times affected by the insufficient budget of municipalities. The differences in the provision of care per region is not experienced as pleasant by the child psychiatrist and a schoolteacher. The barriers, which are experienced in the provision of the follow-up care, are the insufficient exchange of information from secondary- to primary care and poor treatment adherence in children. Two GPs who provide the follow-up care believe that they have sufficient knowledge and competence regarding ADHD, however, it is remarkable that the other professionals do have opposite experiences. Some positive experiences are: children originating from different socioeconomic statuses or ethnicity are treated the same by professionals, children and their parents have a freedom of choice to decide by whom they want to be treated with and they are heard by the professionals.

#### 6.1.2 Recommendations follow-up care

It is the recommendation of the internal tutor to have a telephonic consult of secondary care whereby experiences and knowledge can be shared. A main finding regarding the communication and cooperation between secondary- and primary care is the recommendation of a clear letter with several aspects included. Because of the unpleasant experience regarding the differences in the provided health care per region, it is the recommendation to have more homogeneity in the care. It was the advice of one schoolteacher to ensure arrangements about the requirements of the follow-up care to achieve homogeneity. The same schoolteacher recommended to have more guidance of practitioners to know how they can treat the children with ADHD in school. The use of E-health has been addressed by the child psychiatrist. In that case, children do not have to visit the location of secondary care anymore. Some professionals recommended refresh trainings to be able to provide the follow-up care with good knowledge of the disorder. Finally, it is the recommendation of a doctor working in youth health care to renew the JGZ – directive.

## 6.2 Comparison with the literature

### 6.2.1 The comparison of the results with existing literature

In almost every interview, professionals addressed that there are significant waiting lists in secondary care. Also, a GP and a child psychiatrist indicated that there is a scarcity in child psychiatrist in the Netherlands. Similar findings emerge from four news articles.<sup>68-71</sup> However, little is known regarding the opinion of professionals about these facts while this study identified that some professionals consider it as 'irritating', 'unacceptable' and 'annoying'. A doctor, working in youth health care, recommends reinforcing secondary care to be able to resolve the problem regarding the scarcity. This recommendation is also identified in two news articles.<sup>70,71</sup>

Some professionals indicated that they have the experience that some GPs feel that the provision of care for children with ADHD is too complex. This was also identified by earlier studies with different study designs.<sup>23,24,72,73</sup> However, a study of Hassink-Franke et al.<sup>22</sup> revealed that all the GPs who were interviewed (15) saw a role for themselves to provide the pharmacological treatment for children with uncomplicated ADHD. The same result emerges from this study since two GPs provide the follow-up care without the feeling that it is too complex. However, one of those GPs has been a GP at Ambiq, with the result that she has a lot of work experience in children with ADHD. She also faces a lot of young patients in her general practice with the result that she often gets in touch with children with ADHD. In conclusion, the experienced adequate knowledge regarding ADHD might be related to that. Furthermore, the child psychiatrist and the two doctors working in youth health care have the experience that some GPs have insufficient knowledge regarding ADHD which can be confirmed by a study of Ghanizadeh et al.<sup>74</sup> Nevertheless, it is remarkable that the two GPs, who provide the follow-up care, do not share these experiences. In addition, this study revealed that young GPs are more willing to treat children with ADHD than older GPs which matches with the results of an earlier study.<sup>75</sup> Also, professionals indicated that it is needed for GPs to run through a refresh training regarding ADHD. Similar findings are identified in a report of the Health Council of the Netherlands.<sup>14</sup>

It was already known from a study of Faber et al.<sup>23</sup> that the follow-up care in the Netherlands does not always meet the requirements as stated in the clinical guidelines. The same emerges from this study. Furthermore, this study revealed that GPs experience some barriers in the exchange of information from secondary- to primary care. Similar findings were identified in a study of Janssen et al.<sup>24</sup> However, little is known regarding recommendations to resolve this last problem while this study indicated that a clear letter with several aspects included can be a solution.

Some professionals recommended to involve youth health care and school professionals more within the follow-up care. Similar findings were identified in two pilots and a report of the Health Council of the Netherlands.<sup>14,21,35</sup> However, it is interesting that two GPs did not share these thoughts. In addition, a doctor working in youth health care itself questions whether doctors working in youth health care could provide the follow-up care. Nevertheless, the opinions of the GPs might be related to the experience that, in their opinion, schoolteachers are not easily accessible. Also, they believe that it is the responsibility of the parents to share the information of school.

It was asserted by one GP that especially long-action Methylphenidate ensures fewer fluctuations in the behaviour of the child. However, this cannot be confirmed by a study of Punja et al.<sup>76</sup> whereby the differences in efficacy between short- and long-action methylphenidate were investigated. The Canadian Agency for Drugs and Technologies in Health (CADTH) advises that individualized treatment for each patient is best practice.<sup>77</sup> However, with the experience that not all medication is reimbursed, 'best practice' might not always be achieved. Through this study it became evident that there are some experienced barriers regarding the adherence to methylphenidate of children. Sometimes, children take in the medicine irregularly and some children do not take in the medicine at home. Similar findings emerge from a study of Charach et al.<sup>78</sup>, which shows that only 36 – 68% of children take in the medication consistently. The study also revealed that poor adherence in children with ADHD is a common issue.<sup>78</sup> However, the experience that children do not take in the medicine at home cannot be confirmed by existing literature.

All of the GPs revealed that they believe that the NHG is manageable and complete for the provision of the follow-up care. However, other findings are identified in an article of Luman & de Zeeuw.<sup>79</sup> They wonder whether this directive ensures sufficient steadiness to decelerate the rise of the number of diagnoses and medication use. In conclusion, the opinion regarding the completeness of

the NHG 'ADHD in children' cannot be confirmed by this article and it indicates that the NHG directive is not that as 'complete' as it is experienced.

