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## Diagnostic testing in pediatrics: yield and drivers

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# Chapter 6

## **Pediatricians report an increased demand for medical tests for reassurance**

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## Abstract

**Introduction:** Diagnostic decisions depend on the context in which health care is delivered. We interviewed pediatricians about perceived societal developments and their influence on diagnostic testing.

**Methods:** Semi-structured in-depth interviews with 20 practicing Dutch pediatricians.

**Results:** Pediatricians associated societal developments, such as decreased risk acceptance, with perceived pressure from parents to perform tests. They were motivated to restrict unnecessary tests to avoid harming the child.

**Discussion:** Besides motivation and effort of health care providers, appropriate testing requires system-level actions, such as counteracting a culture of blame and considering societal interests in guideline recommendations.

## Introduction

Medical testing has been rising for years.<sup>1-3</sup> In many instances it is unclear whether this rise leads to better outcomes. To maintain high-quality and accessible care in the Netherlands, efforts are focused on delivering appropriate care.<sup>1,4,5</sup> The boundary between appropriate and inappropriate care requires a value judgement on what constitutes sufficient value to qualify as appropriate care. Evaluating the yield of medical testing is complex. After all, a positive impact of additional information on patient outcomes often occurs indirectly, for example through treatment decisions or lifestyle modifications.<sup>6</sup> The value attributed to care varies depending on the perspective: that of the physician, the patient, or society.<sup>7</sup> The added value of information from testing on well-being may be highly dependent on patient preferences. Patients may value tests and find them appropriate, even if the likelihood of obtaining clinically relevant findings is extremely low, as is the case in tests carried out with the goal to reassure patients.

Other factors also influence decisions about test ordering. Research in adult medicine suggests that characteristics of the physician, patient, as well as the local context (e.g. professional norms) and the broader context (e.g. judicial context) play a role in diagnostic decision making.<sup>8,9</sup> A deeper understanding of decision-making about test ordering in pediatrics has been lacking, though the trade-offs might be different. The decision-making process requires additional transparency, as two decision makers – the physician and the parents – have to decide together on behalf of and for a third party: the (young) child.

We conducted a qualitative interview study to identify considerations of pediatricians' in test ordering behaviour and the factors that influence these considerations. Pediatricians perceived themselves as more deliberate and restrictive in ordering tests, compared to their colleagues in adult medicine, because of the higher burden of testing for children. From this critical stance, they also put more weight on the disadvantages of false-positive findings, diagnostic cascades, and unnecessary costs. They experienced pressure from parents and from guidelines to perform unnecessary tests but were impelled to resist this pressure. Nevertheless, they sometimes requested tests that they felt were unnecessary, to reassure parents – and sometimes themselves – or to comply with guidelines, to avoid negative consequences.<sup>10</sup>

Within the qualitative study we also explored changes that pediatricians observed over the past 5–10 years in terms of medical tests and test ordering behavior. We also asked them about societal developments they associated with these changes.

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<sup>1</sup> Appropriate care is effective care against reasonable cost. It is aligned with patient preferences and requires shared decision making. Care is preferably delivered close to home and organized efficiently. Appropriate care does not only revolve around disease but also around health and self-sufficiency.

## Methods

This is a qualitative sub-analysis of in-depth interviews among 20 pediatricians practicing in the Netherlands regarding their considerations around test decisions. The pediatricians were either general pediatricians or pediatric subspecialists. Participants were recruited from FR's network through a snowballing method: contacted pediatricians were asked to suggest colleagues that differed in characteristics such as age and subspecialty and in opinion. We selected 37 candidates out of 54 suggestions, of which 32 agreed to participate. Participants were included to maximize variation until saturation was reached, after 20 interviews in total. Interviews were conducted between May and August 2020. Transcriptions were independently coded by 2 researchers (FR and SR) and discussed afterwards. **Figure 1** shows the abbreviated interview protocol. Methods are described in detail elsewhere.<sup>10</sup>

