MEDINFO 2007
HISA Ltd Australia
© 2007 The authors. All rights reserved.

Determining Requirements for a Electronic Child Record in Youth Health Care

Anneke Goossen-Baremans[a], Lisanne van Beek[a] Lejo Bouma[b], Judith van der Kooij, William Goossen[a]

[a] *Acquest Research, Development and Consulting, Koudekerk aan den Rijn, The Netherlands*
[b] *Evean group, Icare, Meppel*

Abstract

The Electronic Child Record for Youth Health Care (ECR YHC) is seen as the solution for the problems that are experienced with information exchange. An integral ECR YHC will support youth health care and early risk detection. The Dutch government strives for the introduction of this national ECR YHC on 1 January 2008. Eight organizations had planned a route to involve users in the system development. Method: Eight institutions described technical and functional requirements that serve as a basis for the ECR YHC. For this, the Delphi method was used. Results: An expert panel of 52 experts has given its opinion on the Basis Data Set YHC, functional requirements for an ECR YHC, the data that are exchanged in electronic messages, the flow chart YHC based on the national guideline for YHC, and usability requirements. This showed a high level of consensus on the functional requirements. Conclusion: the method followed yields a high support among the care professionals and the results of this project will be used for the national tender of an ECR YHC.

Keywords:

Electronic Child Record, youth health care, Delphi technique, requirements gathering, system specifications

Introduction

Information exchange is important for a qualitative well functioning youth health care. Optimization of the information exchange is inevitable in two areas. First, the availability and exchange of data between perinatology, the administrations of immunizations, the council administration and the institutions that deliver the care to the youth of zero to nineteen years old. Second, the information exchange at population level for the purpose of epidemiological research like national monitoring. Hereby ICT will play an important role.

In the present situation the information exchange does not run optimal. Problems are [1]:

- Obtaining recent data of the youth costs a lot of effort. Thus, there is no insight in the correlation between the data whereby preventive actions are hard to perform.
- Monitoring of YHC is not possible to the full extend because it is hard to access data or because data are lacking.
- It is hard to indicate what added value the sector delivers to the health of children and the prevention of the risks for health.
- The aims of the national guideline YHC for 0-19 year old children are impossible to reach without information and communication technology (ICT) support. Because uniformity in information and in health care can not be realized, the quality of care is not guaranteed.

The implementation of an ECR for the YHC should optimize the information exchange whereby existing problems will be solved [1]. The Electronic Child Record implies the following for the youth health care institutions involved [2]:

- Optimal care will be given to the youth of 0-19 years.
- Care professionals can have current and relevant data of the child at their disposal at all times.
- Data of the council administration, administration of immunization and birth can be obtained automatically by electronic messages.
- Records can easily, safely and completely be transferred to other institutions by the use of standards for data and messages. For this the Health Level 7 version 3 (HL7 v3) [3] standard will be used.
- More insight in the work processes will be obtained whereby the processes can be organized in a better way.
- Research for the organization itself but also for the system for following the child and for policymaking can take place easier.

For this it is necessary to connect to the' National Health Index (landelijk schakelpunt in Dutch)', an indexing system that makes it possible to electronically query and exchange patient information in a safe way [4] This is part of the national health information infrastructure developed by NICTIZ, the Dutch National IT Institute for Healthcare [4].

For realization of the objectives a project has been started with eight institutions for YHC. The research question for

this phase of the project was: What are the requirements of the care providers for the ECR YHC? The Basis Data Set YHC of NICTIZ [5] and the electronic HL7 v3 messages [3] need to be part of the research.

Materials and methods

Design

To determine the requirements of the care providers a consensus method, the Delphi method, was used. Delphi method is used to systematically reach consensus for certain issues in different rounds by means of the judgment of experts. Normally a Delphi study consists of two to four rounds that follow each other in a period of some weeks. One of the benefits of the Delphi technique is that there is no social pressure on the participants. This makes it easier to give deviant opinions [6]. After each round the answers of the panel are analyzed, summarized and reported.

Different forms of the Delphi method can be distinguished. In this study we used mainly the policy version, because this so called Kantian approach is characterized by problem solution via synthesis of different parts to a rounded product [7, 8]. This is a constructivist form that can contribute excellently to a suitable approach of the development and use of an ECR YHC. Van Houten [9] indicates that this Delphi version is usable for incompletely structured problems that know several solutions and only can be dealt with from several disciplines or points of view [8].