### 6.2.2 The comparison of the results with the theoretical framework

The MOCHA conceptual framework was used with the intention to gather information regarding the 'quality of care'. This was achieved by integrating the factors in the topic guide. Some determinants of the framework correspond with the themes of this investigation, including affordability, accessibility, continuity of care and the equality of care. However, some themes which are identified in this study are new, including financial barriers in the organisation, knowledge of professionals, compliance of clinical guidelines and the coordination between all stakeholders active in the follow-up care. Some professionals indicated that there are financial barriers in the organisation. These barriers can lead to some consequences for the quality of care. For instance, due to the insufficient budget in the municipalities, the follow-up care could not be provided in the general practice of one GP. Therefore, the follow-up care is provided in secondary care which is at times experienced as less accessible. In addition, children with poorer parents might be affected by the insufficient budget which leads to differences between rich and poor. The knowledge and competence of the professionals is not integrated in the framework while this is an important aspect of the quality of care.<sup>51</sup> Clinical guidelines likewise have an influence on the quality of care since they can help improve health care processes, outcomes and costs and the quality of diagnosis and treatment.<sup>20,25</sup> However, this aspect is not integrated in the framework. The integration of primary- and secondary care is embedded in the framework.<sup>51</sup> Nevertheless, regarding the care for children with ADHD, also professionals at school, professionals working in youth health care and the social district teams are involved.<sup>3,80</sup> The cooperation between these providers is not embedded in the framework while a good cooperation between providers, working in the environment of the children, may have an effect on the quality of care. Regarding the framework, only the proximal determinants of the 'output' were used for this investigation. In this investigation, the professionals' perspective was investigated with the result that also factors regarding the 'structure' and 'process' were obtained. However, this might be caused by the fact that likewise the MIDI has been used which leads to the result that aspects regarding the knowledge, clinical guidelines, organisation and cooperation between stakeholders were asked. In conclusion, the MOCHA conceptual framework missed some items to be able to gather a full vision regarding the quality of care through the professionals' perspective and therefore, the framework might be not that appropriate for this investigation. However, fortunately, both frameworks were used within this investigation what has led to the result that a lot of items have been gathered regarding the quality of care since items of the MIDI also have a link with the quality of care.

The MIDI was used to gather information with regard to the recommendations which professionals give for the implementation of new care practices. As can be seen from table 8, most of the themes correspond with the determinants stated in the MIDI. However, the theme 'E-health' does not correspond with the determinants of the MIDI. Through E-health, care could be provided by means of the internet and an increasing attention is being accorded regarding this topic.<sup>81</sup> As a result, a determinant could be added whether the organisation is up-to-date and meets the latest innovations. However, the MIDI is considered as an appropriate model to gather information about the implementation of new care practices in this investigation since it almost corresponds with all the themes which were gathered.

### 6.3 Strengths and limitations

A limitation of this investigation is the risk of selection bias due to the process of recruitment. As mentioned in the chapter 'methods', several institutions were approached to recruit professionals.

Likewise, professionals which were interviewed were asked whether they knew colleagues so that the researcher could interview them as well. However, those institutions or professionals may only have approached professionals which they felt to be appropriate for this investigation. For example, professionals with an affinity and enthusiasm regarding the subject. This might lead to biased results with the consequence that the results cannot be generalised. However, the researcher has tried to create a varied sample by indicating that it is the intention to recruit professionals from different locations, affinity and work experience. Also, when professionals or institutions brought up some contacts to recruit for this investigation, the researcher randomly chose a professional to contact for further recruitment.

Another limitation of this investigation is the result that saturation of data has not been reached. Since approximately two professionals of each stakeholder were investigated in this study, it is not guaranteed that all aspects have been found in this study. However, since all stakeholders active in the follow-up care were interviewed, a broad impression is obtained which is a strength of this study. In addition, regarding the data collection, open questions were used and the interviews were held individually and at a place which was considered as private and practical for the interviewees. These aspects can be considered as strengths of this investigation since there has been tried to gather as much as information regarding the topic by choosing these methods. By doing so, some new and unexpected information could be gathered.

#### 6.4 Implications for clinical practice

For further research, it is advice to consider the following recommendations:

- Since the quality of follow-up care is unclear, it is recommended to investigate the children's, parents'- and policy's perspective as well. By doing so, it can be determined whether there are some different thoughts on the aspects on the quality of follow-up care.
- Regarding the knowledge and competence of GPs, different experiences were indicated by the professionals. The GPs who provide the follow-up care believe that they have sufficient knowledge and competence regarding ADHD. However, the other professionals do have other experiences. To clarify this, it is recommended to conduct a qualitative research with GPs regarding the knowledge and competence of the disorder ADHD. By doing so, it will be more evident whether GPs have sufficient knowledge and competence regarding ADHD.
- Most of the professionals have the recommendation to involve youth health care and schoolteachers more within the follow-up care. However, little information is gathered in this study how this can be established. Therefore, it is recommended to conduct research with all the stakeholders, including municipalities, regarding this subject. It is also recommended to recruit schoolteachers with a lot of work experience for this research since only schoolteachers with little work experience were recruited in this investigation. By doing this research, it will be more evident whether this could be achieved in actual practice.
- Some items were missed regarding the MOCHA conceptual framework in investigating the professionals' perspective regarding the quality of care. Therefore, it is recommended to use a more complete model in the future. Research is needed to determine which model might be appropriate. By doing so, it reduces the risk that some aspects are not addressed during a similar qualitative study.