Item	Questions
<b>1. Practice situations</b>	
Example 1 and 2 Reflection on an example from the pediatrician's practice in which the pediatrician was in doubt about whether or not to order testing	<ul style="list-style-type: none"> <li>– Can you describe the clinical situation?</li> <li>– What made you hesitate?</li> <li>– What considerations played a role?</li> <li>– What other factors came into play?</li> <li>– How did you weigh these elements against each other?</li> </ul>
Example 3 Reflection on an example from the pediatrician's practice in which parents judge the clinical situation differently compared to the pediatrician	<i>Same questions as above</i>
Example 4 Reflection on an example of a situation in which the pediatrician made a diagnosis later than possible ("missed diagnosis")	<ul style="list-style-type: none"> <li>– Do you recall such a situation? Can you describe the situation?</li> <li>– How did you feel about the situation? How did those involved react? Colleagues?</li> <li>– Were you worried about complaints or negative reviews? Have you ever received a complaint?</li> <li>– How did this event affect your medical actions afterwards?</li> </ul>
<b>2. Trade-offs</b>	
Trade-offs If insufficiently explored earlier in the interview	<ul style="list-style-type: none"> <li>– How do you weigh the arguments for and against diagnostics?</li> </ul>
<b>3. Reflections and trends</b>	
	If you compare the reasons why you order tests now with those 5–10 years ago, have things changed? Both for you and in general?
	Do you feel that the patient population has changed over time?
	Has risk acceptance changed? If yes, what changes do you notice? Why is that?

Item	Questions
	<p>To what extent and in what ways have patient/parent wishes and expectations changed?</p> <p>How do these developments affect your test ordering behavior?</p>

**Figure 1. Summarized interview guide\***

\* The results of part 1 and 2 have been previously published.<sup>10</sup> The current article describes the findings of part 3 ('Reflections and trends').

## Results

Pediatricians described an increase in testing options, compared with 5–10 years ago, but also indicated that more emphasis is put on the careful weighing of test benefit and the associated burden and cost (Table 1, Q1).

Physicians mentioned several developments affecting their diagnostic decisions, partly spontaneously and partly on specific inquiry. These included growing medicalization (Q2), decreased risk acceptance (Q3) and decreased willingness to wait and see among parents and patients (Q4). Pediatricians reported that, as a result, parents request testing more frequently and earlier, also in clinical situations in which pediatricians estimate the probability of a medical condition as very low (Q5). As a result, pediatricians experience pressure to request tests purely for reassurance, though they themselves consider the test unnecessary or harmful (Q5). This leads to tension between acting according to their professional values (Q4) on the one hand and, on the other hand, wanting to avoid conflicts with parents (Q6), persisting parental anxiety (Q6) or complaints (Q7).

Pediatricians reported various strategies to protect the child from unnecessary testing. These included good explanations and expectation management (Q8), professional skills such as exploring underlying concerns (Q9), work experience (Q8), consultation with colleagues, and improving guidelines (Q10).

