Signals in the hospital Emergency Room linking objective signs to child abuse knowledge
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Chapter 10

Summary, conclusions and future perspectives
**Abbreviations**

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Description</th>
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<tbody>
<tr>
<td>CACRC</td>
<td>Child Abuse Counseling and Reporting Centre (in Dutch AMK, since 2016 &quot;Safe Home&quot;)</td>
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<tr>
<td>CAN</td>
<td>Child Abuse and Neglect</td>
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<tr>
<td>CPS</td>
<td>Child Protection Services (in Dutch: Raad voor de Kinderbescherming)</td>
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<tr>
<td>ED</td>
<td>Emergency Department</td>
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<tr>
<td>TTI</td>
<td>‘top–toe’ inspection</td>
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Summary, conclusions and future perspectives

Introduction
In this thesis we bring together our studies on screening for and addressing of child abuse and neglect (CAN) in the Academic Medical Center (AMC) in Amsterdam. These studies concern the approach in our academic hospital in general and in particular the approach at the Emergency Department (ED). We describe the results of a new screening method for child abuse at this department, combining a well-known checklist for CAN, the so-called SPUTOVAMO checklist, with an inspection of the fully undressed child, the so-called 'top-toe' inspection (TTI).

Chapter 1
In Chapter 1 we give a general introduction. We discuss the definitions of CAN, the different forms of CAN that can be distinguished, how often CAN is recognized (the prevalence), risk factors and protective factors for CAN, the importance of early recognition, the consequences of CAN, the use of screening instruments at EDs and the screening method used at the ED of the AMC.

CAN is defined by the World Health Organization (WHO) as: ‘All forms of physical and emotional ill-treatment, sexual abuse, neglect, and exploitation that results in actual or potential harm to the child’s health, development or dignity in the context of a relationship of responsibility, trust or power’.\(^1\) In Western societies exposure to intimate partner violence (IPV) is also increasingly recognized as a form of CAN.\(^3\) In the Netherlands, in the Youth Act, CAN is defined as ‘Every form of threatening or violent behaviour towards minors of physical, psychological or sexual nature. This behaviour is forced on minors actively or passively by parents or other persons towards whom minors feel dependent and lack freedom, and (threatens to) cause serious harm in the form of physical or psychological damage’.\(^4\)

Different subtypes of CAN can be distinguished. The World report on violence and health\(^5\) and the 1999 WHO Consultation on Child Abuse Prevention\(^2\) distinguish four types of CAN: physical abuse (PA); child sexual abuse (CSA); emotional and psychological abuse (EA); and neglect. Different and more extensive divisions into subtypes are used in literature (for instance in physical abuse, physical neglect (PN), emotional neglect (EA), emotional (or psychological) abuse, exposure to intimate partner violence (IPV) of parents, paediatric condition falsification (PCF, also called fabricated or induced illness in children (FII), or medical child abuse), exploitation, prenatal abuse and child sexual abuse. Children who are exposed to one type of maltreatment are often exposed to other types on several occasions or continuously.\(^3\)

CAN has a high prevalence and is a major problem in all parts of the world. Current estimates vary depending on the country, the definition of CAN used in the study, the type of CAN studied, the coverage and quality of official statistics and the coverage and
quality of surveys that request self-reports from victims, parents or caregivers.\textsuperscript{3,3} The overall prevalence of CAN in the Netherlands in 2010 was estimated 3.38\% based on agency reports (Child Abuse Counselling and Reporting Centre (CACRC), in Dutch Veilig Thuis (VT), before 2016 called Advies- en Meldpunt Kindermishandeling (AMK)) and sentinel reports (more than 1,000 professionals).\textsuperscript{6,7} A self-study study among secondary school students (using the same strict definition) indicates that the prevalence in 2010 was actually much higher (9.94\%).\textsuperscript{6,7} CAN is often being missed by professionals.

Although CAN is not confined to a certain culture or social class, in the presence of so called risk factors, the risk for CAN increases. The major risk factors reported in the second Dutch prevalence study on CAN (NPM-2010) are parental low education, immigrant status, unemployment and single parenthood.\textsuperscript{6,7} Numerous child factors are associated with CAN, e.g., CAN is about three times as frequent in children with disabilities as in their non-disabled peers.\textsuperscript{8} Girls have a higher risk of being sexually abused.\textsuperscript{3} There also is scientific evidence that a supportive family environment and social networks act as a protective factor for CAN.\textsuperscript{9} The following factors are potential protective: nurturing parenting skills; stable family relationships; household rules and child monitoring; parental employment; adequate housing; access to health care and social services; caring adults outside the family who can serve as role models or mentors; communities that support parents and take responsibility for preventing abuse.

Children who have been maltreated are at increased risk of further maltreatment. Identification of (relatively mild) injuries or other signs of CAN is the cornerstone of early detection of a child at risk for further abuse.\textsuperscript{10} Early identification of abusive injuries is imperative because of the risk of increased mortality with each recurrent abusive event. CAN can be identified in at least 9.4\% of the contact children in the household of the abused patient.\textsuperscript{11}

The consequences of CAN can be profound and may endure long after the CAN occurred. The effects can appear in childhood, or adulthood, and may affect various aspects of an individual’s development (e.g. physical, cognitive, psychological, and behavioural). These effects range in consequence from minor physical injuries, low self-esteem, attention disorders, and poor relations to severe brain damage, extremely violent behaviour and death.