For the follow-up care, it is recommended to consider the following points:

- Since some professionals indicated that there are too many health care providers for children with ADHD which sometimes reduces clarity. Therefore, it is the recommendation to solve this problem. To achieve that, arrangements must be made with all the involved stakeholders to make clear who is responsible for what kind of care. Therefore, clinical

guidelines could be renewed which can create more clarity. Also, through a meeting wherein all stakeholders are involved, thoughts and experiences could be shared with the result that stakeholders might cooperate more and obtain the same information regarding the child with ADHD.

- Since some professionals sometimes notice that the follow-up care does not meet the requirements stated in the clinical guidelines, it is the advice for professionals to raise the alarm as soon as possible when they notice this in practice. By doing so, it will limit the consequences for the child with ADHD.

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## Appendix A: PIF

### Proefpersoneninformatie voor deelname aan kwalitatief onderzoek

## ‘Onderzoek naar de mening van professionals over de follow-up care voor kinderen met ADHD’

Geachte heer/mevrouw,

U ontvangt deze brief omdat u als professional te maken heeft met kinderen met ADHD. Om deze reden vraag ik u om deel te nemen aan dit onderzoek. Vanzelfsprekend is meedoen vrijwillig. Als u besluit mee te doen is schriftelijke toestemming nodig. Voordat u beslist of u wilt deelnemen aan dit onderzoek, krijgt u uitleg over wat het onderzoek inhoudt. Wilt u deze informatie rustig doorlezen en wanneer u vragen heeft, kunt u mij (de onderzoeker) om uitleg vragen. Onderaan deze brief kunt u mijn contactgegevens vinden.

### *Algemene informatie*

Mijn naam is Neline Dijkstra. Momenteel studeer ik de master Health Sciences (gezondheidswetenschappen) aan de Universiteit Twente. Voor mijn afstudeeropdracht doe ik onderzoek naar de opvattingen van professionals over de geleverde zorg voor kinderen met ADHD. Dit onderzoek vindt plaats op verzoek van de Academische Werkplaats Jeugd Twente.

### *Achtergrond van het onderzoek*

Wanneer een kind gediagnosticeerd is met ADHD en een behandeling is ingezet, kan ook de follow-up care worden gestart. Tijdens de follow-up care worden de behandeling en eventuele klachten van het kind regelmatig geëvalueerd door professionals. Tijdens deze follow-up care kan de dosis van de medicatie zo nodig worden bijgesteld en de therapietrouw worden bevorderd. Bovendien kan de follow-up care leiden tot een vermindering van de symptomen van ADHD. Volgens de JGZ-richtlijn ‘ADHD; signalering, begeleiding en toeleiding naar diagnostiek’, de NGH-standaard ‘ADHD bij kinderen’ en de multidisciplinaire richtlijn ‘ADHD bij kinderen’ zijn het de professionals in de eerste lijn die de follow-up care verlenen. Het is onbekend hoe deze follow-up care in de praktijk plaatsvindt, maar er zijn aanwijzingen dat dit regelmatig gebeurt door professionals, werkzaam in de tweede lijn. Dit resulteert in lange wachtlijsten in de tweede lijn en hogere kosten.

In een eerder onderzoek is aan ouders van kinderen met ADHD gevraagd naar hun ervaringen met de follow-up care. Middels voorliggend onderzoek worden de ervaringen van betrokken professionals onderzocht.

### *Doel van het onderzoek*

Het doel van dit onderzoek is om inzicht te verkrijgen in de ervaringen van professionals met de kwaliteit van de follow-up care voor kinderen met ADHD. Wellicht kan naar aanleiding van de resultaten van dit onderzoek de follow-up care voor kinderen met ADHD waar nodig verbeterd worden.

### *Wat meedoen inhoudt*

Om inzicht te krijgen in de ervaringen en aanbevelingen wordt u één op één geïnterviewd. Dit interview zal plaatsvinden op een plek wat voor u als prettig wordt ervaren. Het interview kan ten alle tijden worden gestopt wanneer u hier de behoefte voor heeft. Het interview zal ongeveer 30 à 40 minuten duren en het zal worden opgenomen middels een audiorecorder.

### *Wat wordt er van u verwacht?*

Er wordt enkel van u verwacht om aanwezig te zijn op het afgesproken tijdstip wanneer het interview met u plaatsvindt. Verder is het belangrijk dat u contact opneemt met de onderzoeker wanneer u niet meer mee wilt doen aan het onderzoek of als uw contactgegevens wijzigen.

### *Mogelijke risico's van het onderzoek*

De risico's van het onderzoek zijn voor u minimaal gezien het feit dat enkel uw visie op de geleverde follow-up care wordt besproken.

### *Mogelijke voor- en nadelen*

Het voordeel van uw deelname aan dit onderzoek is dat de resultaten kunnen bijdragen aan een verbetering van de follow-up care voor kinderen met ADHD. Wanneer uit dit onderzoek duidelijk wordt wat goed gaat en waar eventueel verbeterpunten liggen, kan hier in de toekomst aan gewerkt worden. Een nadeel van uw deelname kan zijn dat het u tijd kost voor het interview.

### *Als u meedoet met het onderzoek of op een later moment wilt stoppen*

U beslist zelf of u mee wilt doen aan het onderzoek. Als u besluit mee te doen, krijgt u bij aanvang van het interview de vraag om schriftelijke toestemming te geven. U kunt op elk moment beslissen om te stoppen met uw deelname aan het onderzoek. U hoeft niet te zeggen waarom u stopt. Onderaan deze brief staan de contactgegevens van de onderzoeker vermeld, zodat u bij haar kan melden als u wilt stoppen.

