

Clinical Decision Support Systems in Context

Benefits, Challenges and Future Recommendations
for Implementation in Rural Uganda

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Abstract

Clinical Decision Support Systems in Context - Benefits, Challenges and Future Recommendations for Implementation in Rural Uganda *Beata Thorstensson*

The quality of the health care in developing countries can vary a lot and there is an immense shortage of educated health professionals. At the lowest health care levels in rural areas the situation is even worse, and the facilities are often lacking many important diagnostic tools.

Uganda is one of the countries where these problems are apparent. However, one way to address these issues can be to introduce and make use of computer assisted diagnostic and treatment systems, also known as clinical decision support systems. This has been done successfully in other countries. Still, even with the necessary IT-infrastructure in place, the implementation of these systems has had to face many challenges. Therefore, before starting the development process for a system meeting the needs in Uganda, it is necessary to investigate previous experiences within the field.

By using theories from the field of human-computer interaction, focusing on accessibility, usability and acceptability aspects as well as the people, activities, context and technology framework, different previous experiences from the use of clinical decision support system and clinical guidelines have been investigated and discussed. This has mainly been done by studying a variation of research articles written on the subject and by looking into existing systems.

The results show that the use of clinical decision support systems alone is not going to solve the problems with the health care that are present in Uganda. It can, however, be an important tool for the health workers, a tool that can help them in their work and guide them in decision making. In the end, whether or not the system will be used depends on how well the developers of the system manage to understand the needs and wants of the end-users and other stakeholders. This will affect both the use and the usability of the system. However, more concrete results could have been reached if it would have been possible to come in direct contact with the proposed end-users.

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Sammanfattning

Kliniska beslutsstöd är en form av stödsystem som är tänkta att användas i en klinisk miljö. De erbjuder systematiskt sammanställd information som kan guida användaren gällande beslut angående till exempel diagnostisering eller behandling av enskilda patienter. Ofta är dessa typer av system datorbaserade. Systemet får då input i form av patientdata, detta matchas i sin tur med systemets medicinska kunskapsbas med hjälp av ett logiskt system och slutligen ges sedan output i form av patientspecifika råd. En föregångare till dessa typer av system kan sägas vara pappersbaserade guidelines. Det är ofta dessa guidelines som idag har byggt upp de kunskapsbaser som de datoriserade kliniska beslutsstöden bygger på.

Syftet med att använda sig av dessa typer av system är bland annat för att underlätta informationsbearbetningen för de personer som arbetar inom kliniska miljöer, men också att förbättra kvalitén, göra vården mer i överensstämmelse med vetenskapliga rön och för att hålla kostnaderna nere. På detta sätt kan den här typen av system sägas erbjuda stor potential, men det har visat sig att de på många platser används i väldigt liten utsträckning. Inte heller användandet av pappersbaserade kliniska guidelines kan sägas vara helt problemfritt.

I utvecklingsländer saknas ofta tillgång till internet och datorer, vilket kan ses som en förutsättning för att de datoriserade kliniska beslutsstöden ska kunna användas. Däremot pågår just nu i Uganda ett projekt som går ut på att installera den nödvändiga IT-infrastruktur som behövs för att ett sådant här system ska kunna vara tänkbart att installera. Innan detta blir möjligt är det dock nödvändigt att undersöka vilka typer av utmaningar som kan komma bli aktuella vid en eventuell implementering, vilket är vad denna uppsats syftar till. I övrigt är det av intresse att se över vilka de eventuella fördelarna kan bli samt om det finns speciella faktorer som bör tas i beaktning vid implementering av kliniska beslutsstöd i utvecklingsländer.

Det system som eventuellt kommer att utvecklas kommer att bygga på de guidelines som tagits fram av Världshälsoorganisationen och som är anpassade för användande i fattiga utvecklingsländer. För det första krävs det inte många typer av diagnostiska redskap för att använda dem och för det andra rekommenderar de alltid de billigaste och mest effektiva mediciner som finns tillgängliga. Däremot har det visat sig att det tar alldeles för lång tid att följa dessa guidelines, vilket gör att de i slutändan sällan används. Dessutom kostar det väldigt mycket att utbilda personer i att använda sig av detta hjälpmedel.

För att ett datoriserat kliniskt beslutsstöd ska kunna vara användbart inom hälsovården i Uganda måste systemet anpassas efter olika typer av användargrupper med varierade förkunskaper. Vidare måste slutanvändarna och patienterna lita på och acceptera den här typen av program. Systemen måste vara snabba och flexibla samt fortsätta att låta sjukvårdspersonalen själva fatta beslut i särskilda fall. Hur välanvända systemen blir i slutändan kommer att avgöras av huruvida programmerarna lyckas förstå och tillgodose användarnas behov och önskemål. Det är även viktigt att alla inblandade inser och har förståelse för systemets begränsningar. Datorer har nämligen, till skillnad från människor, inte samma förmåga att fatta flexibla beslut baserat på historia och sammanhang. Naturligtvis måste även hänsyn tas till de ovannämnda tids- och kostnadsaspekterna som har påverkat användandet av Världshälsoorganisationens kliniska guidelines.

Acronyms

CAS	Clinical Assessment System
CDSS	Clinical Decision Support System
CHW	Community Health Worker
CIG	Computer-Interpretable Guideline
EHR	Electronic Health Records
HC	Health Center
HCI	Human-Computer Interaction
ICCM	Integrated Community Case Management
ICT	Information and Communication Technologies
IMAI	Integrated Management of Adolescent and Adult Illness
IMCI	Integrated Management of Childhood Illness
MCE	Multi-Country Evaluation of IMCI effectiveness, cost and impact
MoH	Ministry of Health
PACT	People, Activities, Context and Technology
PDA	Personal Digital Assistant
RRH	Regional Referral Hospital
SALAR	Swedish Association of Local Authorities and Regions
Sida	Swedish International Development Cooperation Agency
TB	Tuberculosis
UCG	Ugandan Clinical Guidelines
UNICEF	United Nations Children's Fund
VHT	Village Health Team
WHO	World Health Organization