In other sources the nominal group technique [10] for reaching consensus will be addressed as well. The specific thing of this method is that in the final round the anonymity is cancelled by organizing a meeting. For the ECR YHC project two rounds have been carried out: one anonymous written round an one panel meeting. The anonymity in this second round was kept by using voting devices with numbers, so the individual responses could not be retrieved.

Expert panel

The expert panel for this study existed of 66 experts in the field of YHC. The participating organizations themselves were responsible for an equal representation of the experts. All relevant health professions were represented in the expert panel.

Questionnaire

A questionnaire was developed because there was no questionnaire available to make an inventory of the requirements of the care providers. For this questionnaire existing documents from YHC and literature on electronic records were used. The questionnaire starts with a couple of characteristics of the respondent including the discipline and institution to which the respondent belongs.

First the Basis Data Set YHC developed by NICTIZ, in collaboration with the Organization of Care Operators (Z-org), GGD Nederland (the Dutch Council Care Service) and the Vereniging Nederlandse Gemeenten (the Association of Dutch Councils) is used. The Basis Data Set YHC is a collection relevant data that is minimally needed for the exchange of data between organizations in youth health care. It is a standard with respect to content with concepts and data relevant to youth health care. With the Basis Data Set YHC it is also possible to perform research in YHC. The set as a whole is included in the questionnaire.

Second, a cluster of unique personal details is presented. NICTIZ has made arrangements on these often occurring data groups, called HL7 v3 Common Message Element Types [3], for the connection to the national infrastructure arrangements. For patient details the CMET patient can be used. Similar arrangements have been made for health professionals in the CMET Provider. All messages from and to the ECR YHC use the same data. The CMET Patient NL has been admitted to the questionnaire as an addition to the Basis Data Set YHC. This consists of common patient data like name, date of birth, gender address and insurance, adapted to the Dutch situation.

Third, to get insight in the workflow of the preventive care for youth of 0-19 and to improve these, a flow chart has been developed (Figure 1). The chart gives an overview of the workflow that are part of the Basis Tasks Package YHC [11]. By means of a time line phases of life that a child goes through from 0-19 years are shown. On this time line the processes and moments of contact are put down. This makes the flow chart an important description of the functionality of the ECR to support the workflow.

The fourth part of the questionnaire are the functional specifications developed by GG&GD Amsterdam and GGD Rotterdam. In these functional requirements it has to be indicated exactly what the ECR YHC should be able to, to make sure that care providers can make complete and reliable reports. These specifications are complemented with requirements for usability of the ECR YHC.

Next to that, the questionnaire has been complemented with results of analysis of documents that are used in the participating institutions.

Cut off point for consensus

The aim of the Delphi method is reaching consensus on the requirements of the care providers for the ECR YHC [6,7,8,9]. For answering the questions a three point Likert Scale has been used. This had the following answering possibilities:

- 0 for not agree
- 1 for unclear or doubt

- 2 for agree

The cut off points for consensus were the following [12]:

1. A percentage agreement equal to or higher than 75%: When 75% or more of the panel members agree with the specification this accepted. Specifications for which there is disagreement have been presented again to the panel in the consensus meeting, together with the comments and the arguments that have been given by the panel members. As a result of these comments some new statements have been formulated.
2. From the remarks that have been given for a specification by the panel members should emerge that the subject was unambiguously understood. When this is not the case, the item is not due for consensus and is presented again, if necessary with explanation.

For questions that do not result in consensus, statements are formulated with the help of the remarks and suggested changes

of the expert panel. In the consensus meeting these statements are presented to the expert panel. By means of electronic voting devices the panel voted using the same answering possibilities and cut off points as described above.