### *Einde van het onderzoek*

Uw deelname aan het onderzoek stopt als:

- Het interview met u is afgelegd;
- U besluit om te stoppen met het onderzoek;
- De onderzoeker het beter voor u vindt om te stoppen;
- GGD Twente of Universiteit Twente besluit om het onderzoek te stoppen.

Het hele onderzoek is afgerond wanneer alle interviews (+/- 8 tot 12 interviews) zijn afgelegd. Wanneer de resultaten van de interviews zijn verwerkt zal ik u de uitkomsten van het onderzoek doen toekomen.

### *Gebruik en bewaren van persoonsgegevens*

De interviews zullen woordelijk worden uitgeschreven, anoniem worden opgeslagen en vervolgens geanalyseerd. Na afloop van het onderzoek zullen de opnames worden vernietigd. U krijgt een identificatienummer dat met uw persoonlijke gegevens wordt gekoppeld. Dit houdt in dat uw naam of andere persoonlijke gegevens worden weggelaten uit de uitgeschreven interviews. Al uw gegevens blijven vertrouwelijk. Alleen ik (de onderzoeker) weet welke code bij welke gegevens hoort. Verder hebben alleen mijn supervisors van de Universiteit Twente toegang tot de gegevens om te controleren of het onderzoek goed en betrouwbaar is uitgevoerd.

### *Heeft u vragen?*

Wanneer u vragen heeft omtrent het onderzoek kunt u contact opnemen met mij (de onderzoeker). De contactgegevens zijn als volgt:

Naam: Neline Dijkstra

E-mailadres: [n.dijkstra@student.utwente.nl](mailto:n.dijkstra@student.utwente.nl)

### *Ondertekenen toestemmingsformulier*

Als u wilt deelnemen aan het onderzoek wordt voorafgaand aan het interview aan u gevraagd om het toestemmingsformulier te ondertekenen. Tevens wordt het toestemmingsformulier door mij ondertekend. Wanneer dit is gedaan kan het interview worden gestart.

*Hartelijk dank voor het lezen van deze proefpersoneninformatie!*

Met vriendelijke groet,  
Neline Dijkstra

Begeleiders Universiteit Twente:  
Dr. M.M. Boere-Boonekamp  
Dr. J.G. van Manen

## Appendix B: informed consent

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

**Titel onderzoek:** ADHD follow-up care; the professionals' perspective

**Verantwoordelijke onderzoeker:** Neline Dijkstra

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

Ik verklaar op een voor mij duidelijke wijze te zijn ingelicht over de aard, methode, doel en [indien aanwezig] de risico's 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.

[indien van toepassing] Ik begrijp dat film-, foto, 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 C: topic guide

# Topic guide

## ‘Onderzoek naar de mening van professionals over de follow-up care voor kinderen met ADHD’

**Namen van deelnemers:**

**Naam interviewer: Neline Dijkstra**

**Datum:**

**Locatie:**

### *Intro*

- Voorstellen
- Doel van het gesprek
- Duur van het gesprek
- Wat gebeurt er met de uitkomsten
- Informed consent tekenen
- Opname gesprek (audio)
- Mogen te allen tijde stoppen met het interview

### *Kennismakingsvragen*

- 1) Hoe lang bent u al werkzaam als ... (huisarts/jeugdarts/etc.)?
- 2) Heeft u veel ervaring in uw werk met de zorg/begeleiding voor een kind met ADHD?
- 3) Welke richtlijnen kent u zoal die te maken hebben met de zorg voor kinderen met ADHD?
- 4) Welke richtlijn hanteert u hiervan?

### *Vier belangrijke topics*

1. Verduidelijking begrip ‘follow-up care’
2. Ervaringen van professionals met de ‘follow-up care’ voor kinderen met ADHD in hun werkveld.
3. Ervaringen van professionals ten aanzien van de kwaliteit van de ‘follow-up care’ voor kinderen met ADHD.
4. Aanbevelingen van professionals ten aanzien van de ‘follow-up care’ voor kinderen met ADHD.

### *Topic guide en mogelijke vragen hierbij*

1. Verduidelijking begrip ‘follow-up care’



- U heeft in de proefpersoneninformatie/introductiebrief als het goed is het begrip ‘follow-up care’ gelezen. Herkent u dit begrip?
- Zo ja, wat verstaat u hieronder?
- Zo nee, interviewer geeft uitleg\*

**2. Ervaringen van professionals met de ‘follow-up care’ voor kinderen met ADHD in hun werkveld.**

1. Kunt u mij vertellen hoe de ‘follow-up care’ voor kinderen met ADHD verloopt in uw werk?
2. Wat gaat er goed en waar loopt u tegenaan?
3. Doorvragen naar ervaringen t.a.v. de 4 gebieden van de ‘MIDI’\*
  1. Innovatie (richtlijnen)
  2. Organisatie
  3. Rol als zorgverlener
  4. Regelgeving

\*Tijdens het doorvragen naar de 4 gebieden van de MIDI houdt de interviewer het model bij de hand waarin alle determinanten per gebied vermeld staan. Zodoende vraagt de interviewer of de geïnterviewde wat kan vertellen over ervaringen in zijn/haar werk t.a.v. de beschreven gebieden- en determinanten. De interviewer heeft daarnaast een model met 4 lege vlakken bij de hand waarin de ervaringen genotuleerd kunnen worden per gebied.