Table of Contents

Sammanfattning	1
Acronyms	2
List of Illustrations	5
1. Introduction	6
1.1 Purpose and Question Formulation	7
1.2 Delimitations	8
1.3 Explanations of Some Important Terms Used in the Thesis	8
1.3.1 Initial terms	8
1.3.2 Guidelines vs. Decision Support	9
1.4 Outline	11
2. Background	12
2.1 Project Background and Description	12
2.2 The Health Care System in Uganda	13
2.3 Uganda Clinical Guidelines	15
2.4 Integrated Management of Childhood Illness	16
2.5 Integrated Management of Adolescent and Adult Illness	18
3. Theoretical Framework	19
3.1 Human-Computer Interaction	19
3.2 Accessibility, Usability and Acceptability	20
3.2.1 Accessibility	20
3.2.2 Usability	21
3.2.3 Acceptability	22
3.3 PACT - Designing Interactive Systems	22
3.3.1 People	23
3.3.2 Activities	23
3.3.3 Context	23
3.3.4 Technology	24
3.4 Design Guidelines	24
3.4.1 Access, learn and remember the system (learnability)	24
3.4.2 Being in control, knowing what to do and how to do it (effectiveness)	25
3.4.3 Safety and securely (effectiveness)	25
3.4.4 Accommodation to the user	25
3.4.5 Additional design aspects	25
3.5 Knowledge Management for Clinical Decision Support Systems	26
3.5.1 Aspects that need to be considered regarding knowledge and updating	27
4. Methodology	29
4.1 Literature Studies	30
4.2 Limitations with Using Secondary Material	32
4.3 Study Visits, Observations and Interviews	33
5. Clinical Decision Support Systems in Context	35
5.1 IMCI Experiences	35
5.1.1 Benefits	35
5.1.2 Challenges	37
5.1.3 Computerized training of IMCI	38
5.1.4 Community IMCI	39

5.2 Computerized Decision Support in India and Tanzania.....	40
5.2.1 The case of India	40
5.2.2 The case of Tanzania	41
5.3 Usability Aspects when Designing for People with Low-literacy Levels and Novice Users	44
5.4 Clinical Decision Support Systems in Sweden and England.....	47
5.4.1 Sweden	47
5.4.2 The CAS-system in England.....	49
5.5 Previous Research on CDSSs	50
5.6 Knowledge management and updating.....	52
5.6.1 Updating and adaptation of IMCI.....	53
6. Analysis.....	54
6.1 People.....	54
6.1.1 Clinical officers.....	55
6.1.2 Nurses	56
6.1.3 Community health workers.....	56
6.1.4 Patients	59
6.2 Activities	60
6.2.1 Organizational aspects	62
6.3 Context.....	62
6.4 Technology.....	64
6.5 Design Aspects.....	65
6.5.1 Visibility.....	65
6.5.2 Consistency and familiarity	67
6.5.3 Control and feedback	68
6.5.4 Recovery and constraints	68
6.5.5 The style.....	68
6.6 Knowledge Management	69
7. About this Study.....	72
8. Conclusions.....	74
9. List of References	75
9.1 Books	75
9.2 Book Chapters.....	75
9.3 Journal Articles	75
9.4 Reports and Other Publications	77
9.5 Internet	79
9.6 Interviews.....	80

List of Illustrations

Tables

Table 1: Health center status and organization in Isingiro district.

Table 2: Results from Nielsen's study of design for low-literacy users.

Figures

Figure 1: Map of Uganda displaying the location of Mbarara district.

Figure 2: Example from the IMCI protocol.

Figure 3: The basic elements in an iterative user-centered design process.

Figure 4: Examples of the interface.

Figure 5: Example of task division.

1. Introduction

Every day over 30,000 children in the world die before the age of five, this adds up to almost 11 million children that die each year. The major cause of death for these children is starvation, or as a result of easily preventable diseases and illnesses. [52] The overall highest levels of child mortality are reached in sub-Saharan Africa, and Uganda is one of the countries where children are still suffering a lot.

However, Uganda's problem with the health care is not only reflected by the under-five mortality rates; the country also has a very high maternity mortality rate. It is a country where 880 women out of 100,000 live births, die as a result of complications during birth. Further, the overall life expectancy in Uganda is only 52.7 years. [68] The top causes of death include HIV/AIDS, malaria, lower respiratory infections and diarrheal diseases. For children under-five the major killing diseases are similar, with the addition that many children die because of neonatal causes. [40]

Similarly to other countries in sub-Saharan Africa, Uganda is lacking educated health professionals. In Uganda there is only one physician for every 10,000 people. In contrast, Sweden has one physician for every 280 people. [66] The situation in Uganda is even worse in rural areas, seeing how most educated people live and work in the cities. Due to this reality, a severe problem with the health care in rural Uganda is the long distances that make it both expensive and time consuming for the population to get medical attention. All in all there are only 43 general hospitals in the whole country, and Uganda is a country with over 30 million people. [31] Therefore, the most accessible interaction with the formal health care system is usually with a nurse on the lowest health care level closest to the community. [65]

Surveys show that when people seek help for health related issues in developing countries, it is common that the patients are not properly assessed and treated by the health care providers. The health-facilities in low income countries such as Uganda, lack important diagnostic support and laboratory services and since the resources are so limited there is also a shortage of both equipment and essential drugs. [65] Another issue that creates problems for the patients is the high variable in quality, when it comes to the health care delivery. [45]

One way to address these problems, with lack of well educated health professionals and variation in quality, is to introduce and make use of computer assisted diagnostic systems. This is something that has been done in India for several years. However, in order for such technology to be a possible solution in rural areas there is a need for development of appropriate health care and IT infrastructure in these areas. [13]

A computer assisted diagnostics systems can be an example of Computer-Interpretable Guidelines (CIGs) or Clinical Decision Support Systems (CDSSs). However, the last two expressions have a much wider meaning. They define all sorts of tools that can be used for a variety of other clinical features, rather than for diagnostics reasons only. Already in the 1960s there were efforts to automate certain aspects of health care. Nevertheless, the adaptation rate and the impact of these tools remain quite low. Some systems have proven

to be very successful tools for reducing errors and costs, encouraging best practices and being helpful in a variety of other ways. But many problems remain and it has been shown to be a much bigger challenge than generally anticipated to create well-working and well-used systems. [9]

Most of the diagnostics systems that have been developed and that are used today in the developed world have been working as stand-alone systems that clinicians or experts can consult with for specific cases. However, there are also existing examples of systems that are connected to the Electronic Health Records (EHR) systems, which often leads to them being more integrated into the clinicians' workflow. [6]

In developing countries there have also been examples of implementation of different types of CDSSs. However, in these countries the lack of IT infrastructure can have contributed to the limited spread of the systems. Instead many developing countries in low resource settings make use of paper-based clinical decision support or clinical guidelines developed by the World Health Organization (WHO) or the national governments. This is something that is currently being done in Uganda where the Ministry of Health (MoH) has developed the Ugandan Clinical Guidelines (UCG). Examples of the WHO developed clinical decision support is the Integrated Management of Childhood Illness (IMAI) and the Integrated Management of Adolescent and Adult Illness (IMAI).