**Table 1. Quotes**

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- Q1 “Science has become more critical towards doing unnecessary things, such as unnecessary treatments or outpatients visits. Appropriate care has been a trend for years. And I do think that as a pediatrician, you are even more selective in what you do and don’t do compared to physicians in adult medicine. Because an intervention can easily be uncomfortable for a child, has to be performed under anesthesia etcetera. So you think twice instead of just saying: ‘please lie down, draw blood, all done.’” (56 years, pediatric subspecialist)
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- Q2 “I do have a bit of a problem with the general phenomenon in the Netherlands that more and more parents think their child has all kind of conditions. That parents accept less that their 4 or 5 year old children can’t walk very long distances. I think to myself: is that a medical condition or perfectly normal? The question is of course whether we encourage this by medicalizing everything.” (48 years, pediatric subspecialist).
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- Q3 “I feel that in general both doctors and patients’ risk acceptance is decreasing. Especially the desire of being in control is increasing in society.” (48 years, general pediatrician)
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- Q4 “In our society, you can arrange many things: everything can be ordered, day and night, everything can be fixed. And this is also how people regard healthcare and their health, and it does not work that way. I have existential discussions with people, that feel like some kind of re-education, which is very complicated.” (36 years, general pediatrician)
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- Q5 “Sometimes it doesn’t matter which lab tests I perform exactly, as long as I draw blood. [...] Because parents still have a kind of magical feeling about testing. [...] So in those children with abdominal pain where you feel that something needs to be done, I still sometimes perform an abdominal X-ray. Parents then say, ‘Well, that’s great, so happy that everything is fine!’ While I think, ‘But what is there to be seen on that X ray? Not much, of course. I think that many people are referred who think: ‘Without testing it can’t be good? Surely my child has something, you have to investigate that!’ I haven’t often hear someone say, ‘I think you do so much diagnostic testing doctor, we should stop doing that.’” (57 years, general pediatrician)
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- Q6 “[I explain to parents] that I would request an MRI right away if I would be worried about a child. But if I think it’s unnecessary, I would not. Sometimes if it’s so important to parents and they insist, then we’ll do an MRI anyway. I don’t expect it to reveal anything abnormal, but it will confirm that everything is alright, and after that we can continue to work towards other ways of dealing with the complaint. Sometimes you have to take your loss. And it won’t bring much to get into a conflict. That’s my consideration in these situations.” (42 years, pediatric subspecialist)
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- Q7 “I think people dare to take fewer risks. We are afraid of complaints, patients have become more empowered. People accept less that we don’t know things, doctors accept less that we don’t know things. So I do think that has changed yes. I think we’re doing more tests because of that.” (42 years, pediatric subspecialist)
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- Q8 People see the pediatrician and just want certainty. That’s an idealistic expectation, and I always discuss very early on what they can expect from me. As I have become more experienced, I have learnt that that’s very important. Parents come to you and want all kinds of things ruled out. [...] So I explain [the limited yield of testing] and really try to manage expectations. Parents very often come to me with wrong expectations and one of the first things I put straight is: this is what I can do for you, and this is the uncertainty that everyone has which is part of life and you have to learn to deal with it.” (36 years, general pediatrician)
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- Q 9 “[If you do test just to screen...] you get all kinds of chance findings that you would rather not know, where the child has to undergo more tests, because we see a strange spot there, and so on. Our profession is all about looking for associations and picking up signals and calculating probabilities. So we cannot exempt ourselves from clinical reasoning. I also don’t believe in all those clinics that sell MRIs, where you can just go and get diagnostic tests. [...] I think you have to stay focused and think about what you’re doing, why you’re doing it.” (36 years, general pediatrician)
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- Q 10 “So [guidelines] on the one hand are a very great thing, their presence has saved a lot of children’s lives. But it has also, in my opinion, led to an awful lot of unnecessary [diagnostic] testing. And of course, in one out of a hundred children we will end up finding that gene or that disease, and we would have missed that otherwise. And that, of course, is what we mean by efficiency. Because how many children can we miss before we call something efficient? And we don’t ask ourselves that question often enough. think we ask ourselves far too little.” (62 years, pediatric subspecialist)
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## Discussion

Pediatricians in our study reported an increase in testing options and clarified their critical attitude towards testing, to protect children from unnecessary harm. They associated societal developments, such as a decreased willingness to accept risks or to wait and see, with perceived pressure from parents to perform tests they themselves considered unnecessary.

### Tests are appreciated

The societal developments pediatricians associated with an increasing demand for testing overlap with previously described factors, such as high societal confidence in the benefit of (early) testing<sup>11,12</sup> and an increased desire for self-direction in healthcare consumers.<sup>13</sup> The growing demand for testing may also arise from other, underlying needs of patients’ or parents, such as better explanations or more guidance from the healthcare provider. Previous studies described that patients have multiple underlying questions and needs<sup>14</sup> and that misunderstandings between health care providers and patients can develop from these diverging motives. Tests that are performed to meet a misinterpreted demand are likely inefficient, because the underlying question is not addressed.<sup>15</sup> It is therefore crucial for appropriate care to explore underlying questions and expectations.

