

Introducing Electronic Child Records

Balancing Personal Interests, System Performance, and Social Values

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Abstract—Improving quality of child healthcare, optimization of child development, anticipation of child neglect or abuse, and other social-values-based childcare activities usually motivate the adoption of electronic child records (ECRs). Having an ECR system in place, many stakeholders concerned with the welfare of children are supposed to use the personal information stored in ECRs in order to do their work effectively and efficiently. Personal data however can only be provided to a limited extent to prevent conflict with privacy laws and ethical values of parents and child. These observations underpin the need for a careful design of introducing ECRs. This paper takes up this challenge. After introducing the problem, we identify a set of potential conflicts between different childcare parties. Based on a case study, we also analyze prototypical childcare processes and related dilemmas. These analyses yield a set of requirements based on which we design a step-by-step process of gradual introducing ECRs. The process takes both technical issues and institutional arrangements into account. Finally, we reflect on the way our integrated approach helps to create the right balance between personal interests, system performance and social values, and draw our conclusions.

Keywords—*electronic child record; ethics; social values and IT; system performance; integrated approach*

I. INTRODUCTION

Despite several still existing uncertainties, the Dutch Minister for youth and family announced the obligation of using electronic child records (ECRs) by all institutions and bodies dealing with the healthcare of children by the end of 2009 [1]. By collecting all crucial information including child's medical history, family situation and circumstances, it is expected that the use of ECRs will increase the quality of child healthcare, will anticipate potential child neglect and abuse, and will enable appropriate interventions, among others. However, such improvements around a complex phenomenon like child development, where many stakeholders are involved, will not just happen of themselves and actually require a proper introduction [2].

Looking for literature on ECRs, one soon encounters many articles on subjects in the related field of Electronic Patient Records (EPRs), while the number devoted to the introduction of ECRs is relatively small. Inspecting papers of the latter, some are just focusing on the technical infrastructure of ECRs for example, at national level, [3]. In other papers, the integration of ECRs with EPRs is highly recommended [4], or

it is chosen to just focus on healthcare issues of children [5]. Still other scientists emphasize the need for democratic control over and structuring of its introduction by clearly staking out what is allowed and what isn't [2]. Some also strongly criticize potential privacy violations: in 2007 for example, the ECR won a 'Big Brother award' while observing that the 'blind trust of authorities that problems will be solved by registration of personal data, is shocking' [6]. At the same time, political parties in the Dutch parliament have shown different opinions regarding the ECR, e.g., related to the starting point whether ECRs should contain, next to medical data, non-medical information as well [7].

From this short sketch it is clear that (the Dutch) society can be (is) critical and skeptical about the introduction of ECRs. Based on this and its underlying arguments, it can be argued that - if their introduction is the point of departure - the need for a careful process design is high and that technical IT issues, personal interests, and social values should be put together on one level. This paper takes up this challenge, first, by analyzing current childcare processes and, second, based on the outcomes of it, by designing a step-by-step procedure in which all actors involved can gradually learn to improve their specific role as contributor to children's development.

The rest of this paper is structured as follows. In the next section, we sketch the context of ECR by analyzing both the technical architecture of ECR systems and the stakeholders (actors) involved including their potential conflicts of interest. By using a case study, we then describe, in section 3, prototypical childcare processes. Having the results of section 2 and 3 in mind, we are able to design, in section 4, an integrated, step-by-step process of gradual introducing ECRs. In section 5, we reflect on how far our design actually reaches and finally, in section 6, we draw our conclusions.

II. CONTEXT OF ECRS

In this section, we present current ideas about technical architecture solutions for ECRs as well as describe the actors involved including their different views on the ECR system.