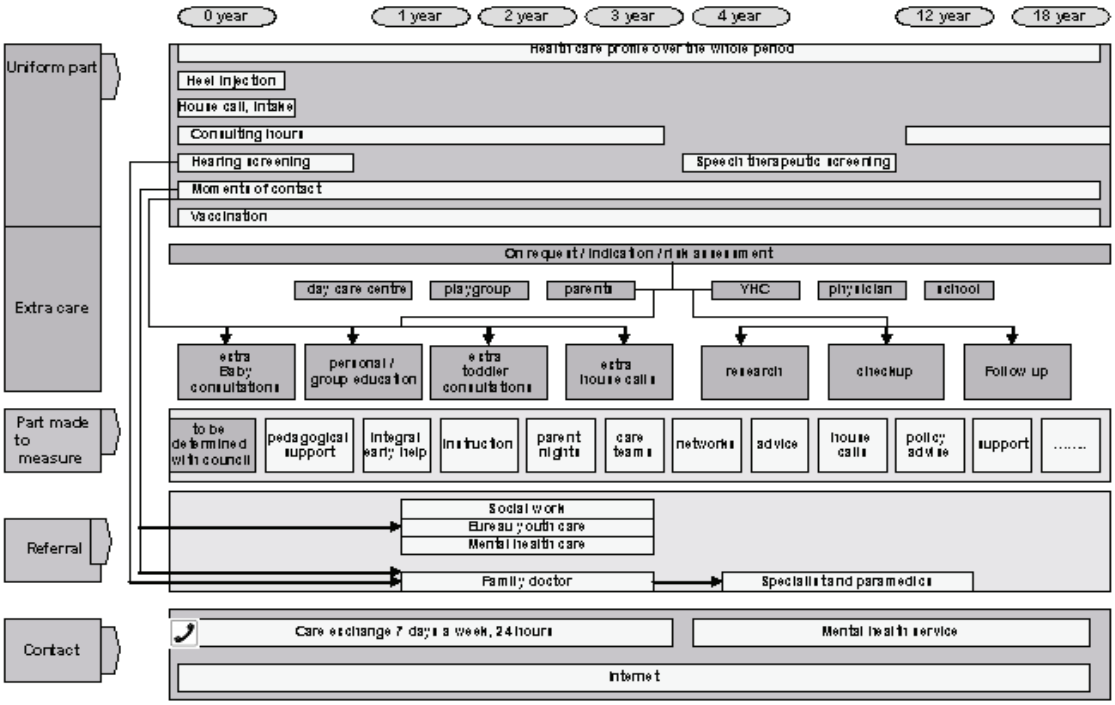

Figure 1 - The workflow chart for the Youth Health Care

Analysis

For analysis of the scores on the questionnaire SPSS software has been used. For answering the question, descriptive statistics has been used. The programme for the electronic voting generates these statistic measures itself.

Results

In total 66 questionnaires have been sent, 52 have been completed and returned (response of 79%). The professions of the respondents are shown in Table 1. The project started with five organizations. After the questionnaire was sent out, another three joined the project. Because of the later participation the representation of these organisations is relatively low compared to the other five. Next to that, for one of the organizations three members of the expert panel filled in the questionnaire together because of time pressure for returning the questionnaire. This has been indicated as three respondents.

At the consensus meeting 52 experts were present (response 79%). On some concepts not everybody voted.

Abstinence of voting on a concept has mainly been done because the subject was one in which one was not involved or not informed.

With the help of the Basis Data Set YHC [4] a Data Set ECR YHC has been developed. The Basis Data Set YHC consists of 53 concepts. For every concept attributes (observation or variable) and value sets (answering possibilities) are formulated.

The 53 concepts of the Basis Data Set YHC have been added to the questionnaire.

The expert panel members were asked for their opinion with reference to the completeness of the data and they were asked if they had additions. The additions needed to be specified as completely as possible. This meant specification in attributes, preferably with value sets.

In the written question round consensus has been reached for 25 concepts (47,2%). For the concepts for which no consensus was reached, 57 statements were formulated. These statements were presented in the consensus meeting. On 47 statements voting took place, for 29 of these, consensus has been reached (62%). On 10 statements no voting took place because new information was available, whereby statements were no longer relevant. The statements for which no consensus was reached have been discussed in focus groups consisting of representatives of the expert panel. The focus groups have decided which concept should be added to the Basis Data Set YHC, in what form and in what way addition should take place.

Example congenital heart defect

In the questionnaire the following statement has been presented to the expert panel: “The specifications ‘congenital heart defect’ are complete.” Sixty percent of the expert panel agreed with this statement. This meant no consensus was reached on this statement. In connection with the written remarks of the expert panel, the following statement has been presented at the consensus meeting: “Heart defect is added in accordance with the national standard Tracing of inherent heart defects.” There was no voting on this statement because one agreed unanimously.