Amongst others, the ACE study (Adverse Childhood Experiences) showed that adults with traumatic experiences in childhood are more likely to have chronic physical conditions like diabetes mellitus, asthma, cancer and vascular diseases (ischaemic heart disease) and suffer more frequent from psychosomatic complaints like belly ache and headache.\textsuperscript{12,13} Higher rates of general admissions and admissions for injuries, infections, mental and behavioural disorders, and external causes of morbidity, were associated with a markedly increased risk of CAN allegations and substantiation. This shows that the hospital can play an important role in the identification of CAN, referral and prevention of re-abuse.\textsuperscript{14}
Early detection rates of CAN at EDs differ between different countries and studies from 0.03% to 10%, likely due to different populations studied, different definitions used and different practice including the use of screening tests.\textsuperscript{15-24} The importance of early identification and protective intervention on behalf of abused children cannot be overestimated. Many EDs have started to use screening instruments for CAN.\textsuperscript{21,25-28}

### Table 1. Dutch SPUTOVAMO checklist

The 9 questions on the Dutch SPUTOVAMO checklist\textsuperscript{a} \textsuperscript{21}

<table>
<thead>
<tr>
<th>Question</th>
<th>Yes</th>
<th>No</th>
<th>Doubtful*</th>
</tr>
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<tbody>
<tr>
<td>Which type of injury? (contusion, stab wound, burn, cut et cetera)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Which place? (construct drawing)</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>What are the external characteristics of the injury? (color, form, border, etcetera)</td>
<td></td>
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<tr>
<td>When did the accident happen? How much time ago?</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>What was the cause of the accident? What explanation is given?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Who caused the accident?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Were witnesses present? Who?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>What measures were taken by parents, caregivers or others?</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Which old injuries can be seen? Did somebody perform an inspection for old injuries?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Were old injuries found?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Do you have a suspicion of child maltreatment?</td>
<td></td>
<td></td>
<td></td>
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</table>

\textsuperscript{a}Translation of the Dutch SPUTOVAMO checklist for child maltreatment at the ED. SPUTOVAMO is an acronym in which each letter represents one question on the form. 
\textsuperscript{*} Direct referral for further assessment by specialized pediatrician
Because of the importance of early detection of CAN, in 2000 the ED of the AMC in Amsterdam implemented a Dutch checklist, the SPUTOVAMO checklist (from here on referred to as SPUTOVAMO, see table 1), with 9 risk factors in order to detect CAN. Although SPUTOVAMO to date has not been formally validated its nationwide implementation, or variations on SPUTOVAMO, has been made mandatory in 2009 by the Dutch Health Care Inspectorate.30,31

During the time period in which this thesis was written two other Dutch accuracy studies at EDs by Louwers and Sittig took place.23,32,33 Louwers estimated the accuracy of a 6 item screening instrument, named Escape, for detecting potential CAN in children 0-18 years old visiting 3 Dutch EDs. PPV was 0.10 and NPV 0.88. The authors state that the Escape instrument is a useful tool for ED staff to support the identification of those at high risk for child abuse. The instrument does compromise a full physical examination, it is unclear in how many instances this complete examination was actually performed.

Sittig estimated the accuracy of the SPUTOVAMO-R questionnaire, also a 6 item screening instrument compromising a full physical inspection in children aged 0-7 visiting the EDs of several Dutch hospitals for the detection PA.33 Only 3 cases of PA were found (a 0.07% prevalence), the estimated PPV for injuries due to abuse was only 0.03 and PPV for injuries due to neglect was 0.05 with a NPV of 1.0.34 The authors conclude that the use of SPUTOVAMO-R ensures detection of PA, although false positive rates are high. Implementation of a screening tool can be difficult, given the barriers in ED personnel to screen for CAN like lack of means or time, high turnover of staff, lack of knowledge of CAN, lack of knowledge of communication with parents in case of suspected CAN.35 It is known that unsuccessful implementation can lead to association of screening with the family’s socioeconomic status.36 Race and ethnicity could also have an effect on willingness to screen.37

Barriers to recognising and reporting of CAN at the ED do exist, like providers’ desire to believe the caregiver, failure to recognize that a child’s presentation could be due to CAN, challenges innate to working in an ED such as lack of ongoing contact with a family and provider biases.38 Barriers to reporting CAN include familiarity with the family, factors associated with the reporting process, lack of follow-up of reported cases, and negative consequences of reporting such as testifying in court.38,39 Reported facilitators included real-time case discussion with peers or supervisors and the belief that it is better for the patient to report in the setting of suspicion.38

Chapter 2
In Chapter 2 we provide the reader with an overview of current screening methods for CAN at the ED and illustrate three policies with cases.40 Screening methods for the detection of CAN can be divided into six categories:
Checklists with risk factors
Throughout the world, EDs use checklists with risk factors for CAN.\textsuperscript{21,25-29} In the Netherlands, many EDs use SPUTOVAMO (Table 1), or a variant of this list, based on personal/local experience or literature on risk factors for CAN. Sensitivity, specificity and predictive values of the SPUTOVAMO list are unknown.

Routine review of all ER records by a trained professional
A systematic review of Woodman et al. showed weak evidence that a community liaison nurse (CLN) improved the performance of the screening assessment in the ER by thorough review of all ED records of children.\textsuperscript{27}

Referring all children known to have had previous contact with social services, mental health services or child protection services
Woodman et al. state in their review on screening methods that this is the most effective protocol.\textsuperscript{27} Sensitivity and specificity of assessing Child Protection Register (CPR) status related to ER presentation is unknown, neither is the positive or negative predictive value. False negative results because the child has no CPR record while the injury is a result from non-accidental trauma are well recognized.\textsuperscript{41} An increasing number of countries, including the UK and the Netherlands, are developing parallel data systems operating as a bridge between key professionals and agencies that offer assessments and services to children\textsuperscript{42}. This should make it easier to determine whether a child had previous contact with social services or child protection services (CPS). To date, strict European laws on privacy protection prohibit large-scale implementation of these parallel data systems. Another barrier is the time consuming aspect of this method.\textsuperscript{43}

Performing a complete physical inspection of every child presenting at the ER
Before the start of our study only one study on the performance of a checklist combined with a physical inspection of the undressed child had been published.\textsuperscript{15} This study, conducted in 1976, dealt with children less than 6 years of age seen with an injury or poisoning in the Montreal Children’s Hospital ED. This ED, at the time of the study, dealt with 6,000 injured children under the age of 6 annually. The clinical assessment comprised full physical examination by specially trained nurses who examined undressed children for bruises, burns and cuts. They also completed a ten-point checklist and discussed their findings with the attending physician. Additional assessment was performed if necessary. Children with suspected abuse were referred to the hospital child protection team (test positive). To ascertain false negatives (abused children not referred), all ED records were reviewed by the investigators and every suspicious case was interviewed by a public health nurse at a special home or hospital visit and, if concerns persisted, referred to the child protection team. The reference standard was confirmation or exclusion of abuse by the child protection team or non-referral to the team. This combined approach of a checklist with a full physical inspection showed a promising sensitivity of 89%, with a false-positive rate of only 1% in this specific group of patients.
Referring all children from parents who attend the ED because of alcohol or drugs intoxication, severe psychiatric disorders or with injuries due to intimate partner violence