A. Technical architecture

The ECR functions in an environment where different stakeholders are active and several databases exist: figure 1 shows them. The technical architecture is divided in a front-end and a back-end. In the back-end several databases exist, located

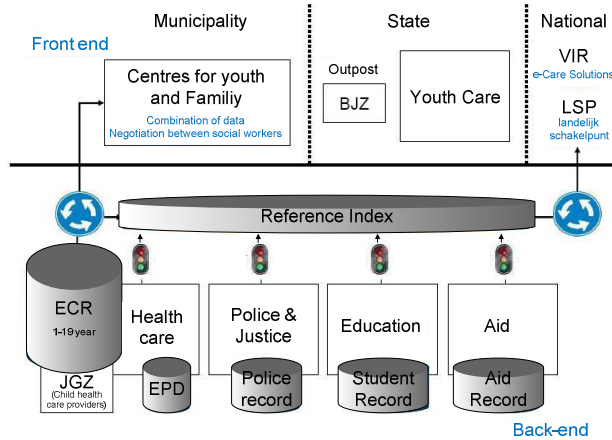


Figure 1: Technical Architecture of ECRs [8].

at different parties. The so-called ‘Reference Index’ (RI) forms the digital link between these different pieces of information. Each party (health care organizations, the police, schools and organizations providing aid otherwise) may ‘raise a flag’. This means that when any party feels that a child might be having problems they can signal this in the system, thereby alerting other parties. The RI has a major restriction: it is aimed at signaling problems only and not at creating a record. Furthermore these signals may therefore only be stored for a restricted period of time depending on the source of the signal. Only after selection and negotiation with the child health care providers (JGZ in Dutch), it may be decided to incorporate a certain signal in the ECR. In the front end, the actors at municipal level and national level are mentioned: the National Connection Point (LSP in Dutch) enables the linkage of distributed data on children at national level.

B. Actors and potential conflicts

The ECR introduces a different way of working in the child health, care and support sectors and affects different parties in different ways. For this research it is necessary to know which actors are involved and in what way, since they all have their own views, responsibilities and powers. To get these insights, an extensive stakeholder analysis was performed the details of which can be found in [10]. The following actors appeared to play a significant role: Ministry of Healthcare, Well-being and Sports (HWS), Child Health Care Provider BJZ, (Union of) Dutch Municipalities (VNG), Municipal Healthcare Service (GGD), Medical Child Healthcare Association in the Netherlands (AJN), Organization of Health Entrepreneurs (ActiZ), Specialist Youth Care Providers, Police, Schools, Parents and children, Software providers, Privacy Right Protection Agency (CBP), Child and Youth Psychiatry (RMPI), National Union of General Practitioners (LHV), Union of Mental Healthcare Providers (GGZ), Advisory and Reporting Unit Children Maltreat (AMK), and the Council of Child Protection. By analyzing their roles and merits related to the use of ECRs [10], we have been able to identify three potentially major conflicts:

1. A major discussion is going on whether the child record should contain only medical information or non-medical information as well. The AJN only wants to incorporate medical information and strongly disagrees on other parties being eventually able to look into their information. The police, schools and other aid providers however, are arguing that all information needs to be stored in the ECR system in order to provide a good overview of the child. Some municipalities have already chosen to include both medical and non-medical data.
2. A conflict exists between the national government (the ministry) and the municipalities that already designed and implemented an ECR system on their own: The ministry is trying to charge these municipalities with the nationally designed ECR. Amsterdam and Rotterdam for example have already a system of their own in use. However, they are not very keen on changing their system, due to new implementation and learning costs. Furthermore, if the national government will decide that only medical data is going to be stored, these municipalities will even lose some functionality they currently have in their own system.
3. There are disagreements about how far one may or should go to protect a child. For example, is it allowed for the GGD to share information with other healthcare institutions like BJZ? The CBP and parents are especially afraid that the privacy rights will be violated [11], [12]. Governments and doctors on the other hand all consider an ECR purely in the benefit of the child.

These examples make clear that potential conflicts and dilemmas do exist between different groups of stakeholders. Therefore, the differences in vision on how to apply ECRs can be huge and there is high need to find a good balance.

III. CHILDCARE PROCESSES AND THEIR DILEMMAS

In order to get better insight into the role of the different actors, we also performed a case study where prototypical childcare processes as well as additional issues and dilemmas have been identified. We report on the outcomes in this section and refer, for details, again to [10].

A. Choice and background information of the case study

The focus of our case study was the city of Rotterdam, the ‘worst city to live’ in for children [13]. A most typical characteristic of Rotterdam, that seems to play a huge role in these problems, is the strong presence of non-natives living in relatively poor circumstances. Almost half of the total amount of young people in Rotterdam has a non-western background [14]. The percentage of their children having a high risk of problems is above average. Twenty percent of the children in Rotterdam grow up in families living from a social minimum income. Thirty percent is raised in a family with one parent and in primary schools 85 percent of the children have foreign parents.