In the focus group it was decided to add the following attributes and value sets to the Basis Data Set YHC (see Table 2).

Table 1 - Panel

Discipline	Amount	%
Health centre physician	9	17,3
Health centre assistant	3	5,8
Physician	4	7,7
Nurse of staff	1	1,9
District nurse	13	25,0
Physician of youth health care	6	11,5
Nurse of youth health care	3	5,8
Assistant youth health care	2	3,8
Remedial educator	1	1,9
Speech therapist	1	1,9
Epidemiologist	2	3,8
Manager	5	9,6
Secretariat	1	1,9
Assistant physician of youth	1	1,9
Total	52	100

Patient data

Of the four statements that have been presented to the expert panel consensus has been reached for three of them (75%). For the concept ‘occupation’ no consensus was reached.

Flow chart YHC

Figure 1 shows the flow chart. The statement about the flow chart was as follows: ”In the flow chart all important processes that are relevant for the ECR YHC have been taken in.” For this statement there was a 82,2% consensus. This meant that the flow chart developed by two of the organisations (ICARE and GGD Drenthe) has been accepted by the other six organisations. That is why the flow chart will serve as a starting point for the design of the ECR YHC and is inserted in the specification.

Functional specifications

On the functional specifications ECR YHC of the GG&GD Amsterdam and Rotterdam 13 statements have been formulated. For two of the functionalities no consensus had been reached. Next, nine statements have been formulated for the consensus meeting. In this meeting consensus was reached for seven statements (78%).

Example

In the questionnaire the following statement has been presented to the expert panel: “The specifications in relation to the data registration are complete.” In round one 60,4% of the expert panel agreed on this statement. As a result the following statements were presented at the consensus meeting:

1. Add: For research it is possible to search in all records on the basis of entries. For this statement 100% agreed.
2. Add the working area of the employee, for example for which school district one works. For this 56.8% agreed. The statements and the results have been discussed in a focus group. The group decided that it should be possible to mention the school in the ECR YHC.
3. In one glance it should be visible what risk factors there are for a child. For this statement there was 100% consensus. This requirement was added.
4. The system gives a timely alert when certain time limits are about to be exceeded. For this 97,8% agreed. This requirement was added to the specifications.
5. It should be possible to register in the system how many times parents/care takers call to consulting hours by telephone and with what questions. For this 90,5% agreed. This requirement was added to the specifications.

Table 2 - Additions for the concept of 'Congenital heart defect

Attribute	Value set
Examined	0=Not examined 1= Examined, no special circumstances 2= Examined, special circumstances
Intervention	0=None 1=Education/advice 2=Extra moment of contact 3=Referral
Follow up	Free text
Overall impression researcher	1=Fatigued 2=Passive 3=Undernourished impression, thin 4= Dysmorphism
Overall impression parents	Free text
Effort tolerance	First year during feeding of effort (for example crying): 1=Easily fatigued 2=Perspire 3=Rapid breathing 4=Hungry, but can not empty bottle 5=Stops drinking from the mother's breast 6=Blue or grey skin colour Toddler age: 7= Rapid fatigue with effort like walking (stairs), cycling 8= interruption of play by crouch School going and Adolescent age: 9= Fainting (in particular with effort) 10=Easily fatigued 11=Heart palpitation 12=Pain in the chest

Usability requirements

On the requirements for usability 29 statements have been formulated. For 25 statements (86,2%) consensus was reached. In the consensus meeting three new statements were presented to the expert panel. For these 100% agreement was reached.

Example

In the questionnaire the following statement had been presented to the expert panel: "I can work in more than one record at a time." Next, in the consensus meeting the following statement has been presented: "More records of children of one family can be edited at the same time." For this 96% agreed and it was added to the specifications.

Discussion and conclusion

Aim of this project was to determine the requirements for an Electronic Child Record for Youth Health Care. This aim has been reached to a high extend. For most concepts there was agreement. For some concepts consensus could not be reached and were elaborated on in focus groups of experts. The response in round one (the questionnaire) was 79 %. The attendance at the consensus meeting was high as well, again 79%. All members of the project team participated enthusiastically in determining the Data Set ECR YHC and further specifications for the system.