Since the beginning of 2009 Uganda and Sweden are together working in the project ICT4MPOWER to improve the health care delivery in Uganda by the use of Information and Communication Technologies, also known as ICT. This means that the necessary IT infrastructure will be put in place and among other things an EHR-system will be developed and implemented. Thoughts were then raised that the use of computer-interpretable guidelines or clinical decision support systems could be helpful for the health workers and beneficial for the patients. [47]

1.1 Purpose and Question Formulation

Since the success for implementation of CDSSs and similar systems has varied considerably, there is a need to investigate the reasons for these variations and to identify the challenges and problems that these types of systems have encountered. By gathering some of the lessons learned within this field, the purpose of this thesis is to suggest some recommendations for future development of a system like this for Uganda. However, the fact that this particular system is meant to be used in a low resource setting only adds to the challenges, because the conditions in Uganda differ a lot from the developed world. The following research questions will be covered within the scope of this master thesis.

- In what ways can Clinical Guidelines or Clinical Decision Support Systems be useful for health workers in rural areas in general, and Uganda in particular?
- What are the implementation challenges that have been experienced for these types of systems in other parts of the world, and what are the lessons to be learned from previous work in Uganda?

- What types of adjustments have to be made and what aspects need to be taken into consideration in order for a CDSS to fit the Ugandan low resource- and rural conditions?

1.2 Delimitations

Within the scope of this thesis, the term clinical decision support system will represent a type of diagnostics and treatment system that will be developed for use in Uganda. Today, there are many diverse systems that can be used for the same purpose, but that are named differently. This thesis does not aim to give an account of all the different systems.

Rather, the aim is to investigate the systems that appear to have something in common with the system that will be built for the use in Uganda, without taking into account what type of system it is and what type of technological basis it has.

The focus for this thesis does not lie on technical aspects regarding the equipment that should be used for the clinical decision support system. Issues regarding the technology and energy solutions have been dealt with by other thesis workers within the scope of the ICT4MPOWER project. Further, this thesis will not deal with expert systems meant to be used by medical personnel working with specialized care. All the systems that are produced by the ICT4MPOWER project are being developed for primary care settings, as will the CDSS. Economic, moral and ethical aspects are only introduced in this thesis and they are not thoroughly investigated.

1.3 Explanations of Some Important Terms Used in the Thesis

To give the reader a better understanding of the meaning of some of the important terms that are used in this thesis, these will be introduced and explained below. Seeing how Uganda is described as a developing country and the system is intended to be used in a rural low resource setting, it can be of interest to describe what is meant by this. Further, the difference between guidelines and decision support will be dealt with.

1.3.1 Initial terms

- **Developed countries**, also known as industrialized or western countries, are all the countries that can be referred to as having a high income. The people living in these countries have a high standard of living and all in all these countries contain about 15 percent of the world's population. [62]
- **Developing countries** are usually described as countries having a low or middle level of gross national product per capita and a low level of industrialization, and where about 85 percent of the world's population live. [62] Uganda can, according to the United Nations, even be said to belong to the least developed countries in the world. These countries are characterized by low income, weak human assets and economic vulnerability. [63]
- **Low resource settings** refer to areas where the resources are scarce.

- **Rural settings** are areas outside the limits of a city. In Uganda about 80 % of the population is living in rural areas. However, only 20 % of the doctors are working there. [61]
- The term **System** can be a very wide term. One definition is that a system is a group of interacting, interrelated, or interdependent elements that are together forming a complex whole. In this thesis the term system is often used to refer to the clinical decision support system that will be developed. [60]
- **Interactive system** is a term that covers the components, devices, products and software with the primary concern to process information. [1] A CDSS is one type of interactive system.

1.3.2 Guidelines vs. Decision Support

Clinical guidelines can be defined as recommendations that are based on the latest available evidence regarding the appropriate care and treatment of a patient suffering from a certain condition. These types of guidelines have been developed to increase the quality of care, lower the cost and eliminate differences in practice. A typical example of these types of guidelines is the Ugandan clinical guidelines that were developed by the ministry of health in Uganda.

Clinical guidelines can be paper-based as well as computerized (in this case referred to as **computerized clinical guidelines**). However, it has been proven that in order for the guidelines to actually affect the clinician's behavior they have to provide patient specific advice at the time of the patient encounter. One way of doing this can be to turn the narrative guidelines into **computer-interpretable guidelines**. CIGs are guideline-based decision support systems (and cannot only be considered as guidelines), similarly to clinical decision support systems they are building on an algorithmic approach and providing automatic interference based on patient specific data. [10]

The definitions of **clinical decision support systems** vary in the different texts that I have come across during the work with this master thesis. One example is the below mentioned definition from the Health Services Advisory Group and DOQ-IT [46].

“A clinical decision support system (CDSS) is software designed to aid clinicians in decision making by matching individual patient characteristics to computerized knowledge bases for the purpose of generating patient-specific assessments or recommendations.” [46]

Another similar definition is provided by Wyatt J. and Spiegelhalter D. [55].

“Clinical Decision Support Systems (CDSS) is an expression used for computerized systems with the aim to impact clinician’s decision making regarding specific patients at the point of care.” [55]

From this we can draw the conclusion that CDSSs are computerized systems, providing patient-specific advice at the point of need. However, in other cases it clearly states that the clinical decision support systems do not have to be computerized, but that this is usually the case.