Like patients, physicians appreciate medical testing and underestimate the disadvantages.<sup>12,16</sup> Forgoing testing can on the other hand lead to (fear of) negative consequences. These include patient harms through delayed diagnosis, dissatisfaction if demands are not met, reputation damage, fear of formal complaints or disciplinary law suits, or financial losses.<sup>17-19</sup> To what extent negative consequences are feared and will also depend on societal and system factors, such as judicial system and societal perceptions regarding testing.

### What physicians can do for appropriate care

Appropriate care requires a trade-off between efficiency and thoroughness.<sup>20</sup> Delivering appropriate care means that physicians sometimes will refrain from testing, because they acknowledge limits of available knowledge for prognosis or treatment. This could also happen when they accept the probability of missing a diagnosis and are motivated to resist requests for inefficient testing. Pediatricians describe that their motivation to do so is based on an understanding that the party who requests inefficient testing – the parents – differs from the person that has to undergo testing: the child. Pediatricians typically want to protect the child from unnecessary burden. They describe various strategies to deliver appropriate testing: exploring the parent/patient's underlying question or concern, diligent history taking and physical examination, clinical reasoning, explaining their thinking to parents, providing boundaries, investing in good patient-physician relationship, and safety-netting.<sup>10</sup> These strategies have been described in studies in adult medicine.<sup>21-23</sup>

### System approach also needed to achieve appropriate testing

Individual professionals can contribute to appropriate care. Yet to reduce the negative personal consequences for physicians their have to be choices and adjustments at various levels of the healthcare system.<sup>24</sup> Continuity of care, adequate exchange of information between professionals<sup>25</sup>, and medical leadership may help to make proportional decisions about testing, rather than choosing the most defensive strategy.

To genuinely make a difference we have to move away from blame culture, which is ingrained in institutional quality systems but does not align with newer insights of quality improvement. These new views advocate learning from all outcomes, including from (exceptionally) good outcomes.<sup>26</sup> Physicians operate in a system of scarcity and are expected to weigh the interests of other patients as well. Their actions should thus be viewed in this context. Difficult but necessary, secondly, is adjusting the payment structure to reduce incentives to produce more care.

We also need further discussion and eventually consensus on the threshold between efficient and inefficient – and thus inappropriate – testing. Tests are currently ordered because of presumed effects on non-medical outcomes, such as well-being through reassurance.<sup>6</sup> One may question to what extent such individual benefits outweigh individual disadvantages, such as burden and harmful consequences of false positives.<sup>27</sup> How do societal negative consequences in terms of environmental burden and costs weigh in? These can lead to a loss of health, through direct harm and through diversion of resources from other public sectors that are important for population health, such as social services.<sup>28</sup> Limits must be placed on testing for reassurance in low-risk situations for the sake of efficiency, if societal resources are allocated to foster public health. To properly weigh the interests of all citizens, now and in the future, it is helpful to estimate the financial, human and environmental burden of testing and to weigh net benefit against the health effects that could be achieved with alternative investments.<sup>29,30</sup> Including societal interests will help in delineating appropriate from inappropriate testing. Such weighing can more often than is currently the case lead to an informed negative recommendation of tests in guidelines, insurance coverage decisions, and population screening.

Guidelines committees are now mainly staffed by medical specialists who look at the effects of care in their silo. Official bodies, such as the Zorginstituut, could represent society's interests in guideline committees, to achieve appropriate care. Improving guideline methodology for recommendations about testing could also help to identify inefficient testing, by evaluating more explicitly the positive and negative effects of testing on medical outcomes.

Negative recommendations about screening or other forms of testing provide an excellent opportunity to publicly explain negative effects of testing. These can serve as a strong argument against the mantra that more and earlier testing is always beneficial. Without active measures the many drivers of testing will continue to increase the amount of testing, without proven added value.

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