Different risk factors play a part in the child problems. These factors vary from, violence, youth crime, problematic

alcohol and drug use, abandoning school and teen pregnancy. Nevertheless, the main origin of child problems is in the family affairs of the child. A familiar pattern can be seen if parents are not able to cope with life, they often lack as a parent. In Rotterdam almost 10 percent of the parents report psychological problems, 9 percent work problems and 2 percent drug or addiction problems. From the children, on the other hand, 8 percent report physical abuse from which 5 percent consist of sexual abuse of girls. Furthermore, 20 percent of the youth says to recently have suicide ideas and 6 percent already attempted. These facts are only the reported cases. There are some commonalities in the behavior of children. Frequent aggressive behavior is common among young people between the age of 9 and 10 years. In this early age they also experiment with different stimulants, like alcohol, marihuana and cigarettes. The more young people smoke, drink alcohol or use drugs the more often they show more problematic behavior. Regarding the somewhat older youth there are a significant number of incidents regarding sexual behavior. The numbers of sexually transmitted diseases are increasing and there are relatively high numbers of teen pregnancies [15].

The majority of the problem children can be helped with the effective assistance of parents, friends, schoolteachers or social workers. Yet for the other group this does not apply. Therefore it is important that this 'risk-group' will be detected in an early stage. The responsibility lies with the parent and the youth (health) care institutions of Rotterdam. Starting point of the municipal policy is that every child has the right to proper healthcare, protection and participation. In Rotterdam there are different institutions in the (youth) care sector that have the task to detect and assist people with all sorts of problems.

B. Business Processes in childcare

By interviewing several people from major actors in the field (for details on the way these interviews have been executed, we refer again to [10]), a set of currently prototypical business processes in the childcare sector could be identified. To portrait a high level overview, a distinction was made between the different parties. These stakeholders are observers, indicators and specialized childcare providers. The overview is depicted in Figure 2. From the day a child is born the children are registered and a blank document is made by the GGD.

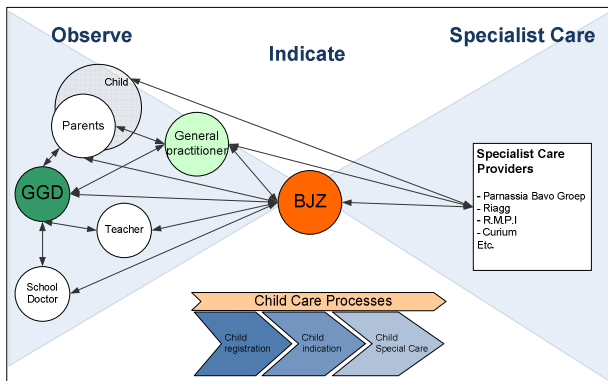


Figure 2. Prototypical Childcare Business Processes.

the child grows, medical information is stored, such as vaccine information and doctor information, and additional information if the child has other medical problems. Furthermore, the GGD gathers information with child checkpoints at different ages. Here, questionnaires must be filled in and school doctors check the children. If social or emotional problems are detected the BJZ will be contacted. This can happen through schools, school doctors, parents, or a general practitioner. When a school believes that the behavior of a child is troublesome or shows some potentially emotional problems, they contact the BJZ. From there, the child will be registered and the BJZ will start to indicate the kind of problems that play a role. Here, not only the child, but also the parents will be looked at. This is done by social workers of the BJZ. They talk to the family (in the office) and sometimes also go to the homes of the children to take a look at the situation to get an impression of potential problems, which is required for further assistance. These problems can be simple or complex. Complex problems consist of multiple problems in a family. Therefore not only the child, but also other family members need further assistance as well. Besides the school, parents may also voluntarily contact the BJZ to ask for help or guidance. When parents worry about their child that something might be wrong, a social worker is assigned to this family. The same goes for a general practitioner. Here, the family of the child will be contacted by BJZ and BJZ will send a social worker to indicate social or emotional problems.