**3. Ervaringen van professionals ten aanzien van de kwaliteit van de ‘follow-up care’ voor kinderen met ADHD.**

1. Kunt u mij vertellen wat uw ervaringen zijn ten aanzien van de kwaliteit van de ‘follow-up care’ voor kinderen met ADHD?
2. Doorvragen naar de 8 gebieden van het MOCHA model\*
  1. Affordable
  2. Accessible
  3. Acceptable
  4. Appropriate
  5. Continous
  6. Coordinated
  7. Equable
  8. Empowering

\*Tijdens het doorvragen naar de 8 gebieden van het MOCHA model houdt de interviewer het model bij de hand. Zodoende vraagt de interviewer of de geïnterviewde wat kan vertellen over de ervaringen in zijn/haar werk t.a.v. de 8 gebieden. De interviewer heeft daarnaast een model met 8 lege vlakken bij de hand waarin de ervaringen genotuleerd kunnen worden per gebied.

**4. Aanbevelingen van professionals ten aanzien van de ‘follow-up care’ voor kinderen met ADHD.**

1. \*Herhalen van aspecten t.a.v. de follow-up care die uit ervaring van de geïnterviewde nog niet vlekkeloos verlopen
2. Wat zijn dan hierop uw aanbevelingen voor de toekomst?
3. Doorvragen naar de 4 gebieden van de MIDI/8 gebieden van MOCHA
4. Als u de ‘follow-up care’ zelf zou mogen inrichten, hoe zou u dat dan doen zodat het kind met ADHD het beste functioneert?\*

\*Tijdens deze vraag houdt de geïnterviewde het MOCHA- en MIDI model bij de hand zodat dit eventueel als steun gebruikt kan worden.

### *Afsluiting*

- Hiermee ben ik aan het einde gekomen van mijn vragen, heeft u nog vragen?
- Bedankt voor uw deelname!
- Audio uitschakelen
- Nadat ik alle interviews heb afgenomen ga ik de verkregen data verzamelen en analyseren tot een verslag. Heeft u behoefte aan een exemplaar van dit verslag? Zo ja, naar welk email-adres zou ik het kunnen sturen?
- Wanneer u nog vragen heeft na dit interview kunt u mij te allen tijde mailen op [n.dijkstra@student.utwente.nl](mailto:n.dijkstra@student.utwente.nl)

## Appendix D: translation quotes

Dutch fragment	Translation
<b>Quality of care</b>	
Maar wat heel erg irritant is dat, dat er gewoon onze wachtlijsten enorm gaan toenemen in de GGZ. Dus ook vooral, dat is echt heel erg vervelend..	<i>'But it is irritating that the waiting lists in secondary care are growing tremendously. That is really annoying.'</i>
Als ze er maar eenmaal binnen zijn. En de wachttijd tussen verwijzen en intake is, ja, onacceptabel lang. Ja 3 maanden soms. En vaak op het moment dat de ouders bij jou komen met, met een kind met gedragsproblemen dan is de nood heel hoog. Want die hebben daar heel lang mee, mee aangetoet en rondgetoet.	<i>'The waiting time between referral and intake is, yes, unacceptably long. Yes sometimes 3 months. And at the time that parents come with their child with behaviour problems, the situation is highly critical. Because it has been around for a while.'</i>
Nee, maar ze hebben ook wat meer afstand wat ze af moeten nemen om uiteindelijk daar te komen. Ja, nou kijk in het begin, voor een aantal bezoekers is dat geen probleem, voor veel mensen hoor. Als ze goed geholpen worden, maar je kunt je voorstellen als er een aantal jaren behandeling is dat ze dat dan prettig zou zijn als er een stabiele situatie als dat in de huisartsenpraktijk zou kunnen.	<i>'But they have to travel through more time to be able to finally reach the location. Yes, and well in the beginning, for some visitors, that isn't really a problem, for a lot of people though if they are treated well. But you can imagine that when the child has received treatment for several years, it would be more pleasant when a child is stabilised, that it can be treated in the general practice.'</i>
Wij zijn goed bereikbaar. We zijn telefonisch te bereiken tussen 8 en 17. En ze hebben de mogelijkheid, wanneer nodig, om op huisartsenbezoek te komen in 1 of 2 dagen.	<i>'Well, we are good accessible. We are available by telephone from 8 till 17. And they have the opportunity, when they need it, to visit the general practice within 1 or 2 days.'</i>
Er zijn soms teveel aanbieders of verschillende mensen betrokken bij het gezin waarbij het ene aanspreekpunt het overzicht dan niet meer heeft. Soms is het teveel. Maar ja dat zorgt soms voor onduidelijkheid.	<i>'There are sometimes too many providers or different people involved with the family, in which one of the contact points no longer has an complete overview. Sometimes, it is too much. But yes, this point sometimes reduces clarity.'</i>
Zijn ze goed ingesteld kunnen wij controles doen. Maar ze moeten dan wel weer heel makkelijk terug kunnen als ze het niet goed gaat vind ik. - En waarom kunnen ze niet terug dan? - Wachttijden.	<i>'We can do the check-ups when the children are stabilised. However, in my opinion, we need to be able to send them back easily to secondary care when it is not going well with the child. - And why can't you them back easily? - Waiting lists, scarcity in child psychiatrists'</i>
Ja, ja. Ja ik denk de follow- up die wij als Karakter bieden, die vind ik gewoon goed. Want wij hebben gewoon goeie behandelaars, hoog opgeleide mensen. Hebben wij in huis. Wij hebben zorglijnen, hé dus er zijn mensen in de zorg, ADHD die heel erg ja soort gesupergespecialiseerd zijn in ADHD. Maar die aan de andere kant geen oogkleppen op hebben. Dus ook zicht hebben op andere psychopathologie die je natuurlijk ook bij kinderen kan zijn. Hé en die follow-up zorg, ja die proberen wij gewoon zo slim en efficiënt en goedkoop mogelijk in te richten. Met een hoogopgeleide professional met goeie kennis	<i>'Yes In my opinion, the follow-up care which we provide as Karakter, is simply good. Because we have good practitioners, high educated people. We have integrated care pathways, so there are people in the health care, which are specialised in ADHD. But on the other hand do not take a blinded view. So they also have a view on the other psychopathology which children can have. And the follow-up care, we try to structure the care as smart and efficient as possible with a high educated professional with knowledge.'</i>
Nou wat ik daarin, in merk is dat de huisartsen niet altijd voldoende kennis hebben. Wat ik mij heel goed kan voorstellen want ze hebben natuurlijk maar vaak een paar patiënten met ADHD in hun praktijk.	<i>'Well, what I notice is that GPs not always have enough knowledge. Which I can imagine because they only have a few patients with ADHD in their practice. '</i>
Dus ik vraag mij af, de huisarts voldoende kennis heeft van de, van alle milieus	<i>'So I am wondering, whether the GP have sufficient knowledge, of all the environments.'</i>
En we merken eigenlijk dat het alleen maar als een kind net gediagnosticeerd is dat dan die follow-up nog wel een keer komt. Maar niet als het langer aan de orde is bij een kind.	<i>'We notice that the follow-up care is provided when a child is recently diagnosed with ADHD. However, after a while not anymore.'</i>
Of ja, ik hoef alleen maar een receptje in te leveren en het kind wordt niet eens gezien voor lengte, gewicht en bloeddruk meten. Dus, die ervaring heb ik ook nog wel. Dat ik dan denk van hé maar dat klopt niet?	<i>'Or yes, I only need to deliver a prescription and the child is not considered for length, weight and blood pressure. So, I have that experience. And then I am thinking, that is not right.'</i>