The term system in clinical decision support systems indicates that it is a computerized system. Nevertheless, the WHO protocols is something that will be refer to as a type of clinical decision support. This is due to the fact that the protocol consists of a set of algorithms (a formula or set of steps for solving a particular problem), where patient data should be used and that give patient-specific advice in the end. However, seeing how it is not computerized in its original form the term system has been removed when discussing the paper-based IMCI (Integrated Management of Childhood Illness) or IMAI (Integrated Management of Adult and Adolescent Illness) protocols. The reason why this is mentioned is to point out that the IMCI and IMAI are much more than just narrative clinical guidelines. However, to not confuse things further, IMCI/IMAI will mainly be referred to as the IMCI/IMAI charts or the IMCI/IMAI protocols. The term CDSS is used for the end product that we wish to develop and for the types of computerized systems that have been evaluated within the scope of this thesis. Seeing how the term CDSS is much wider than CIG I have chosen to primarily use the former, to not complicate things too much.

The knowledge bases of the CDSSs have often been built up from expert physician opinions or from clinical guidelines (in this case it can also be referred to as a CIG). However, there are also CDSSs that are nonknowledge-based systems. Instead the system use a type of artificial intelligence called machine learning, where the system can use clinical data to recognize certain patterns. These types of systems will not be covered within the scope of this thesis, but it can still be interesting to know about different possibilities and it might be useful for future development of the CDSS. [15]

The aim and use of clinical decision support systems can vary in many ways. For example the timing of support can differ; the support can be given before, during or after the clinical decision has been made. [6] Further, the support can regard different types of clinical actions that can be divided into four groups:

1. Administrative: Authorization of procedures and referrals.
2. Managing clinical complexity and details: Tracking orders, follow-up on referrals and preventive care.
3. Cost control: Monitoring of medication or drug orders, avoiding unnecessary tests and duplications.
4. Decision support: Promotion of best practices, providing support for clinical diagnosis and treatment procedures. [21]

The last group will be the one that is most relevant for this study. To facilitate for the reader I will now present the outline of this thesis.

1.4 Outline

This thesis has started with a shorter introduction, with the aim to give the reader a quick insight into the subject. The purpose of this thesis and the research questions have then been presented, after which some of the terms that are important for the understanding of this thesis have been explained.

The introductory chapter is followed by a presentation of the background in chapter 2. The background chapter covers information regarding the ICT4MPOWER project, the health care system in Uganda and its actors, and an introduction to the Ugandan clinical guidelines and the WHO IMCI/IMAI paper-based medical protocols. The background is an important part of this thesis and therefore a whole chapter will be dedicated to these aspects. This also describes a bit more of the context in which the system will be used.

After the background chapter the theoretical framework that is being used within the scope of this thesis will be presented, this will be done in chapter 3. The theoretical chapter includes texts from the field of human-computer interaction (HCI), emphasizing on the usability aspects of interactive systems in general. This framework will form the basis for the analysis in chapter 6.

Chapter 4 provides information regarding the methodology that has been used and some of the consequences that it has had for this thesis. The sources used for this thesis are mainly secondary. However, some primary sources with experiences from working with clinical decision support systems and health care in Sweden have also been a part of this work.

Chapter 5 presents the results from this study. The chapter includes an evaluation of the IMCI protocol, a review of two different CDSS in use in developing countries today, a presentation of studies performed regarding users with low-literacy levels, CDSS in use in Sweden and England, a compilation of some meta-reviews on the subject of CDSS and implementation challenges, and finally a section covering some aspects of knowledge management.

The result chapter of the thesis is followed by chapter 6, analysis. In this chapter the theoretical framework is used as a basis for an analysis of the results of this study. The chapter is divided into different sections following the theoretical framework and the people, activities, context and technology (PACT) division.

After the analysis the evaluation of the method and results of this study will be presented in chapter 7. The evaluation is followed by a short summary of some of the most important conclusions that can be drawn from this thesis work. The conclusions will be presented in chapter 8.

2. Background

To be able to understand the prerequisites and context for the ICT supported health care system that is meant to be implemented in Uganda (for which the CDSS is considered as one of the parts), it is important to get some insight into the project background and the health care system in Uganda. This part of the thesis will also introduce the reader to the clinical decision support developed by the WHO and the Ugandan clinical guidelines. These are the documents that were suggested to be used as a basis for the CDSS development, by the project management.

2.1 Project Background and Description

The project named ICT4MPOWER started in April 2009 and it is planned to continue until March 2012. The initiative for the project came from the MoH in Uganda, the Uganda Communications Commission and the Ministry of ICT. From the Swedish side the involved parties, who are in charge of providing the technical support, include the Biomedical Engineering Department at Karolinska University Hospital, Karolinska Institute, Ericsson AB and The Royal Institute of Technology. The project is equally sponsored by both Swedish and Ugandan parties. [57] The Swedish funding is handled by SPIDER, an organization sponsored by the Swedish International Development Cooperation Agency (Sida) that works to support developing countries in the use of ICT for development and poverty alleviation. [58] The Ugandan funding is coming from the Uganda Communications Commission. Another partner from Uganda, who is involved in the project and is supporting the technological work, is Makerere University. The involved actors from Makerere include the College of Health Sciences and the Faculty of Computing and IT. [57]

The overall aim of the project is to increase the effectiveness of the Ugandan health system, to improve the information flow from the community to the district and regional levels and to empower the health workers by the use of ICT; all for better health outcomes of the rural population in Uganda. [47]

To achieve the goals the necessary E-infrastructure will need to be put in place, which will be done with the support from Uganda Communications Commission. Other parts of the project include implementation of an effective electronic health record management system, creation of a unique patient identification system, establishment of an electronic patient referral and feedback system, creation and implementation of an e-learning system, establishment of a mechanism for tele-consultation support and establishment of a system for human resource development. During the work with the EHR-system, the idea came up to closer investigate the possibilities to also include and incorporate a clinical decision support system that could be combined with the other services offered. [47]

Initially the project is limited to implementation in Isingiro district, which is a remote rural district in the Mbarara Region, right on the border with Tanzania (see Figure 1 below). In this particular district there are about 400, 000 people living. The majority supports themselves by small scale farming or pastoralism. The district is chosen

because it has one of the lowest health indices in Uganda and therefore it was found to be a good place for proof of concept. The goal is to develop and implement a well working system that can help to improve the health indices of the district, and which can later be implemented on a national scale. [47]



Figure 1: Map of Uganda displaying the location of Mbarara district.