It is a well-known fact that parental alcohol and/or drug dependence, psychiatric illnesses and intimate partner (domestic) violence are risk factors for CAN.44-63 In the Hague, The Netherlands, in 2007 a new policy has been introduced in which an attendance of a parent at the ER with injuries related to intimate partner violence, alcohol or drugs intoxication or with a severe psychiatric disorder is automatically followed by a mandatory report to the CACRC of all children in this household.64 The hospitals and CACRCs involved in this protocol claimed that 98% of reported cases of possible CAN proved to be cases of CAN indeed. A slightly different approach is used in Amsterdam; here, ERs of all hospitals refer children, from the same categories of parents attending the ER, within 1 week after initial presentation to a pediatrician specialized in social pediatrics.65 The pediatrician carries out a full protocol for possible CAN and, if deemed necessary, refers the family for further help and intervention. In a later published comparing study we found that the CACRC identified more maltreatment than pediatric staff (98% versus at least 51%), but referrals to services were similar (82% versus 80% of the total sample) and parents were positive about both interventions. Physical examination revealed signs of maltreatment in 5%. We concluded that, despite the differences, both procedures can serve as suitable methods to identify and refer children at risk for maltreatment.66

Identifying and referring all pregnant women presenting at the ED with specific well-defined psychosocial risk criteria related to drug addiction, mental insufficiency and particular social circumstances of possible relevance to problems of pregnancy and early child development

A pregnant woman’s psychological health is a significant predictor of postpartum family violence.67 Early home visitation and parent education programs are examples of evidence-based prevention programs which, when introduced early, can prevent CAN.68,69 Prenatal referral allows for early intervention, treatment and, when necessary, introduction of a guardian already before birth and early out of home placement. Routine screening for psychosocial concerns of all pregnant women presenting at the ER could be a promising tool for early recognition and prevention of CAN.

Chapter 3

Chapter 3 describes the results of the implementation of a new screening protocol for CAN based on the study of Pless et al at the ED of the AMC in Amsterdam directly after introduction (February 2010) and 9 months later.55,70 This protocol consists of adding a so called ‘top–toe’ inspection (TTI), an inspection of the fully undressed child, to the screening checklist for CAN, the SPUTOVAMO. Implementation of this new screening protocol for CAN was only mildly successful and declined in time. In February the complete screening protocol was performed in 42% of all children, in November in 17%.
A correlation between completion of the SPUTOVAMO and having a TTI performed was found. Older age and presence of a chronic illness influenced the chance of having both SPUTOVAMO and TTI performed negatively. The completion rate of SPUTOVAMO was influenced by ICD code. Completion of TTI was influenced by type of investigator. The best performing professional was the ED physician followed by the pediatrician followed by the ED nurse.

The reasons for not performing a TTI were not documented. Refusal of the TTI by a patient or parent was reported three times. A practical recommendation resulting from this study could be that, if CAN screening protocols prove to be effective in detecting CAN, regular training sessions have to be held. Filling out the checklist is something that could be performed by ED nurses. Performing a TTI is perhaps easier for the ED physicians to make part of their daily routine.

Chapter 4
Chapter 4 describes our study in which we estimated the accuracy of a screening checklist (SPUTOVAMO), a complete physical examination (‘top-to-toe’ inspection, TTI) and their combination in detecting child abuse and neglect (CAN) at the ED.

We designed a prospective study to estimate the individual performance of SPUTOVAMO at the ED because this checklist was made mandatory and is used (or variations of this checklist) widely but has never been validated. We also wanted to assess the individual performance of TTI at the ED because of the promising results published by Pless et al., and because the two other Dutch ED studies used methods making assessing the individual performance of TTI impossible. In addition, we wanted to assess whether combining both screening tests significantly increases the number of test positives and leads to more CAN cases detected than using either test.

The study was performed in the AMC of the University of Amsterdam. Between January 1th, 2011 and July 1th, 2013, both a SPUTOVAMO and a TTI had to be performed in all patients aged 0 to 18 years presenting at the emergency department. TTI and SPUTOVAMO were conducted independently of one another by different ED employees, to better assess their individual contribution. TTI was scored positive whenever an injury was found for which an insufficient or a questionable explanation was provided by parents/caregivers, or if other symptoms or signals in behavior, clothing or care that matched with CAN were observed.

If SPUTOVAMO and/or TTI scored positive, the ED professional had to consult the pediatrician on duty for further assessment and a report to CAN Team TASK-Amsterdam (from here on TASK) had to be made. A final expert panel diagnosis was made in all children who tested positive by TASK, using the criteria published by Maguire and Mann. Children in category group 1 (abuse confirmed during case conferences, family, civil or criminal court proceedings, admitted by perpetrator) and in group 2 (abuse confirmed by stated/referenced criteria including multi-disciplinary assessment) received a final positive CAN diagnosis.
In patients with a negative result on both screening tests, and in patients testing positive not reported to TASK, adapted follow-up data were collected in the database of the CACRC (adapted procedure). Against protocol, 153 of 421 children (36%) with one or two positive screening tests were not reported to TASK. Cases were scored as false-negative if a child was reported to the CACRC because of suspected CAN between six months before and six months after the ED visit and CAN was confirmed by the CACRC. We hypothesized that this time-period would be sufficient to rule out CAN not related to the ED visit.

Because of the differential verification, with different methods for verifying positives and negatives, sensitivity and specificity estimates cannot be calculated. To express the accuracy of the individual screening tests and the combination, we calculated positive and negative predictive values. In principle, a true positive was a screening test positive in whom the CAN diagnosis was confirmed by the CAN team TASK. A false negative was defined as an all screening test negative case in which the CACRC had assigned a CAN diagnosis. Since not all screening test positives were reported to the expert panel, and some test negatives were also reported to the panel, we combined both reference standards in calculating the positive and negative predictive values. Screening tests positives not evaluated by the panel but in whom the CACRC had assigned a CAN diagnosis were classified as true positives; screening tests positives not evaluated by the panel but in whom the CACRC had rejected CAN were classified as false positives; screening test negatives evaluated by the panel in which an expert CAN diagnosis was made were classified as false negatives. Accuracy statistics were calculated in the total study group, in age subgroups (0-1, 1-6, 6-12 and 12-18 years old), and in children with and without an injury. We also evaluated the accuracy of the individual SPUTOVAMO questions.