Hé want de huisartsen, voor al die het leuk vinden, die hier wat feeling mee hebben en die het ook durven, hé is echt verschillend per huisarts.	'Because the GPs, who especially like it, who have a feeling with it and dare to provide the care, it is really different per GP.'
Maar hé weetje, het lastige vind dat niet elke regio in Nederland op dezelfde manier is georganiseerd.	'But you know, I find it hard that not every region in Netherlands is organised in the same manner'.
Want ik merk zo enorm verschil tussen het team hier in Enschede en het team in Hengelo. Ik denk dan van dat kan toch eigenlijk niet. Dan word je eigenlijk benadeeld omdat ze in Hengelo wonen of zo.	'But what I notice is that there is a huge difference regarding the team here in Enschede and the team in Hengelo. And then I am thinking, that cannot be right. For people in Hengelo, it is a disadvantage.'
Dus het ging allemaal een beetje, een beetje raar vond ik. Ik vind niet dat je een kind zo kunt gaan diagnosticeren. Ik vind dat daar meer bij hoort, en meer. Ik had het idee dat het vrij makkelijk ging. Och wil je ADHD, alsjeblieft hier heb je ADHD.	'It went a bit weird I think. I do not believe that you can diagnose a child like that. I believe that more is needed. I had the feeling that it was being done too easily'.
En wat ik echt een enorm groot probleem vind is, maar goed, ik focus weer even op medicatie hoor. Dat niet alle medicatie vergoed wordt door de verzekeraar. En dat niet alle ouders, slash best wel heel veel ouders, het geld niet hebben om de medicatie zelf te betalen.	'And what I consider as a big problem, well okay, I am focusing again on medication. That not all medication is reimbursed by the health insurer. And that not all parents, slash a lot of parents, do not have the money to buy the medication by themselves.'
En wanneer je langwerkende preparaten voorschrijft, dat is vaak veel stabiel. Maar daarnaast ook duurder. Dat is jammer toch? Dat een verzekeraar niet even denkt om dat te gaan vergoeden.	'And when you provide long- action methylphenidate, than it is of course much more stable. But likewise very expensive. That is a shame right? That a health insurer does not think to just reimburse it.'
En er zijn natuurlijk op een gegeven moment ouders die zeggen van ja luister, ik wil niks met het sociale wijkteam te maken hebben. Het budget van de gemeente is op. Ik heb genoeg geld, ik ga naar een particuliere psycholoog. Want dat zie je ook gebeuren. Weet je dat, dat is natuurlijk heel fijn voor de ouders die het kunnen betalen voor hun kind. Maar er zijn genoeg ouders die niet kunnen betalen. En, dan krijg je dus wel 2 deling in de zorg.	'There are at certain moments parents who say; listen, I do not want anything to do with the social district teams. The budget of the municipalities is limited. I have enough money, I will go to a private psychologist. Because that is what you experience. And you know, that is of course very pleasant for those parents who can pay it for their child. However, there are enough parents who cannot effort that. And the result is a division in the health care. And that is something wat concerns me.'
Maar alles hangt natuurlijk af van een warme overdracht van de tweede- naar de eerste lijn. En daar schort het naar mijn inziens nog wel aan.	'But everything depends of a 'warm transmission' from secondary care to primary care. And that is what is lacking at the moment in my opinion.'
Dat die dus de medicatie nog wel eens wisselend nemen en soms nemen ze het alleen als ze naar school moeten en niet in de thuissituatie omdat het systeem dan zo druk kind, schijnbaar beter aan kan dan op school. Dus die medicatie speelt wel een hele grote rol, hé de medicatie trouw. Daar lopen wij wel eens tegenaan.	'So they take in the medication variously and sometimes they only take the medication when they go to school and not when they are at home because, apparently, the system of the child can handle it more than when a child is at school. So the medication does play a big role, the medication compliance. So we come across that from time to time.'
Ja, nou ik vind dat dat is niet doenlijk, als ik daar achteraan moet gaan bellen. Want je krijgt die leraren nooit te pakken.	'Yes, well in my opinion, that is not feasible if I have to call them. Because you never reach the schoolteachers.'
Ja. Of je belde de huisarts dan terug. Nou die zitten vervolgens ook weer in consult. Je krijgt	'Yes. Or you called the GP back. Well, then they are in a consult again. You can hardly consult each other and that is just unpractical.'
Maar wat gewoon wel mijn ervaring is door de jaren heen. Is als ik onderwijs van de huisartsen geef, die roepen ook altijd ja jullie zijn nooit bereikbaar in de GGZ	'But what my experience is through the years, is that when I offer education to GPs, they always tell me that we, as secondary care, are never accessible.'
Bijvoorbeeld dat op school kunnen ze de zorg echt neerleggen. Van of, helemaal meegaan in wat de leerklacht dan zegt. Terwijl ze dan bij de huisarts bijvoorbeeld kunnen afzwakken. En dan wordt er een ander verhaal aan de huisarts verteld waardoor die een andere conclusie kan trekken.	'For instance at school, they can lay down the care. Of or, go along in which the schoolteacher says. While they can moderate a bit at the GP. And in that case, another story is told to the GP whereby another conclusion will be made.'
Ja ik vind het wel, wel jammer want juist die korte lijnen zijn heel erg belangrijk want je gaat het kind niet zomaar bijvoorbeeld medicatie geven. Je wilt ook het effect van de psycho-educatie meten.	'Yes I find that regrettable, because especially those short lines are very important because you just do not easily provide medication. You also want to measure the effects of the psycho – education.'