A severe problem with the health care in rural Uganda is the long distances that make it both expensive and time consuming for the population to get medical attention. One solution to this problem, which is currently being tested in the country, is to educate people in the villages and establish so called community health workers (CHWs). With a 2-3 months long education they will attain basic health care knowledge. CHWs are lay people working either as volunteers or for pay, to serve their community in association with the local health care system. The CHWs will be chosen by the local communities and must be interested to learn more about health related questions. An additional requirement is that the CHW should be able to read and write, at least in the local language. [37]

The clinical decision support system is meant to help and support these community health workers, but if possible it will also guide nurses and clinical officers on a higher level in the health care system. The system will help them to make the correct diagnoses by using the patient's symptoms to get advice and suggestions for treatment. The type of system that is developed should be based on the medical algorithms in the WHO IMCI and IMAI protocols. Information from the Ugandan clinical guidelines should also be used.

2.2 The Health Care System in Uganda

In Uganda different kinds of primary health care services are provided on different health care levels in the country. For each level people with various types of education and experiences are working. This will in turn result in the clinical decision support system having many different types of users. Therefore, it is important to get an understanding of the health care system in Uganda.

First of all, the ministry of health is the decision making authority for the health sector in Uganda. However, the provision of health services has been decentralized and the districts and health sub-districts have the responsibility to deliver health services on their respective levels. [31]

The national health system in Uganda is a combination of the public sector and the private practitioners and it consists of all organizations and actors whose primary goal is to achieve and sustain good health. The private system includes the private health providers, private not for profit providers and the traditional and complementary medicine practitioners. [31]

Second, the public system in Uganda is divided into different levels depending on the actors employed, their competences and the services they provide. At the top of the organization are the national referral hospitals. There are only two of these hospitals in the country. The services that they provide are very specialized and they are also involved in health research and teaching. In Uganda there are also 11 Regional Referral Hospitals (RRHs). In addition to the services that are also provided by the general hospitals, the RRHs provide specialist clinical services and higher level of surgical and medical services. Further, there are 43 general hospitals all over the country. They provide preventive, promotive and curitative services within the fields of maternity, in-patient health services, surgery, blood transfusion, laboratory and medical imaging services. [31]

Third, all hospitals have the responsibility to support supervision to the lower health care levels. The lower levels are all on the district level and are divided into different types of Health Centers (HCs): HC4, HC3 and HC2. The HC1 level does not actually have a physical structure; rather it is constituted by a team of people also known as the Village Health Team (VHT), which consists of several of the above mentioned community health workers. They are working as a link between the health facilities and the community. [31] Their tasks include performing home visits, health education and promotion, community based management of common conditions, disease surveillance and follow up during and after pregnancies. Health education regarding personal hygiene, sanitation, nutrition and sexual practices, among others, can help to prevent diseases such as malaria, tuberculosis, upper respiratory infections, and HIV/AIDS. In Uganda over 75% of the diseases people are suffering from are preventable, and could be avoided if people became more educated and changed their health behavior. [37]

In Isingiro district they have a total of three HC4, 14 HC3 and 35 HC2, which includes both the governmental and private facilities (see Table 1). [34] An HC4 normally consists of a clinical officer, a nursing officer, midwives, nurses, a laboratory assistant, nursing assistants and a health inspector. The number of people employed can naturally vary between different HC4 clinics. An HC3 have one or more midwives, a clinical officer, a nursing assistant, a laboratory assistant and a nurse, whereas an HC2 only has a nursing officer. The nurse is limited to providing out patient care and community outreach services. This is the first level of interaction between the formal health sector and the communities and this person also serves as a linkage to the VHTs. [32] Within the scope of the ICT4MPOWER project only the health centers up to level 4 will be included.

Health Center Level	Number of HC in Isingiro	Staff
HC4	3	Clinical officer, midwives, nursing officer, nurses, laboratory assistant, nursing assistants and health inspector
HC3	14	Clinical officer, midwife, nursing assistant, laboratory assistant and nurse
HC2	35	Nursing officer
HC1 (Village Health Team)	NA	Community health workers

Table 1: Health center status and organization in Isingiro district.

During a field trip to the Isingiro district the workflow on the different HC-levels were investigated and later described in the Work flow analysis report for Isingiro (2010). This report only describes a detailed workflow at an HC4 clinic. The nurses' tasks include the gathering of signs and symptoms, whereas the clinical officers are in charge of making the diagnosis and prescribing drugs. [32]

2.3 Uganda Clinical Guidelines

In 2010 the MoH in Uganda published the Uganda clinical guidelines 2010 (also known as the UCG), which is a revised version of the national standard treatment guidelines that were published in 1993. The guidelines are developed with the aim to provide useful and updated information to health care professionals working in both upper and lower level health facilities. By compiling different guidelines the combined material is meant to cover the management of all the common conditions present in Uganda. All in all the UCG 2010 offers information regarding important elements of clinical diagnoses and guidance on required basic investigations. Further, it is proposing cost-effective treatments and guidance when to refer or admit patients. Even though the guidelines in the end suggest some type of treatment, this advice should not be followed blindly, according to the ministry, it is still necessary to use clinical judgment and experience for the particular needs of individual patients. The UCG was reviewed and approved at a special national consensus workshop organized by the MoH. In order to keep the guidelines updated and be able to make improvements, the ministry wants the users to send them feedback continuously. [35]

The guidelines are divided into different topics such as infections, parasitic diseases and respiratory diseases etcetera. Each topic consists of a number of diseases or conditions for which certain information has been included. The initial information is more of a general nature, which is then followed by the causes of the disease, common features, differential

diagnosis, investigations and prevention. The guidelines also include a management section for each condition that is covered. This section is meant to encourage appropriate and cost-effective use of essential medicines. Developing countries like Uganda have very scarce resources, which means that the supply of essential medicines often is limited or even not available at all. Further, even if the drugs are available, they are not always appropriately used by health professionals. [35]

In the introduction to the guidelines the recommended work process for clinicians is proposed. The work process suggested by the UCG is to first greet the patient, look for general danger signs (severe breathing, distress, lethargy or unconsciousness, severe pain, cyanosis), ask about symptoms, look and listen for signs, decide on the most likely diagnosis, consider differential diagnosis and use UCG to check these conditions to get symptoms to ask for, if possible take laboratory test to confirm, to refer the patient if necessary and decide on treatment. To make a diagnosis, or rather to classify a child's condition, parts of the WHO protocol for integrated management of childhood illnesses are available. The UCG also covers some of the aspects of the IMAI protocol for adults and adolescents. [35]