During the study period, there were 17,229 ED admissions of 12,198 unique children aged 0 to 18. One or both screening tests were positive in 421 children (4.7% of screened children), 152 of them (36%) were reported to TASK. Additionally, 18 children without screening and 48 with negative tests were reported to TASK. In total 218 visits were reported to TASK (1.3% of the total study group), reflecting 215 unique children; three children visited the ED two times and were reported twice. In total 107 children (0.88% of the study group) had a final positive diagnosis of CAN; 91 consensus diagnoses (0.75% of the study group) and 16 CACRC diagnoses (0.13% of the study group).

We performed a sensitivity analysis, in this way we recalculated PPV and NPV taking into account the fact that the tests were performed less frequently in the age group 12-18 years old. In this way the PPV of SPUTOVAMO was recalculated at 0.46 (95%CI 0.37-0.56). The NPV of SPUTOVAMO was recalculated at 0.997 (95%CI 0.996-0.998). The PPV of TTI was recalculated at 0.44 (95%CI 0.33-0.55). The NPV of TTI was recalculated at 0.994 (95%CI 0.99-1.00). The PPV of combination was recalculated at 0.43 (95%CI 0.32-0.54). The NPV of combination was recalculated at 0.998 (0.96-1.00).
Seven children of the 120 with a positive TTI screening result and a negative SPUTOVAMO had a final diagnosis of CAN (5.8%): in one of 17 of them CAN would have been missed if TTI was not added to SPUTOVAMO. Twenty children of 99 with a positive SPUTOVAMO and a negative TTI had a final diagnosis of CAN (20%).

We observed that combining both screening tests significantly increased the number of test positives, leading to more CAN cases detected than using either test: combining the TTI with SPUTOVAMO led to 1 extra final diagnosis CAN in every 17 screened children with a final diagnosis of CAN.

The PPV of our combined and individual tests were considerably higher compared to the PPV of the ESCAPE instrument of only 0.10. The same holds true for SPUTOVAMO-R: The PPV of SPUTOVAMO-R for injuries due to abuse was only 0.03 and the PPV for injuries due to neglect was 0.05. The six questions in the ESCAPE instrument varied in PPV’s between 0.04-0.21; question 6 of SPUTOVAMO (‘Is the person who caused the accident present at the ED?’) had a lower PPV of 0.15 and the PPV of question 1 (‘Is an injury present?’) was comparable: 0.20; all other questions had a higher PPV compared to ESCAPE (0.25-0.41). Our higher percentage of positive screening results compared to the ESCAPE study might reflect a higher percentage of actual TTI’s performed. The PPV of SPUTOVAMO, TTI and the combined test were all higher in children without an injury compared to children with an injury.

Our study has several important limitations; the first and most important is the moderate implementation of the screening protocol, bias due to selecting patients for screening is likely. However, our implementation is comparable to the multicenter ESCAPE study with a completion rate of 48% (actual performance of TTI not known). In our study a complete screening procedure (TTI and SPUTOVAMO) was performed in 22.1% of visits, SPUTOVAMO was completed in 46.4% and a TTI was completed in 32.9% of visits. We have to conclude professionals have thresholds towards performing screening and especially towards performing the TTI because during the study period none of the parents or children reported problems concerning either test, in accordance with the results of our study on parental acceptance of a routine head-to-toe examination of children as a screening instrument for CAN (Chapter 8). In regular meetings with ED staff, lack of time and space were mentioned most often as a cause for not performing the screening tests.

Another important limitation is the fact that not all patients with a positive SPUTOVAMO and/or TTI were reported to TASK. It is possible that the pediatrician was able to discard the suspicion of CAN. It is unknown in how many instances this was a reason for not reporting the case. Because reporting of a suspicion of CAN to the CACRC is not mandatory in the Netherlands, the estimated PPV was likely to low and the estimated NPV likely to high.
We showed higher accuracy results and higher prevalence of CAN in our total and screened study group compared to other Dutch studies, both for the individual tests and for the combination.\textsuperscript{23,34} We showed in the group of children in which combined screening was completed 5.8% of children with a positive diagnosis had only a positive TTI, and could have been missed with SPUTOVAMO only. Vice versa 20% with a positive diagnosis had only a positive SPUTOVAMO and a negative TTI, and could have been missed with TTI only.

We recommend the implementation of the combined screening with SPUTOVAMO and TTI in every ED for all children 0-18 years old, at the cost of a high false-positive rate. Practical recommendations resulting from this study and our earlier study on implementation of a screening protocol for CAN at the ED are that regularly training sessions have to be held and a dedicated nurse should be appointed to stimulate adherence.\textsuperscript{70} Filling in SPUTOVAMO could be performed by ED nurses. Performing a TTI is perhaps easier for the ED physicians to make part of their daily routine. In addition, a mandatory electronic page in the patient file, which has to be filled before the file can be closed, should be implemented. This electronic page should be automatically send to the CAN team if one or two of the screening tests scores positive.

Chapter 5
Chapter 5 gives an overview of diagnoses and interventions of our CAN team, named ‘TASK-Amsterdam’.\textsuperscript{75} We describe the number and characteristics of the cases reported to our team in 2010-2012. In 2004, this interdisciplinary multiagency CAN team was established in the Emma Children’s Hospital – AMC, Amsterdam, The Netherlands (from here called TASK).\textsuperscript{76} Our goal is to improve detection of potential CAN, to support decisions related to CAN in the AMC, provide education for a broad public within and outside the hospital, and to perform research into evidence-based medicine regarding CAN. The team consists of a broad range of experts from inside and outside the hospital.