Dat heeft denk ik te maken omdat die, die GGZ instellingen ook op scholen komen en kijken. Bijvoorbeeld Karakter, of Mediant ja, die hebben allemaal van die trajecten waardoor ze ook op school komen om begeleiding te bieden dus ook wel kunnen zien of een school kan signaleren of dingen. Op orde heeft en een huisarts is toch wel wat meer qua afstand dat het wat lastig is denk ik.	<i>'That is due the fact that GGZ-institutions visit the school and take a look at the schools. For instance Karakter, or Mediant, yes, they all have some processes whereby they visit the school to provide some guidance and at that moment, they can see that school can also detect or whether school has things in place and a GP is yet at a more distance so that makes it difficult I guess.'</i>
Wat ik tegenwoordig goed vind sinds die transitie that veel sociale wijkteams, sociale wijkteams werken kort samen met scholen. Basisscholen en middelbare scholen.	<i>'What I consider as good nowadays is that in the transition, a lot of district teams, social district teams cooperate closely with the schools. Primary schools and secondary schools.'</i>
Ik probeer juist wel juist met het kind in contact te komen. Het is een beetje afhankelijk van leeftijd natuurlijk. Maar zeker als ze er zelf wat over kunnen zeggen dan, ik probeer wel te vragen hoe, hoe het kind ervaart dat het. Dat het gaat, en, en dan kijk ik wel met ouders of dat klopt wat de ouders zien. Maar sommige kinderen kunnen heel goed aangeven van ja, ik ben nu veel rustiger in mijn hoofd. Dat is heel grappig, maar dat kunnen ze wel goed aangeven.	<i>'I try to come in contact with the child, depending on the age of course. But certainly, when the child is able to say something about it, I'm trying to ask what the experiences are of the child. Later on, I check the given information with the parents of the child. But some children can indicate very well like 'I'm a much calmer person'. That is really funny, but they can indicate it well.'</i>
En, ik vind ook dat in de richtlijnen ook mag staan dat bijvoorbeeld de GGZ laagdrempelig beschikbaar is voor de huisartsen, kinderartsen, jeugdartsen, sociale wijkteam om even mee te denken.	<i>'And I believe that for instance the fact that the GGZ is accessible for GPs, paediatricians, doctors working in youth health care and social district teams to share thoughts can be added in the clinical guidelines.'</i>
En dat huisartsen ook wel luisteren hé, als ouders zeggen joh ik wil perse daar of daar heen. Dat dat ook wel gebeurt. Ja. Dat is wat ik hoor hé.	<i>'And that GPs also listen right, if parents say I want to be treated over there or there. That that also happens. Yes, that is what I hear.'</i>