In addition to the previous described voluntary forwarding processes, there also exist forced ways of referencing a child towards the BJZ. This occurs when a child is relegated to the BJZ by a judge based on legal grounds. When such a so-termed 'indication' is given, the BJZ will construct an advice based on an examination of the child. The advice consists of assigning a child, or the complete family, to the appropriate specialist care provider. This care can be foster care, home assistance in form of day care or 24 hour care, psychiatry, child protection, etc. When the appropriate care providers are selected, BJZ will perform monitoring activities to check whether the right treatment is given.

Forwarding a child towards special health care providers can also be done via general practitioners. This is because insurance companies, special health care providers and general practitioners have made their own agreements or arrangements to forward a child directly to them. When a child (or parent) wants to contact a specialist care provider directly, they will be sent back to the general practitioner first. Going directly to a specialist care provider is not possible. During their consult at the general practitioner, there might however be decided to indeed send the child to the desired specialist care provider. After receiving this reference, the child can be taken into treatment at the specialist care provider.

Information exchange is sometimes needed between the organizations, not only to or from the BJZ, but also between the GGD and the different organizations. After all, the GGD is the one who manages the children's record with medical facts and maybe more. However, the willingness to exchange or provide information by care providers remains uncertain. The different organizations are different institutions having their own behavioral codes and having different financial

backgrounds. Because of this, it is not uncommon for a care organization to protect their clients (or themselves) from others who demand certain sensitive information. This is one of the dilemmas that will be further discussed below.

C. *Issues and Dilemmas*

During the interviews with the various stakeholders, several issues and dilemmas in the main processes of childcare came to the surface. In order to address and discuss these dilemmas accurately, a more detailed image of the business processes had to be made. We therefore executed a study in depth of current business processes in childcare, the details of which can be found in appendix III of [10]. Based on this detailed analysis, it was possible to identify several dilemmas that exist between different groups of actors. These dilemmas appear to be strongly related to the potential conflicts identified earlier (in subsection IIB of this paper). What further became noticeable is that ethical values play a dominant part in the issues and dilemmas found:

Ethical issues:

- Privacy (of the individual)
- Permissions/Trust (granted by an individual to institutions)
- Trust (between institutions)
- Integrity (institutions can treat individuals differently).

Non-ethical issues:

- Cultural differences (between different institutions)
- False positives (identified by an algorithm)
- Decentralized forwarding (currently done by BJZ and the general practitioners: there is no central coordination at this point).

First of all, privacy of the individual is an issue: when a child is born and its e-record is created, this record is, in principle, blank. However, if there are significant problems known to occur in a family, it might be appropriate to incorporate this information of parents and other family members into the child's record immediately. This does raise the question whether the linking of such private information is actually allowed, which concerns a delicate dilemma. It puts forward the question under which circumstances it is (not) allowed to store certain information in an ECR. In addition, the question pops up which organizations get access to ECRs? And one may also wonder what types of interventions are allowed based on the information in ECRs?

One way to safeguard privacy is to ask permission to the parents. However, the problem then still pops up whether this permission has to be asked at every exchange of information. Of course, an ECR system in this case will not work effectively and efficiently.

Problems also exist regarding the trust between different childcare organizations: one can easily imagine that organizations in principle are not willing to make their (sensitive) information available to others. In the interviews it became transparent that this is indeed an issue to be resolved.

Additionally, integrity can be an issue, namely, in case individuals are being treated in different ways by different institutions. It is therefore important that their protocols are aligned with each other.

Besides issues of ethical nature, there are also issues of non-ethical nature. One of these non-ethical issues is cultural difference. Organizations may have a different financial background, may be a different institution, may have different expertise, may apply different protocols and may even have different opinions about what is best for a child. This dilemma is important because it can obstruct the cooperation and information exchange between childcare organizations.

Further, when an ECR system and/or a reference system is in place, and each childcare organization exchanges information and reports on problems with a child, the system may be prone to information overload. Besides unnecessary redundancy, this may result in a high amount of so-called 'false positives'. So there is the dilemma about the amount of information that should be stored and exchanged between organizations in order to get an optimal overview of the situation of a child.