During the study period 642 cases of suspected CAN were reported to TASK. Ninety-two of these cases (14.3%) were based on parental ED presentation. Twenty-seven cases (4.2%) were prenatal referrals. Forty-six percent (n= 246/ 533) of the children reported were boys. Age was non-normally distributed, skewed towards older children. Median age was 5 years, IQR 2-11 years. Overall, in more than half of the cases (55.2%, n= 354/ 642), CAN was confirmed according to TASK assessment, in approximately a quarter (26.9%, n= 173/ 642) the diagnosis CAN was rejected, and in 17.9% (n= 115/ 642) it was uncertain. With an average of 14,964 annually hospital visits of unique children under the age of 18; 533 reports of children represents 1.18% of all unique children visiting the hospital (either visiting the ED, the OPD, or being admitted); 2.1% of 16,858 children visiting the ED were reported to TASK. The rate of confirmed cases of CAN is 0.79% or 1 in 127 unique children visiting the hospital. Diagnosis was confirmed in 44% of the ED cases reported to TASK (N=153). This is in 0.91% (N=153/ 16,858) of unique children visiting the ED during
the study period. Both suspicion and confirmation rate are comparable to the 1.3-2.6% suspicion rate\textsuperscript{15,19,21,23,73,77} and 0.1-2.6% confirmation rate\textsuperscript{18,20,22,28} found in ED studies. Our suspicion and confirmation rates are higher compared with the results found by Thun-Hohenstein in Salzburg who found a suspicion rate of 0.7% and a confirmation rate of 0.4%, a study among inpatients in pediatrics and pediatric surgery only.\textsuperscript{78}

Types of CAN most commonly reported to TASK were physical abuse (32.7%, n= 210/ 642), physical neglect (25.7%, n= 165/ 642), and emotional abuse (23.8%, n= 153/ 642). Analysing only child reports, ignoring parental and prenatal reports, types of CAN most commonly reported to TASK were physical abuse (39.3%, n= 206/ 523), physical neglect (30.4%, n= 159/ 523) and sexual abuse (25.0%, n= 131/ 523). Compared to these studies sexual abuse is relatively infrequently reported to TASK-Amsterdam. It is likely that we follow a different policy compared to most hospital-based teams because of our parent reports, which are not mentioned in other studies\textsuperscript{78-81}, explaining our high rate of reported suspicions for witnessing IPV (21%), but if we do only analyse reports based on children this percentage is still 16%. Our policy does also explain the amount of prenatal abuse reported.

In confirmed cases of CAN, witnessing IPV is the most common type of CAN (31.2%, n= 106/ 340) followed by physical neglect (30.0%, n= 102/ 340) and emotional abuse (29.7%, n= 101/ 340). The most frequent cases with more than one type of CAN were cases with physical neglect and emotional abuse (N=31) and physical abuse and physical neglect (N=30). Almost all suspicions of prenatal abuse (92.6%) and more than three quarter of the suspicions of witnessing IPV (79.4%) were substantiated. Two-thirds of suspicions of physical neglect, emotional abuse and PCF were substantiated. Physical abuse was the type of CAN of which the suspicion was relatively frequently (rejection in 44.8%, n= 94/ 210) rejected.

Witnessing IPV and emotional abuse were not documented in several other studies.\textsuperscript{78-80,82} Thomas et al do mention witnessing IPV but in only 2% of the cases.\textsuperscript{81} Sexual abuse, followed by physical abuse, is the most common type of CAN in the confirmed cases described in the study from Switzerland.\textsuperscript{79} They do mention emotional abuse but not witnessing IPV. Our results indicate that all types of CAN are found among hospital attendances and all three types of reports (based on children, parents and prenatal reports) are valuable. Interdisciplinary CAN teams should have experience with and knowledge of all types of CAN, including witnessing IPV and emotional abuse and their appropriate diagnostic interventions and initiation of support for the child and the family.

TASK encourages hospital staff to discuss every suspected case. Especially when there is a low suspicion and one does not know how to deal with the case, we recommend colleagues to report the case to TASK and to receive advice from our interdisciplinary perspective. The AMC approach is that CAN is a consideration in all differential diagnoses when a child has suffered a physical injury which cannot be easily explained by the history
of the child, the parents and/or witnesses. It is likely that the experts participating in TASK are better able to distinguish unintentional injury from CAN; this would be in keeping with the literature. In sexual abuse, most suspicions which were later rejected arose in children who were young (median age 4 years old in contrast to median age of 7.5 years old in confirmed cases) and had either a genital infection, e.g. Herpes Simplex with a low association with sexual abuse, or had parents who were involved in a custody struggle.

TASK added new or better interventions in 81.2% of the cases. Overall, if CAN was confirmed an intervention was offered in 98.3% of the cases (n= 348/354); if the diagnosis was unclear an intervention was offered in 83.5% of the cases (n= 96/115), if the diagnosis of CAN was rejected a voluntary supportive intervention was offered in 64.2% of the cases (n= 111/173). A CACRC report was obtained in 25.4% of confirmed cases (n= 90/354). In only 11.9% of confirmed cases (n=42/354) an involuntary out of home placement was ordered and in only 10.8% a guardian appointed (n= 38/354). The highest percentage of involuntary out of home placement and appointing of a guardian was ordered in the prenatal referrals (18.5%). Placement in out-of-home care (OHC) indicates serious childhood adversity and is associated with multiple adverse outcomes, especially when children experience foster instability. This low percentage of out of home placements could be a good feature and is in accordance with the Dutch guidelines, in which reporting CAN to the CACRC is not mandatory. A strong emphasis is placed on motivating families to accept voluntary help, which is reflected in the 57.3% of families of the confirmed cases that were offered a voluntary intervention before discussing the case in TASK and another 40.9% of families of the confirmed cases that were offered a voluntary intervention after the TASK meeting.

In 2% of the confirmed cases in which no intervention was made, this was because the family withdrew the child from care, and no contact information was known to the hospital. The total number of involuntary protective measures and foster care placements might actually become higher, as new developments in the situation at home might have occurred after the case was removed from the agenda by TASK. Even if the diagnosis of CAN was rejected, a voluntary supportive intervention was offered in two-third (64.2%) of these cases. No children in this category were appointed a guardian or were placed in foster care.