### Recommendations

maar dan zouden er afspraken gemaakt moeten worden, in dit geval met de gemeente om die financiering van die zorg in de huisartsenpraktijk en daar loopt het op vast want die is er nog steeds niet.	<i>'But appointments should be made, in this case with the municipalities, to ensure the financials of that care in the general practice. However, it gets jammed on that aspect nowadays because that is not there yet.'</i>
Hé want wat je ziet, soms even een half uur even met een huisarts aan de telefoon, prima het is ontzettend fijn, het is hartstikke leuk juist. Omdat met elkaar even af te stemmen. Om de kennis te kunnen delen. Maar dan denk ik ja, het moet wel betaald worden. Dus ik vind ook dat daar vanuit de gemeente budgetten moeten hebben. Voor even die consultatie vraag.	<i>'Because what you notice, half an hour with a GP on the phone, all right that is totally fine. It is actually great. To adjust some information. To share some knowledge. Yes that is really nice, I always love to do it. But then I am thinking, it needs to be paid. So I have the opinion that budgets are needed from the municipalities, for those consultations.'</i>
Dan zou het wel fijn zijn als we gewoon een heldere brief kregen, waar, waarin een samenvatting staat wat er allemaal gedaan is. Waarin een medicatie voorstel staat, waarop op een kind stabiel ingesteld is.	<i>'Than it would be pleasant that we receive a clear letter, where, wherein a summary is stated of what is done. Wherein a proposal of the medication is indicated wherein the child is marked as stable.'</i>
Maar misschien dat zij nog iets zouden kunnen met een telefonisch spreekuur. Maar een telefonisch spreekuur waarbij bijvoorbeeld de school met toestemming van ouders natuurlijk. Dat we ze kunnen bellen om even af te stemmen. Hoe vinden we dat het gaat. We lopen hier tegenaan, denk eens even met ons mee. Hoeft niet perse hier te komen.	<i>'Maybe they need to do something with a telephonic consultation. Wherein for instance the school, by courtesy of the parents of course, that we can call them to adjust some information. How we think it is going, problems we encounter, think with us. They do not have to visit our place, but just that we can negotiate.'</i>
Nou meer, ik denk dat je, dat je, dat scholen handvatten moeten krijgen om hun kind te begeleiden. Want het grootste deel van de dag is het op school. En ik denk dat het heel goed is dat, dat er ook wordt gedacht van hoe kunnen wij dit op school aanpassen.	<i>'Well more, I believe that they, that schools need to receive some guidance to guide the children. Because the children are at school most of the day. And I believe that it is good, that it is thought through how we can adjust things on school.'</i>
Met de juiste training, want dat is, in dat geval moet de kennis opgekrikt worden. Dus scholing over, over de medicatie zelf en waar je op moet letten.	<i>'With the right training, because that is, than the knowledge needs to be jacked up. So training about, about the medication itself but also where you need to pay attention to.'</i>
Want dan zou ik eigenlijk de JGZ-richtlijn, want dan heb je het ook over, nou ja het aanpassen van de dosering en dergelijke.	<i>'Because in that case the JGZ-directive, because than you talk about, well yes the adjustment of the medication and so on. Then, it has to be absorbed in the JGZ-directive.'</i>

Met, met, wij hebben dan visie dan is de beveiligde skype of facetime mogelijkheid. Dus dat, collega van mij met wie ik een beetje ontwikkelen ben ook. In Zwolle, is dat de ouders gewoon thuis met het kind. Of dat het kind op school bijvoorbeeld en dat je dan met facetime een beetje contacten legt en dan kan je natuurlijk je gesprek met de ouders en met het kind ook. Maar dan moet je wel natuurlijk en je bloeddruk en je lengte en gewicht. Maar dan zou je dat eigenlijk bij de huisarts verder doen ofzo. Of dat de jeugdarts, dat kan natuurlijk ook. Dus daar kun je natuurlijk best wel weer dingen verder in ontwikkelen.	<i>'In that case Skype or Facetime would be a possibility. The parents are just staying at home with the child or for instance at school and through Facetime, contact can be established. But you still need to measure the blood pressure, length and weight. But that can be established at for instance the general practice. Or the doctor of youth health care of course. Those things could be developed.'</i>
ik kan zorgen dat iets meer assistentes in kunnen zetten die een aantal van die controles, die moeten dan ook opgeleid worden.	<i>'I can ensure that more assistants are being deployed who could provide some controls at the child. However, they need to be educated.'</i>
En voor de follow-up care denk ik vooral dat het heel goed is om, ja ik weet niet of de afspraken of er een, een, een, een wet is of iets wat, wat, aangeeft of dat het heel vrij is hoe je de follow-up care inzet. Ik denk dat het goed is dat, dat, dat er dezelfde dingen worden gedaan. Want ik merk zo enorm verschil tussen het team hier in Enschede en het team in Hengelo.	<i>'And for the follow-up care, I do believe that it good that the same things are being done. Because I experience a huge difference in the district team here in Enschede and the district team in Hengelo.'</i>
Maar die hebben gewoon hele korte lijnen met het kind zelf. Die zien het kind elke dag. Dus ik denk wel dat dat ook daarin iets moet komen van nou wat is dan het stukje zorg wat de school kan leveren.	<i>'But they simply just have short lines with the child itself, they see the children every day. So I believe that something is needed, like what is the part of the care which they can deliver.'</i>
En ik denk dat de jeugdartsen best een grotere rol, een grotere rol kunnen spelen ook in de follow-up van de kinderen met ADHD. En ook met autisme of met depressie.	<i>'And I do believe that doctors working in youth health care could have a bigger role within the follow-up care for children with ADHD. Likewise with autism or with a depression. Because they are more educated than people working in a social district team.'</i>
Ik vind wel dat je, dat je dat als arts moet doen en dat je dat dus niet door een POH of door een doktersassistente moet laten doen. Ja die kan de medicatie niet voorschrijven. Die kan ook niet zeggen van goh neem maar een pilletje meer of een pilletje minder. En een POH-GGZ daar, die neemt ongeveer een half uur en soms een uur. Daar waar ik denk, ik ben met 10 minuten klaar waar moet je het verder nog over hebben.	<i>'I do believe that the follow-up care has to be provided by a doctor and not by a POH-GGZ. They cannot prescribe medication. They cannot say like 'take a pill more or less'. And a POH-GGZ takes more than half an hour and sometimes an hour in which I think, I am done within 10 minutes.'</i>
Dus, je zou je kunnen voorstellen dat één van ons dat op zich neemt om daar wat meer kennis over op te doen. Zo'n taakverdeling hebben we hier ook al.	<i>'You can imagine that one of us takes the responsibility and acquires the required knowledge. We have already such a task division.'</i>