Finally, because there is only some hierarchical way of working in the health care, decentralized relegation occurs. For instance, general practitioners can forward children directly towards specialist health care providers instead of only to the BJZ. Therefore they both perform the same task without notifying each other directly. An ECR system needs to resolve this and store the right information, in any case.

Concluding and summarizing this section, we observe that child healthcare is like a web of all sorts of different care organizations. Some form of hierarchy can be found between health care organizations in the way institutions have the responsibility to monitor and document a child. However, childcare, as in Rotterdam, can be a complex problem. Different institutions are involved, with their own professional codes and protocols, and their possible dislike to interfere with others or get insight in what they are doing. Dilemmas such as privacy, trust and cultural differences are important issues that need to be addressed when designing an ECR system. Looking at the business processes the care of a child is highly dependent on the cooperation of all the different organizations. If organizations refuse to provide information, it is often due to the (non-)ethical issues we identified. The cultural differences must be overcome to establish future cooperation between these organizations. Without it, information exchange for gaining a better overview of the condition of a child, might never work. This makes it, besides privacy and trust, one of the most important issues to be taken into account. Also what can be concluded from the processes is that organizations work alongside each other, like the BJZ and general practitioner. Lastly, each organization has its own records that contain information they do not likely want to share with others. They are professionals, who want to keep the details or sensitive content of their work private. Their clients are top priority and these institutions all have their own behavioural codes to safeguard clients' privacy and maintain their trust.

IV. DESIGN

Having identified the set of stakeholders actively involved in childcare and having identified a set of dilemmas, it is time to take up the challenge of designing a solution that deals with these problems. To address the many different aspects, we decided to divide the design in three subcategories, namely, a *process design* (describing which steps have to be followed to get the implementation process going forward again), an *institutional design* (concerning the institutional arrangements between the institutions involved) and a *technical design* (providing recommendations concerning a balanced implementation). The seven ethical and non-ethical issues identified in the previous section, will all be handled in (at least one of) the three design approaches.

A. Process Design

First of all we observe that it is crucial to involve the critical actors in the process of introducing ECRs. However, not too many actors should participate, otherwise, the process will get stuck very quickly due to the variety of interests and goals of the different actors. Besides BJZ and the GGD, the following parties have an important, specific role in childcare and should therefore delegate a representative: the doctors association (AJN), the general practitioners association (ALV), the specialized care organizations (e.g. psychological care), the schools, and the police.

In addition to identifying the crucial stakeholders, their specific roles should be made explicit. Considering the existing childcare processes (see section 3), we observe that BJZ would be the right party to fulfil a central role in the process. BJZ is, actually, the practical problem owner on the lower level (municipality), whereas the Ministry is the problem owner on a national level as indicated during the introduction. This central role obviously puts more pressure and responsibilities on BJZ and they will have to require additional resources to manage this. Besides the BJZ, the GGD will also fulfil a dominant role in the process because they possess important medical information about all children in their region. The roles of the other actors, besides GGD and BJZ, are of great significance as well and need to be carefully defined (to be elaborated below). In order not to forget the important interests of the clients themselves, representatives of parent unions can be consulted for advice at regular basis.

The next challenge will be to actually get all these parties to work together. To realize this, a clear 'incentive structure' is required [16]. In Rotterdam, for most actors, the prevention of another 'Maasmeisje case' (an infamous case of 2006 where a little girl was discovered dead in the river Maas due to miscommunication and passivity by all kinds of stakeholders [10]) is a very important incentive, especially for BJZ who was largely held responsible for the casualties in this case.¹ Furthermore the efficiency benefit can be another incentive for parties to join the process of introducing ECRs. BJZ, specialized care providers and psychiatrists for example can look up previous medical history and medication. Also for the

¹ Actually, the 'Maasmeisje case' started the whole discussion on whether an information sharing ECR-type of system had to be implemented or not and how this would have to be developed.

general practitioners and doctors it will be a lot easier to consult medical records of a child and thus time is saved. Sharing information thus also reduces redundancy of information. This also provides the possibility for the actors involved to make their process more efficient, which is another great benefit and, therefore, an incentive. Finally for the specialized care providers it is useful to cooperate with BJZ, because BJZ forwards clients to them. Better cooperation with BJZ thus means more clients, which is of great importance because they have to operate in a competitive environment.