Another document that has been developed by the ministry of health, and that is meant to be used together with the UCG 2010, is the Essential Medicines List of Uganda 2007. The medicines presented in this list are those that are thought to satisfy the needs of the majority of the population. All the medicines should be safe, efficient and cost-effective. This list has been put together by a group of experts in collaboration with the responsible people for different technical programs at the MoH. Similarly as with the case of the UCG, the MoH are asking clinicians to help improve the list and keep it updated by sending their experiences from the field. The essential medicines list of Uganda also describes at which level of health care facility different drugs should be available and may be used as a standard treatment for diseases or conditions. This differentiation has been made on the basis of what type of diagnostic and clinical skills that are available at specific levels. [33]

2.4 Integrated Management of Childhood Illness

The IMCI protocol was developed by the WHO and the United Nations Children's Fund (UNICEF) in the mid 1990s as an integrated approach to improving child health. It has now been introduced in over 75 countries. The strategy is divided into three parts: improved case-management, improved health systems support and improved family and community practices. The aim is to improve the health care delivery within primary care. [65]

The first part of the IMCI protocol consists of a set of medical algorithms. These algorithms will guide clinicians in the examination of a child and indicate what type of investigations that should be carried out (see Figure 2). The algorithms in the IMCI protocol cover the following symptoms: cough and difficulty breathing, fever (with or without an ear problem) and diarrhea. Clinicians are also encouraged to check for general danger signs, malnutrition and anemia, and the immunization status of the child. The results of the investigations that are carried out by clinicians will in the end lead to a

classification of the sick child. The classification is divided into three parts, after the severity of the condition. The three different types of classifications are represented by the color red for severe cases that need to be referred urgently, yellow for a moderate classification of the illness and green for the least severe cases. [44]

THEN ASK ABOUT MAIN SYMPTOMS: <i>Does the child have cough or difficult breathing?</i>		SIGNS	CLASSIFY AS	TREATMENT <small>(Urgent pre-whereal treatments are in bold print)</small>
<p>IF YES, ASK:</p> <ul style="list-style-type: none"> • For how long? 	<p>LOOK, LISTEN, FEEL:</p> <ul style="list-style-type: none"> • Count the breaths in one minute. • Look for chest indrawing. • Look and listen for stidor. • Look and listen for wheezing. <p>CHILD MUST BE CALM</p> <p><i>If wheezing and either fast breathing or chest indrawing: Give a trial of rapid acting inhaled bronchodilator for up to three times, 15-20 minutes apart. Count the breaths and look for chest indrawing again, and then classify.</i></p>	<ul style="list-style-type: none"> • Any general danger sign or • Chest indrawing or • Stidor in a calm child 	<p>SEVERE PNEUMONIA OR VERY SEVERE DISEASE</p>	<ul style="list-style-type: none"> ➤ Give first dose of an appropriate antibiotic. ➤ Refer URGENTLY to hospital!
		<ul style="list-style-type: none"> • Fast breathing 	<p>PNEUMONIA</p>	<ul style="list-style-type: none"> ➤ Give oral antibiotic for 3 days. ➤ If wheezing (even if it disappeared after rapidly acting bronchodilator) give an inhaled bronchodilator for 5 days** ➤ Soothe the throat and relieve the cough with a safe remedy ➤ If coughing for more than 3 weeks or if having recurrent wheezing, refer for assessment for TB or asthma ➤ Advise the mother when to return immediately ➤ Follow-up in 2 days
		<ul style="list-style-type: none"> • No signs of pneumonia or very severe disease 	<p>COUGH OR COLD</p>	<ul style="list-style-type: none"> ➤ If wheezing (even if it disappeared after rapidly acting bronchodilator) give an inhaled bronchodilator for 5 days** ➤ Soothe the throat and relieve the cough with a safe remedy ➤ If coughing for more than 3 weeks or if having recurrent wheezing, refer for assessment for TB or asthma ➤ Advise mother when to return immediately ➤ Follow up in 5 days if not improving

If the child is:	Fast breathing is:
2 months up to 12 months	50 breaths per minute or more
12 months up to 5 years	40 breaths per minute or more

Figure 2: Example from the IMCI protocol.

Each classification is connected to a set of treatment advice. These advices also include information on when, or for what reasons, the patient should return to the clinic. To find out which type of antibiotic to use, the clinician has to go to the treatment section in the booklet to find the correct drug and dosage. The drugs are supposed to be given to the children according to their weight, or age if it is not possible to measure the weight. The correct dosage for a certain child can be found in a table. When the correct drug have been identified, the clinician is instructed to provide the caregiver with some advice regarding for example how to give oral drugs at home or how to treat local infections. Other types of advice to give when counseling the caregiver are also available in the booklet. They include feeding recommendations for both sick and healthy children. [44]

Since the IMCI is produced from a global perspective, the content has to be adapted to fit to national conditions as well. Things that can vary from country to country are for example 1st, 2nd and 3rd line of drugs that should be used for certain diseases and the feeding recommendation i.e. what type of food to give to the children to ensure that they get enough nutrition. The protocol should also be adapted to other national health policies. In addition the protocol should be adapted to linguistic prerequisites. [43]

2.5 Integrated Management of Adolescent and Adult Illness

The integrated management of adolescent and adult illness (also known as IMAI) is using a similar approach as the IMCI. It was developed to aid clinicians with their work in primary care in low-resource settings. But instead of caring for children the IMAI is developed for adults and adolescents. One important part of the IMAI is also to guide the health workers in the decision of which patients that should be screened for HIV. The IMAI strategy is divided into five modules: chronic HIV-care with antiretroviral therapy and prevention, general principles of good chronic care, acute care, palliative care: symptom management and end-of-life care, and tuberculosis (TB) care with TB-HIV co-management. [67] It is the acute care section that is using a similar syndromic approach as the IMCI protocol. This section includes instructions on which patients that can be treated at the first-level facilities and which patients that need a referral to the hospitals.