The main reason why the majority of children who were not abused still received care was that the health problem for which they visited the hospital often had a social component or origin even though the diagnosis did not meet the criteria for CAN. We do not know the percentage of the recommended interventions that has been accomplished in the long-term. A prospective follow-up study of children discussed within a multiagency CAN team to assess the effectiveness of the interventions and the long-term outcome of families would be a valuable addition. As no reference standard for the confirmation of the true
existence or absence of child abuse exists, a derived reference standard could involve quality of life studies among the children involved, or examination of re-reports to TASK, the CACRC, CACPB or other (voluntary) child welfare organizations. Prior studies have found that being reported to the CACPB is a huge risk factor for being re-reported later on in childhood. On the other hand, others have shown that child abuse prevention programs are associated with a lower chance of being reported to the CACPB.

Our results show that CAN is a significant health problem in our hospital. Being a witness of IPV, physical neglect and emotional abuse are the most common types of CAN that were identified. TASK is able to initiate voluntarily support for the majority of children, even in cases where the diagnosis of CAN is rejected or indecisive, in many cases, a supportive intervention was offered. Our results support that the expertise of a hospital-based CAN Team needs to be broad given the different types of CAN reports and the high need for (in) voluntary interventions offered in all groups. In practice the interdisciplinary composition of our hospital-based CAN team, combining the expertise from professionals within and outside the hospital, is essential in addressing the needs of children and families where CAN is suspected and/or diagnosed.

Chapter 6
Chapter 6 is a systematic review showing the evidence for using a screening physical examination to detect CAN. We included studies published before August 9th, 2013. We systematically searched the databases of MEDLINE, EMBASE, PsychINFO, CINAHL, and ERIC, using a sensitive search strategy. Studies that i) presented medical findings of a complete physical examination for screening purposes in children 0–18 years, ii) specifically recorded the presence or absence of signs of CAN, and iii) recorded CAN confirmed by a reference standard, were included.

Two reviewers independently performed study selection, data extraction, and quality appraisal using the QUADAS-2 tool. The search yielded 4,499 titles, of which three studies met the eligibility criteria. The prevalence of confirmed signs of CAN during screening physical examination varied between 0.8% and 13.5%. The designs of the studies were inadequate to assess the diagnostic accuracy of a screening physical examination for CAN. Because of the lack of informative studies, we could not draw conclusions about the diagnostic value of a screening physical examination in children without prior suspicion of CAN.

Chapter 7
Chapter 7 describes the results of a survey across all hospital EDs accessible to children in the Netherlands between November 1st 2012 and March 12th 2013 describing the varying policies used to screen for CAN in Dutch EDs. Eighty five hospitals with an EDs were approached, 80 of which completed the questionnaire and 77 provided copies
of their screening checklists. All participating hospitals use a screening checklist, 41% a screening physical examination, 60% a screening based on parental risk factors and 3% a retrospective review of all charts (a CAN specialist reviews the charts of all visiting children for any signs of CAN that were overlooked by emergency staff). However, 11% of the hospitals do not screen all children, but only those presenting with an injury (9%) or when CAN is suspected (3%).

Different emergency departments screened children in different age categories. There was a large variation in the checklists used. Of all the hospitals that provided checklists, 21 used a checklist that has been reported in the literature (27%). The SPUTOVAMO checklist was used in 12 hospitals (16%), the ESCAPE Form 71 was used in 6 hospitals (8%) and the SPUTOVAMO-R checklist was used in 3 hospitals (4%). The other 56 hospitals (73%) used modified versions of the above checklists or another checklist that has not been reported in the literature. Two hospitals reported using the Benger-pediatric flow chart, but their checklists were different from the original Benger flow chart (with the following items: delay, consistency of history, unexplained injuries, behavior and interaction). Twenty-eight hospitals (35%) used a two-step screening approach: a limited pre-screening checklist in all children followed by an extended list if one item on the pre-screening checklist was positive or if there was a clinical suspicion of CAN.

Forty-eight EDs used a screening based on parental risk factors to identify CAN. Using this screening method, all adults visiting the ED because of intimate partner violence, substance abuse or a suicide attempt were asked whether they had children in their care. If so, all these children were referred for further CAN investigations, either to the CACRC (23 EDs), a CAN committee within the hospital (13 EDs), a pediatrician (5 EDs), the Bureau for Youth Care (5 EDs) or to another youth care organization (2 EDs).

The empirical substantiation for these screening methods is largely lacking, and, as mentioned earlier, at least 73% of the hospitals use a checklist that has not been reported in the literature.

Sixty-seven participating hospitals (84%) indicated that the influence of the Dutch Health Care Inspectorate (who made screening for CAN in EDs compulsory in early 2009) on screening methods for CAN in the ED had been perceived as stimulating in a positive way. Twelve hospitals (15%) indicated that they had not perceived any influence (neutral). We do not know the actual compliance with the reported screening methods.

Chapter 8
Chapter 8 is a written questionnaire study describing parents’ opinion about a routine head-to-toe examination of children as a screening instrument for CAN in children visiting the ED of the AMC during the study period, from April 1 to May 31, 2013. It also includes
a systematic review on parental acceptability of screening for CAN. To improve detection of CAN, many EDs, as mentioned above, use screening methods. Apart from diagnostic accuracy, possible harms of screening methods are important to consider, especially because most children are not abused and do not benefit from screening. In short, we searched 4 databases and various reference lists for studies presenting the opinion of parents about a screening method for CAN. We included 7 studies: 4 observational cross-sectional surveys\(^95-98\), 2 cross-sectional qualitative studies\(^99,100\), and 1 randomized controlled trial.\(^101\) The screening methods for CAN under study were a self-administered questionnaire for parents in 3 studies and an interview with parents in 3 studies. One study was about parental acceptance of the TTI, although it was not used as a screening for CAN.\(^96\) All 6 studies involving questionnaires or interviews showed that the large majority of parents were positive about screening. The only study on parental acceptance of a TTI was performed on non-abused children in Norway, as part of a larger study.\(^96\) Children aged 5 to 6 years old were physically examined, including an anogenital examination at a pediatric outpatient department. The aim of the study was to explore how non-abused children and their parents would perceive the anogenital examination. Results showed that 66.4% of parents reported “no anxiety/distress of children,” 30.3% reported “a little,” 2.6% reported “some,” 0.7% reported “a lot,” and none reported “a whole lot.” Although the results of all of these 7 studies report that the large majority of parents have a positive attitude toward screening, it is important to remark that 4 of the studies are mainly aimed at screening children who witness intimate partner violence\(^95,99,100\) (although one study also screens for physical abuse toward the children by the partner\(^98\)) and one study is about the TTI in general\(^82\), leaving only 2 studies that include screening for corporal punishment\(^101\) or several types of CAN.\(^97\)

Our cross-sectional study used a written questionnaire about parents’/caregivers’ (henceforth referred to as parents) opinions about the TTI performed at the ED of the AMC send by mail to all parents of pediatric visitors within 2 days after their ED visit. A return envelope, enabling parents to return the completed questionnaire without additional costs, accompanied the questionnaire. After 2 to 6 weeks, nonresponding parents were sent a reminder text message via SMS and a second copy of the questionnaire via mail. During the study period, posters were placed in the waiting rooms of the ED to inform all visitors about the study.