To facilitate the gradual (and successful) transition into efficient and effective cooperation between the various stakeholders, we further propose a *stepwise implementation* consisting of several rounds. In the first round (that of *exploration*), the rules of the implementation process itself are fixed. This means that the 'rules of the game' with respect to issues like exit and entry rules of parties, setting the agenda, divisions of tasks and responsibilities, confidentiality of information, general decision-making, speed of the process, and distribution of budgets should be agreed upon.

Once the parties have established general consensus about these rules, the second round (that of *technical phase one*) can be used to start actual cooperation between all stakeholders involved based on the idea of the Reference Index (as explained in section 2), a relatively simple ECR system where stakeholders can 'raise a flag'. By working together this way, a start can also be made with handling of ethical issues and defining of workflow protocols.

After having accomplished the first phase of the technical system, the actors can proceed with adopting a more advanced version of the ECR-system in the third round (that of *technical phase two*). Where the initial technical system only signals problems, this second version could also comprise actual records of the children. The same access rules and protocols that have been negotiated in the previous round may be applicable. However, some agreements have to be altered a little bit, because the system designed together here will contain actual client's information (which probably has to be protected more strictly than a simple signal).

Finally, in the fourth round (that of *technical phase three*), the parties have to agree on sharing all their information while keeping the ethical values of their clients in mind. This round includes the introduction of an intelligent, automatic signalling system that is able to indicate in advance possible problems of children to relevant stakeholders. Defining the correct decision rules will be part of the discussion in this round. Again each party has to make clear what they find ethical towards the children and/or parents.

Having successfully introduced the most advanced system, the maintenance phase starts where the parties involved will have to reach consensus on future developments as well as the maintenance of the (technical) system.

B. Institutional Design

The design of institutional arrangements is needed to regulate the positions and relations between parties. The arrangements can be fixed at several levels (layers). To do so,

we here adopt the four-layer model by Koppenjan & Groenewegen [17]. Layer 4 describes the informal institutional environment of, in this case, the ECR system. Layer 4 is introduced to describe the ethical values that are at stake. The way all actors behave and the choices they make can be seen as a reflection of the ethical values they attach importance to. This also holds for the manners of interaction between each other, and for the way they apply information technology (p.3 of [18]). As was mentioned in section 3, there are a lot of issues and dilemmas concerning ethical values around ECRs including privacy, trust and integrity. Right from the start, these dilemmas caused a great deal of controversy that, one way or another, needs to be resolved. Actually, we have no ‘ready-to-cook’ solution here but we claim that the stepwise introduction of ECRs (as explained above in the process design) is key in gradually establishing the informal institutional arrangements needed to appropriately deal with the numerous existing ethical issues and dilemmas. This is based on the assumption that the realization of mutual trust between the many stakeholders is a long-term process that needs a careful and prudent approach.

Layer 3 of the chosen model [17] describes the formal institutional environment of the ECR system. These institutions - such as formal rules, laws and regulations - determine the legal positions of the different actors and coordinate the formal transactions between them. There are a number of laws that constrain the ECR design. Some of these laws address some of the ethical values in the fourth layer. However, they do not solve all the issues and dilemmas discussed above. As a starting point, here an overview is given of the existing privacy regulations that apply to the design of an ECR system:

- Children after the age of 12 are allowed to see their own files and flags.
- When children are below the age of 12 parents are allowed to see their children’s files and flags.
- Patients have the right to ask for removal of files or flags.
- Patients always have the right to ask for adjustment of files.

For more examples, we again refer to [10]. Furthermore, in the process design, when different organizations gather and agree to unite, even more regulations might surface.

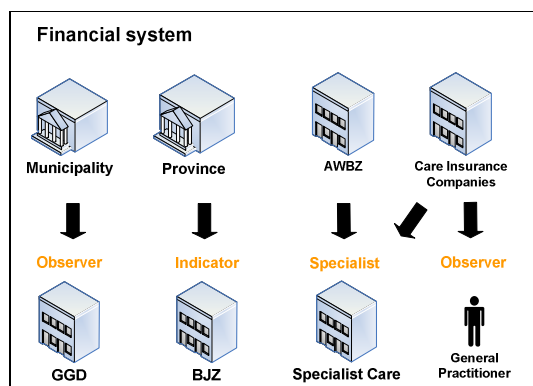


Figure 3. Financial funding of childcare actors.