Despite everyone's effort a short comment on the study should be given. First on the Delphi method. In this study two rounds were used: one written question round and one consensus meeting. Next, in the focus groups it has cost time and effort to get to complete specifications for the data set ECR YHC and the system. It might be that this effort would not have been necessary when extra rounds had been scheduled. We did not choose to have extra rounds because of planning of the project and the amount of investment in time and manpower that these extra rounds would have cost.

The second comment relates to the completeness of the Data Set YHC. Performing the study was under time pressure because of project planning. Because of that the results of the written question round have not all been checked with the Basis Data Set of NICTIZ. In the consensus meeting a discussion started on a couple of statements because these were about concepts that were already in the Basis Data Set YHC. Next to that, for a statement on the immunization administration new information was presented during the consensus meeting what made the statement irrelevant. Because of the effort of the experts in both the consensus meeting and in the focus groups, a Basis Data Set ECR YHC and a list of specifications were created that gained a lot of professional support.

The controversial subjects that still exist have been discussed in the focus groups. A part of these subjects relate to the planning of contact moments and registration of data for both internal and external use. At that moment it was decided to start a working group that had to tackle the issues concerning requirements for the ECR related to planning and registration. Currently, a national tender is ongoing for the procurement of the ECR YHC, and this work is part of the specifications.

Acknowledgments

We want to thank the eight youth health care institutions, ICARE, GGD Drenthe, GGD regio Noord Veluwe, GGD Gelre-IJssel, Vérian, Yunio, Zuwe and Vitras, for their devoted participation in this study.

References

[1] Nationaal Instituut voor ICT in de Zorg (NICTIZ). Plan van Aanpak Programma Informatisering Jeugdgezondheidszorg versie 1.2. Leidschendam, 2004. [in Dutch]

[2] Bouma L. Projectplan EKD JGZ. Meppel, ICARE, 2005. [in Dutch]

[3] Health Level 7. Message standards. WWW documents. http://www.hl7.org/ Accessed November 2006.

[4] Nationaal Instituut voor ICT in de Zorg (NICTIZ). Specificatie van diensten en functies binnen het LSP versie 1.2. Leidschendam, 2005. [in Dutch]

[5] Nationaal Instituut voor ICT in de Zorg (NICTIZ). Basis Dataset JGZ versie 1.0. Leidschendam, 2005. [in Dutch]

[6] Klop R, Wijmen van FCB. Delphi-Methode bij onderzoek naar voorwaarden voor overdracht van zorg. In: Francke AL, editor. Kwalitatief onderzoek in de verpleegkunde. Amsterdam/Lisse: Swets & Zeitlinger; 1990; 43-57. [in Dutch]

[7] Mitroff II, Turoff M. Philosophical and methodological foundations of Delphi. In: Linstone HA, Turoff M. (Eds.) The Delphi method, techniques and applications. Reading Massachsetts: Addison-Wesley Publishing Company; 1975. p. 17-36.

[8] Houten van HJ. Vijf variaties op het Delphi-thema. In: Daniels JJMC, Duijzer G, editors. Delphi: methode of mode? Symposiumverslag. Amsterdam: Siswo publicatie 327; 1988; 5-34. [in Dutch]

[9] Houten van HJ. Mogelijkheden en dilemma's van beleidsgericht Delphi-onderzoek. Amsterdam: Delphi Consult; 1988. [in Dutch]

[10] Murphy MK, Black NA, Lamping DL, McKee CM, Sanderson CFB, Askham J., Marteau T.. Consensus development methods, and their use in clinical guideline development. Health Technology Assessment; 1998;2(3):i-iv, 1-88.

[11] Ministerie van Volksgezondheid, Welzijn en Sport. Basistakenpakket Jeugdgezondheidszorg 0-19 jaar. Den Haag; 2002. [in Dutch]

[12] Goossen WTF, Epping PJMM, Dassen TWN (1997). Criteria for Nursing Information Systems as a component of the Electronic Patient Record: an International Delphi study. Computers in Nursing, 15, 6, 307-315.

Address for correspondence

Anneke Goossen - Baremans, Acquest, Dorpsstraat 50 2396 HC Koudekerk aan den Rijn,
the Netherlands,
AnnekeGoossen@cs.com, acquest@acquest.nl