In April and May 2013, exactly 1000 pediatric patients visited the ED. The parents of all these 1000 patients received a questionnaire; in total, 372 questionnaires (37.2%) were returned to the investigators and analyzed. Of the respondents, 194 (52% of the total responders and 58% of respondents who answered this question) reported that their child underwent a TTI. Children of responding and nonresponding parents did not differ in age or sex. However, children of responders who underwent TTI were younger than children who did not undergo a TTI. The majority of the respondents had a positive opinion about treatment
of their child at the ED in general. Answers of parents with children who underwent a TTI were similar to or a little more positive than answers of parents with children who did not undergo a TTI. According to the parents with children who underwent a TTI, 23.2% of the children found the TTI burdensome, and 62.9% did not find it burdensome; 17.5% of the children found the TTI painful, and 64.9% did not find it painful; and 18.0% found the TTI scary, and 67.0% did not find it scary. The overall attitude of respondents towards the TTI was positive: 77.3% of the responding parents found the TTI acceptable, 1.5% found it not acceptable, and 21.1% gave no opinion. Seventy percent of the respondents agreed with the theorem that all children who visit the emergency department should have a TTI performed, and only 7.3% disagreed. Because of the small number of parents who found the TTI not acceptable (N = 3) and the small number of parents who disagreed with the theorem “I believe that all children who visit the ED should have a TTI performed” (N = 14), we did not perform statistical analysis on correlations with characteristics of parents and children or their opinion of treatment at the emergency department in general.

Our study on parents’ opinion about a TTI of their children when visiting the emergency department shows a high parental acceptance of screening aimed at detection of CAN. Contrary to what is commonly believed, both in our systematic literature review and in our questionnaire study, the majority of participating parents agree with screening for CAN in general and with the TTI specifically. Thus, although we do not know the opinion of nonparticipating parents, it seems that the opinion of parents should not form a barrier against implementing the TTI at the ED.

Chapter 9
In Chapter 9 we describe how research can be carried out with personally identifiable data without asking informed consent to the not actively participating subjects. According to the Declaration of Helsinki, participation of human subjects in medical research is only acceptable if subjects have given their consent. But in child abuse and neglect, many studies use a design in which subjects do not actively participate. Data in these studies are gathered from sources such as medical records or Child Protective Services. As long as such data are used anonymously, this does not interfere with individual privacy rights. But in some situations, the use of anonymous data does not suffice, e.g., because the data needs deduplication or linking to data from other sources. The use of such data could potentially cause problems or harm to the subjects or their parents when it is misused or ends up in wrong hands. In research that is carried out in our hospital, we aim at linking data from different sources (medical records, records of Child Protective Services and community services, and self-reported data). This is only possible by using personal data. Whereas, we know that, in principle, all subjects should provide informed consent before their data is used, we experience that this is often not feasible, e.g., because the child and his or her parents are not traceable or—in case of large-scale database studies—it lacks means and time to approach each individual subject. Another problem is that in child abuse research, asking for informed consent may lead to a serious non-response bias.102,103
We discuss in which situations and under which conditions a research project could be performed without obtaining informed consent of the research subjects. In doing so, we refer to two our accuracy study described in Chapter 4 and a second recent study performed in the AMC in which we encountered these issues. As described in Chapter 4 we had to use, next to the reference standard (a diagnosis made by our interdisciplinary hospital-based CAN team, TASK) an adapted procedure for a final diagnosis, using follow-up data collected in the CACRC database. We had to follow this procedure for children with a negative result on both screening tests (SPUTOVAMO and TTI) to evaluate the proportion of false negative test results and for children who had a positive screening test but were not evaluated by TASK (missed diagnosis). Therefore, we needed to search the AMK database, which is not part of usual care and would require the use of personal identifiable data. After consideration, we did not want to ask informed consent for the CACRC database search because we were concerned that parents who were maltreating their children would be less inclined to participate in the study. This would result in an overestimation of the sensitivity of the screening tests, with potentially dangerous consequences for future maltreated children.

In the other study performed in the AMC we wanted to evaluate a recently implemented hospital-based guidance protocol to improve identification of abused or neglected children in hospitals. This new protocol was based on a protocol developed in The Hague, The Netherlands in 2007. In the new protocol, all adults attending the emergency department because of medical problems due to intimate partner violence, substance abuse, or a suicide attempt were asked whether they care for children less than 18 years of age. If so, children and their parents were referred to the outpatient pediatric department for an examination. After this visit, referrals to services could be arranged. If parents refused to cooperate after several reminders, children were reported to the CACRC. To evaluate this protocol, we used several outcome measures. First, we used parent- and child-reported outcomes, for which we asked informed consent. However, based on previous studies and the opinion of other authors, we expected a low participation rate. We were concerned that there would be a substantial nonresponse bias that would severely limit the external validity of the results. We expected that eligible subjects who were unwilling to participate in the study suffered from more problems than subjects who were willing to participate. In order to collect results from an unselected group, we wanted to include reports of hospital staff, CACRC records, and CPS records of all eligible subjects in the study (thus without asking for informed consent). We could not use anonymous data, because we wanted to link data from different sources and, because the study was conducted in multiple hospitals, and to remove duplicates.