Layer 2 includes the mechanisms that actors use to coordinate their interactions and transactions. Therefore, we first analysed the current funding structure, the ‘big picture’ of which is visualized in Figure 3. Like we have argued, to implement an ECR system successfully, institutions involved with childcare, need to adjust their way of cooperation. More particularly we found that especially two institutions need to adjust their organizational arrangements [10]. These two are the schools and BJZ. A school is a vital part in the education and development of a child. Therefore they need access to the information on the ECR system. However, not every teacher on every school should have this access. A solution may be that every school points out one responsible person working as student counselor related to the ECR system. This student counselor will stay in touch with BJZ. BJZ should inform the student counselor of the protocols that are in use and should provide the necessary information. When a teacher then wants to add something in the ECR system, whether this is a flag or a record, he/she should get in contact with the student counselor. This design should create more transparency for the parents as well as for BJZ.

As is explained in the process design, BJZ will be the central stakeholder within the hierarchy of stakeholders involved with the ECR system. This will create much more work and responsibilities for BJZ. Therefore BJZ will need to make adjustments in their organizational arrangements. Within BJZ, one department is needed that focuses solely on the ECR system and its environment. This means that a new structure is needed within the BJZ and additional employees are a must. It is clear that the proposed new organizational arrangements may need additional funding. This is something the current funding authorities need to reach agreement upon.

Layer 1 describes the individual actors and the way they interact and/or influence each other. Referring back to the analysis phase, past year the responsible minister changed his view on the ECR on a regular basis [10]. The final design of the ECR system can therefore still be influenced by the views of other political parties and health care organizations. In addition, the media plays a huge role in how people look at an ECR system. Currently, many health care providers (GGD, BJZ) are not content with this. This only leads to more distrust, while trust is one of the most important aspects that lead to the success of an ECR system. Therefore the relation of the media and the main actors that are going to be the central players of the ECR system is crucial, because their influence is very high in the way people perceive the ECR system. Based on what we noticed from experts in the field we have got the feeling that the more ethical values are being taken into account (in every step of the design), the likelihood of acceptance of an ECR will be higher.

C. Technical Design

With respect to the technical design, we here confine ourselves to formulate a set of basic, concrete specifications for the technical implementation using the above-defined phases of the process design. Here, it is tried to balance between the efficiency of the system, the personal interests of children and the social values at stake (again, more details can be found in [10]):

Phase one: Raising flags

- A flag can only be raised when the party has approval of the patient.
- Only one party, in this case BJZ, should get an overview of all flags.
- Other parties may only see their own raised flags or those raised by BJZ.
- BJZ is authorized to show other flags to different parties, provided BJZ has got approval of the patient.
- A flag can be removed when a patient rightfully demands it.
- A flag raised by BJZ is active for twenty-four months.
- A flag raised by other parties is active for twelve months.

Phase two: Sharing information

- Stored files are only visible for the party that stored the information.
- BJZ needs to ask permission to exchange files between multiple parties.
- Documents or records are stored without first asking permission.
- When documents or records are stored, a patient will get a notice from this.
- Only practitioners involved with that particular patient should have access to the records.
- Practitioners should get authorization codes for accessing the dossier of their patients.
- The system should keep a record of who added or edited which dossier. This should only be visible to BJZ.
- A patient must have access to his dossier. If the patient is older than 12 he himself is allowed to have access. If he is younger than 12, the parents will have this access right. Children older than 12 can deny their parents this right.
- Records of a patient might be protected against the patient's parents, provided that BJZ finds that these parents play a vital role in the problems of the patient.
- A patient has the right to complement or remove information in his dossier, provided that he is older than 12. If the patient is younger than 12, the parents have this right.
- A patient has the right to demand for the destruction of a dossier, provided that he is older than 12. If the patient is younger than 12, the parents have this right.
- A health care practitioner should be able to share a patient's dossier with a third (judicial) party in case of 'circumstances beyond his control'.