Similarly to IMCI the first step of the IMAI is to check for danger signs, this is followed by checking or asking for additional problems. The problems that are included in the IMAI are: fever, diarrhea, genito-urinary symptoms or lower abdominal pain in women, skin problems or lumps, headache or neurological problems and finally mental problems or additional conditions. The discovered problems should then be classified and treated accordingly. Prevention advice should be provided and the patient must be advised when to return for a follow-up.

These guidelines have been simplified to be used by nurses and lay providers in communication with a supervising district clinician such as a clinical officer. [42] This background chapter will now be followed by an introduction to the theoretical framework that will be used as a base for the analysis in chapter 6.

3. Theoretical Framework

To analyze the findings made within the scope of this thesis project, there is a need to get familiarized with the theories from the field of human-computer interaction (also known as HCI). The texts of various authors have been studied; however large parts of the theoretical framework come from the HCI author David Benyon. This chapter will cover accessibility, usability and acceptability aspects as well as the people, activities, context and technology approach for interactive system design. As mentioned, a clinical decision support system is one example of an interactive system. Finally, this part of the thesis will include some interface design guidelines and knowledge management aspects, which are important for the development and maintenance of CDSSs.

3.1 Human-Computer Interaction

When designing an interactive system, such as a clinical decision support system, the interaction between the people, or users of the system, and the computers is an important aspect to take into consideration. The study of this type of interaction is also known as human-computer interaction. This field covers social and behavioral science, on the one hand, and computer and information technology, on the other hand. The focus lies on understanding how people make use of different computer systems and devices and also how these can be made more useful and usable. The work includes the understanding of the tasks and work practices of the users and their organization. [7] The actual interaction between the users and the computers takes place at the user interface, where the interface includes both the system software and the hardware.

In the early days, the development of computer software started according to Shneiderman [5] with programmers that were involved with designing different applications to themselves and their peers. This meant that the complexity of the programs did not really matter to the users; instead it was often appreciated. However, when the office automation started, and the use of home and personal computers spread, the new users were not always as dedicated to the technology as the initial users had been. For new users, the use of computers is often not self-evident, since their background is more tied to their workflow rather than to the technology. The design of the system should therefore always be based on observation of and collaboration with the users in question, to fit into this workflow. Prototypes should be tested early in the process together with the usability and acceptance of the system. [5]

When designing a system a people-centered view is to prefer, because the main idea is that the designer should think about what it is that the people want to do, rather than what the technology is able to do. According to this view presented by Benyon [1] people differ from machines in the way that they are creative, compliant, attentive to change, resourceful and able to make flexible decisions based on context, which is something that computers are not. The people-center view also encourages the involvement of people in the design process and design for diversity, also known as universal design. Some of the principles of universal design includes: equitable use, flexibility in use, intuitive use, perceptible information and tolerance for errors. [1]

Following from the people-centered view is the user-centered design approach. With this approach the user's needs, wants, problems and limitations are being taken into account. These aspects should be what set the grounds for the development of the user interface, and according to Gulliksen and Göransson [4] the interface will in turn dominate the design for the rest of the system. User-centered system design focuses on the users during the whole phase of the development and throughout the life cycle of the system. The users should always be in the center of the work process and the system development should be iterative. The basis in an iterative user-centered work process starts with analysis of the end-users, their tasks and the context. This is followed by the design of a prototype, which is also an iterative process in itself. The prototype should be evaluated and the feedback can be used for making improvements. Then the iteration starts anew (see Figure 3). A prototype of the system should be evaluated by the end-users as early as possible to get the necessary feedback and be able to make the changes. [4]

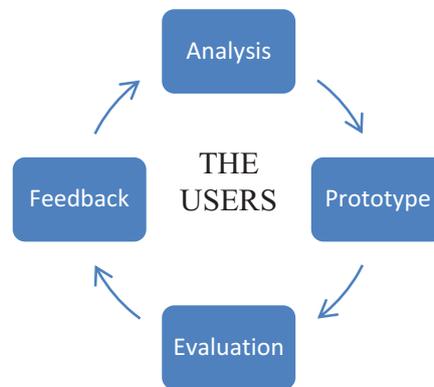


Figure 3: The basic elements in an iterative user-centered design process.

3. 2 Accessibility, Usability and Acceptability

There are many aspects that need to be taken into consideration when designing an interactive system. Among other things, the system that is being developed must meet the following criterion regarding accessibility, usability and acceptability.

3.2.1 Accessibility

A system with limited access for some users will naturally not be used in the way that it was meant to be used, or by the people who were meant to use it. Therefore, Benyon [1] means that it is essential to overcome the barriers to access that may exist. The existing barriers can vary and be of different types. The barriers can be of a physical, conceptual, economic, cultural and social nature. First of all we have the physical barriers, which regard the possible hindering of the use of the technology itself. Examples of physical barriers can be the design or the location of the equipment that should be used. The second type of barrier is the conceptual one, which can exclude people that do not understand complicated instructions or are unable to form a clear mental model of the system. A mental model is the understanding and knowledge that a person have when it comes to a certain system. Mental models are incomplete models of the reality, which means that people will understand certain parts of a system better than others. Mental

models are also unstable seeing how people tend to forget details and explore new ones. Further, a mental model does not have firm boundaries, therefore similar devices and operations can easily get confused with each other. The third type of barrier is the economic barrier. For example, if people cannot afford to buy all the technology or other tools that are needed this can also result in people being left out and prevent people from using the system. The fourth type of hindrance to accessibility is cultural exclusion. This means that the designers of the system sometimes make certain assumptions regarding the users, their work and their culture, or way of living, that may be inappropriate and that can affect the accessibility. A social barrier can for example be that the content is not adapted for different social groups or if equipment is not available at an appropriate time or place for some users. [1]

3.2.2 Usability

A system's usability refers to the quality of the interaction between the system and the user. The quality can for example be reflected by how long time it takes to perform certain tasks, the number of errors being made and how long time it takes to learn the system and become a skilled user.

- “Usability: The extent to which a product can be used by specified users to achieve goals with effectiveness, efficiency and satisfaction in a specified context of use.”