After discussing our dilemma in a multidisciplinary team (including a hospital lawyer specialized in privacy matters, a dedicated hospital privacy officer, and a pediatrician specialized in CAN), we used the following protocol in handling personal data: in both studies,
only the main researcher (after signing a confidentiality agreement) searched for hits in the CACRC and CPS records. In the context of our approach, we could not inform subjects individually about our study, but in the majority of the participating hospitals, the general hospital leaflet contains a statement that, without objection, personal medical information can be used for research and patients will never be identifiable in any publications. There are instructions on how to object to this. If subjects would raise an objection against the use of their personal information in research, all information would be destroyed immediately. Only the main researcher had access to personal data and no information was handed over to other parties (such as the CACRC). The researcher asked the staff to make a notification about participation in our study in the subjects’ records. During the study, all personal information was coded, and a key list was only kept by a trusted third party (a senior researcher, who was experienced in the field but not involved in the study). As soon as all data analyses were finished, all personal information was destroyed carefully. This careful procedure is possible under current European and Dutch law.

When medical data research is involved, the main rules are provided by binding legislation (“hard law”) of the European Union (EU). We refer at a directive, adopted in 1995, on the protection of individuals with regard to the processing of personal data and on the free movement of such data (Directive 95/46/EC). The directive offers no more than a general legal framework. In this area, non-binding (“soft law”) rules and principles, developed by, e.g., the Council of Europe and the European Science Foundation, provide further guidance. When, despite reasonable efforts, it would be impracticable to seek the individual’s consent, these “soft law” rules and principles state data may be gathered without the individual’s explicit consent, provided that certain conditions are met. One of these conditions is that the data subject knows about the possible use of his or her data for scientific research (right to be informed on a general level) and has not objected to this (right to “opt-out”).

In the Netherlands, in the context of medical data research, two laws are relevant: the Personal Data Protection Act (in Dutch: Wet bescherming persoonsgegevens) and the Medical Contract Act (in Dutch: Wet inzake de geneeskundige behandelingsovereenkomst), a section of the Dutch Civil Code. The latter is the one that provides specific rules for disclosing patient data for medical research. On the basis of Article 7:457 Civil Code, a physician or caregiver may disclose identifiable patient data to researchers when the patient authorized the disclosure. However, when obtaining consent appears to be impossible or would involve a disproportionate effort, that requirement may be dropped under the following conditions. First, the research project should serve a public interest; second, the research could not be carried out without the data concerned; third, the data subject is informed about the possible use of his/her data for research and has not explicitly opposed to this; and fourth, adequate security measures (technical and organizational) are taken (e.g., encoding the data). We would like to note that, whereas this framework fits within the present EU-directive, it might come in conflict with the future EU-regulation.
In CAN research, studies using linkable data of unselected samples are often necessary to yield unbiased results of sufficient quality. Since the results of these studies can have important consequences for the social, mental, and medical well-being of maltreated children and their families, we argue that, in very specific circumstances, it should be possible to perform such research without informed consent of the child and/or the parents involved.

We formulated two recommendations. First, an improved opt-out procedure in the sense that it is better secured that patients and/or their legal representatives are really aware of the fact that their medical records could be used in research, and that they are always entitled to object to such use. This information should be available explicitly; hospitals could develop special leaflets for using medical data for research and put these posters or leaflets in waiting rooms, and the information could be put prominent on their websites. Second, when researchers refrain from obtaining informed consent while they make use of personal data, we recommend a review of the research proposal by a medical ethics committee (MEC) or comparable body, especially in sensitive research areas as on CAN. Although this is not a current requirement under Dutch law, it is recommended by non-binding documents such as the Council of Europe’s Recommendation No. R (97) 5 on the Protection of Medical Data (February 13, 1997).

Conclusions
CAN is a common problem with serious short and long term consequences. The importance of early recognition in the hospital can not be overestimated. The AMC (TASK Amsterdam) multiagency-interdisciplinary CAN team child received reports of suspicions of many different types of child abuse, and in many cases, in a large number of patients, TASK carried out very different voluntary and involuntary interventions, both in cases with proven diagnosis and in cases where the diagnosis was rejected or insecure. The expertise of a child abuse team should therefore be broad.

There are many different ways in which the ED could screen for CAN. At the Dutch EDs we identified a wide variety of methods of screening, largely lacking empirical support. Implementation of our combined screening method for child abuse was difficult; we found that parents’ opinion about screening should not be a barrier. By means of systematic review of literature research, the accuracy of a TTI as a screening tool for CAN could not be determined.

We have designed a prospective study to determine the individual performance of SPUTOVAMO at the ED because the use of this checklist (or variants) was mandatory, but the checklist was never validated. We also wanted to assess the individual performance of the TTI at the ED because of the promising results of Pless et al., and because the two other Dutch ED studies used methods that failed to assess the individual performance of the TTI. Only with a creative research design waiving informed consent this study could be conducted without great bias, this was possible under current Dutch and European legislation under strict conditions.
By means of a sensitivity analysis, we calculated predictive values of the individual tests and the combination that were significantly better than in previously published studies: a PPV of 0.46 for SPUTOVAMO, a PPV of 0.44 for TTI and a PPV of 0.43 for the combination. We also found that the combination of both screening tests significantly increased the number of positive tests, which led more often to the diagnosis of CAN than using one of the tests separately: leaving behind the TTI would lower the number of children with a final CAN diagnosis with a percentage of 5.8.

**Future implications**

Given the results of our study we provisionally recommended combined screening with SPUTOVAMO and TTI at every ED for all children aged 0-18 at the expense of a high number of false positives.

We recommend the above-mentioned measures to increase the implementation (regular training sessions, electronic compulsory page to be completed before the medical file can be closed, an attention officer who continuously stimulates the use of the screening method and a proper division of tasks in terms of execution by different types of professionals).

But we are not there yet. In our view, it remains important to keep looking for screening methods with a higher accuracy, for instance using checklists that differ according to the type of injury the child presents with (based on scientifically established characteristics associated with CAN or just are pleading against CAN. In addition, it is important to investigate whether a simple reminder like “are you sure that there is no form of child abuse in this patient” could replace SPUTOVAMO. In these studies one could randomize for the type of screening used. In order to prevent bias we recommend using all measures that can promote the implementation of the study protocol. In addition, we recommend that when the screening is positive, the CAN team is immediately electronically notified. Also for other departments where children present themselves, scientific studies on the accuracy of screening for CAN are useful.

Finally, we recommend that the Board of Directors of Hospitals play an active role in the implementation of screening for CAN and in facilitating a multiagency- interdisciplinary CAN team.
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