Phase three: Using an intelligent system

- The intelligent system should give an alarm if enough 'critical keywords' are found.
- Critical keywords should be decided on by the stakeholders.
- BJZ is the only party that receives alarms from the intelligent system.
- BJZ can discuss the alarms generated with involved parties without permission of the patient.

We do not further consider implementation issues here but it should be clear that all kinds techniques from Business Intelligence can be used to provide the decision support information needed. Therefore, it is highly recommended to pay attention, right from the beginning, to (secure) data storage techniques like data warehouses that enable careful monitoring of individual childcare activities (while strictly living up to the ethical and non-ethical principles described above).

V. REFLECTION

In this paper we analyzed the introduction of ECRs, strongly based on a case study performed in a big city in the Netherlands. This raises the question to what extent our analysis and design also hold for other places (in the world). It is the aim of this section to reflect on this and some other questions related to the possibility of generalizing our results.

The ethical issues that were identified will most certainly play a significant role in other regions of the Netherlands as well. In Amsterdam for example, the way privacy is protected will not be very different. It is also assumable that, in that city, privacy will be the most important value to protect as well. We are aware of the fact that for other countries, the added value of our analysis with respect to personal interests and human values and dilemmas may be different, simply because cultural differences, and therefore ethical and human values, are experienced differently. But at least for countries in the so-called 'Western World', our analysis has most probably an added value.

The design for dealing with the (non-)ethical issues and dilemmas encountered has been mainly based on a process and an institutional view where the role of the identified actors has been taken into account. These actors are often also active in other regions of the Netherlands. Therefore it is very likely that these designs are also applicable in those other regions.

For similarity reasons, a stepwise advancement of the technical system (finally ending up in a truly intelligent ECR system) is generally thought to be a good approach. The complementary approach, that of developing one national system that incorporates everything right from the start, is considered to be almost impossible simply due to complexity of the childcare organisation and the big differences in vision and interests of the various stakeholders. Instead, the suggestion to start with a simple system in each region that will be gradually expanded is highly recommended under the assumption that basic national governance and steering is implemented with respect to the technical IT standards to be

used. This will prevent all kinds of incompatibility problems between different IT systems in the future. Especially the communication standard to be used is a key issue. It should be clear that similar arguments hold if we look at the introduction of ECRs at European or other international scale.

During our design, we have tried to balance between, among others, systems performance, personal interests and human values: (a) it is the personal interest of children to get the best childcare possible, (b) stakeholders of the ECR system are supposed to work together effectively and efficiently to get optimal system's performance, and (c) human values are taken into account by solving ethical dilemmas. We cannot say that we have found the right balance already. Instead we think our contribution is more about (i) expressing the important aspects related to systems performance, personal interests and human values and (ii) providing a road map (defined by the gradual advancement of the ECR system) to find a better balance between these aspects in the near and long-term future.

The solutions proposed so far are based on the information we were able to collect during our research project. This information has come to us both from literature, from experts in the field and by some logic reasoning. Therefore the design solutions proposed actually need additional testing and validation. Furthermore it is clear that, in order to correctly assess whether the design solutions provided in this report can be applied to other regions and countries, additional field studies are needed.

VI. CONCLUSIONS

We finalize this paper through drawing some conclusions. By analyzing the roles of the different stakeholders involved in childcare, we first discovered a set of 'potential conflicts'. By performing an additional field study, we identified a series of ethical and non-ethical issues and dilemmas that confirm and further refine the potential conflicts.

In order to find a solution for the ethical and non-ethical issues and dilemmas identified, we have designed a roadmap based on a process design, an institutional design and a technical design where the ECR system gradually becomes more advanced (and ends up in a truly intelligent system that supports better decision making). By using the three design views, we have been able to come up with (beginnings of) solutions. However, improving childcare to a state where children are truly better off is a long-term challenge where much effort, patience, obligingness, and perseverance of the various stakeholders is required. It is thought to be crucial to apply a step-by-step approach in which the cooperation between the different healthcare providers can gradually grow and become more complex. It is important to give one organization the coordination role at regional or city level while some additional (inter)national steering is also required, especially with respect to standardization of the communication software to be used.

Further studies are needed to refine our proposals concerning the introduction of ECRs and to check to what extent they hold in other regions and countries in the world.

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