Where;

- “Effectiveness: The accuracy and completeness with which users achieves goals.”
- “Efficiency: The resources expended in relationship to the accuracy and completeness with which users achieves goals.” [24]

In order for a system to have a high degree of usability it is not enough that it is efficient, effective and gives the user satisfaction. According to Benyon [1] it also has to have the following characteristics:

- Easy to learn: It has to be easy to learn how to do things in the system but also easy to remember how to do things even after some time (if the system is not being used frequently).
- Safe to operate: The system has to be safe to operate in all those contexts where it is meant to be used.
- Utility: The system can do those things that the users want it to do.

The greatest benefit with designing usable systems is the increased productivity that they can offer. If a system follows usability principles and is adapted to the users' way of working then the users do not have to waste time on struggling with complex functions and ill-working interfaces; instead they will be able to work effectively. If a system is

usable then the user will be able to concentrate on the task at hand rather than on the tool itself. [18]

By working on the interface and system design the potential benefits are reduced errors and reduced need for training and support. A well-designed system can reinforce learning and therefore reduce training time as well as the need for human support. A well-designed and usable system can also increase the user acceptance and enhance the reputation of the system. [18]

3.2.3 Acceptability

The third aspect that has to be taken into consideration, regards fitting the technology into people's lives and thus increasing the acceptability of the system. The main difference between usability and acceptability is that the latter only can be understood in the context of use, while the former in principle can be tested in a laboratory. There are five key features of acceptability:

- Political: This can be a simple question of whether or not the users trust the system that has been implemented. However, this area can also cover broader matters regarding legal issues, human rights, power structures and principles.
- Convenience: The design of the system should fit into the work of the user and not force people to do things or hinder them in their work.
- Cultural and social habits: This aspect reflects how people like to live their lives and whether or not the system has accommodated for these preferences.
- Usefulness: This aspect concerns usefulness in context, which goes beyond the notion of effectiveness and efficiency.
- Economic: There are many economic issues that can affect a technology's acceptability. Price is one of these issues and another one is whether or not the technology offers value for money. [1]

3.3 PACT - Designing Interactive Systems

When it comes to human-computer interaction there are, according to Benyon [1], two relationships that need to be optimized. The first one regards the direct interaction between the people and the technology, which means the user interface. The second relationship also refers to the interaction between people and technology, but the technology is looked at as a whole. This view provides us with the term people-technology system interaction. If the goal is to optimize both of these relationships it is not enough to only look at the people and the technology, it is also important to take into account the activities that are being undertaken by the people and the context in which these activities are being carried out. Technologies are meant to support the activities that people are performing and if the technologies are changing so will the nature of the activities. [1]

Another way to describe usability, than the one mentioned above, is by finding the balance between the four principal factors that represents a people-technology system interaction perspective. These factors have been given the acronym PACT, which stands for:

- **P**eople
- **A**ctivities people want to carry out
- **C**ontext where these activities and interactions take place
- **T**echnology, representing both hardware and software

PACT is a framework that can be used for designing interactive systems in a specific design situation. [1]

3.3.1 People

As we know, people differ from each other in various ways. Some of these aspects are physical differences, psychological differences, social differences and varying mental models, which is something that was mentioned above. The type of questions that the designer should try to find the answer for is what type of physical differences that exists and what type of abilities that people have. One of the major design principles to follow is that a system should be designed in a way that people can form a correct mental model of the system, i.e. how they work and what they do. Novice and expert users can differ very much when it comes to what types of requirements they have. A novice user will need to be guided in a different way through the interactions. A system designer does not only have to involve and be considerate towards the end-user in the development process. All the stakeholders should be included in this work. [1]

3.3.2 Activities

The activities that people want to carry have many characteristics: temporal aspects, cooperation between people, complexity and the definition of tasks, safety-critical and the nature of the content. Temporal aspects can cover for example time pressure, how often certain activities are being carried out and whether or not they are continuous. Safety-critical activities represent such tasks where mistakes can result in serious consequences. The nature of the content describes what type of data that is necessary for a certain activity. [1]

3.3.3 Context

The context can be of a social or organizational nature, or simply represent the physical environment. Exactly what the context is can be difficult to describe. It can be something that is surrounding an activity or something that is connecting two activities with each other. [1] Seeing how the system is to be placed into a social context there is also a need to take the organizational requirements into account. If the system is developed from these requirements it will help to support management, communication and collaborative work. When for example the tasks, which the users are meant to perform, are grouped in an appropriate way this will lead to increased motivation and satisfaction among the employees. An ideal system should allow autonomy and flexibility, provide feedback to

the user and give the opportunity to develop new skills. To find out the organizational requirements it is necessary to get a certain understanding of the current power structures, different obligations and responsibilities, level of control among the employees, values within the organization, and ethics and privacy issues. There is also a need to take legislative requirements into account. [18]

3.3.4 Technology

The technology aspect has its focus on the input and output of the system, together with communication and the content, which more or less means the data in the system and the form it takes. The system content should be accurate, up-to-date, relevant for the users, and well presented. [1] The input and output of the system is very much connected to different design aspects. Therefore, a presentation of some design guidelines will follow below.

3.4 Design Guidelines

To increase the usability and acceptability of a system and to design a good interactive system there are some principles that can guide the designer. The principles can also be used to evaluate or critique different prototypes of design ideas. Some of these principles are very abstract whereas others are more specific.

Benyon [1] have gathered some design principles from different researchers in the field. Among these researches we find Jakob Nielsen with his ten usability heuristics and Ben Shneiderman with his eight golden rules. The principles can be grouped into three different categories: learnability, effectiveness and accommodation.

3.4.1 Access, learn and remember the system (learnability)

1. **Visibility** – A system should always keep the users well informed what it is currently doing and clearly show the functions that are available. It is easier to recognize things than having to remember and recall them. Objects, actions and options should therefore always be made visible. Instructions regarding the use of the system should also always be visible and easy to retrieve. The users should not have to remember information from one part of the work to another.
2. **Consistency** – A designer should be consistent regarding design features. This applies to both physical and conceptual consistency. A user should not have any doubts regarding a words meaning in different situations and what kind of output an action will result in.
3. **Familiarity** – It is important to use language and symbols that the users are familiar with. If a concept is foreign to the users it can sometimes be valuable to use metaphors that they recognize. In general there should be a good match between the system and the real world of the users and information should appear in a natural and logical order for the user.

4. Affordance – This concept represents the properties that different things have. One clear example of this is that buttons should look like buttons so that users know that they should press on them etcetera. Affordance is something that is culturally determined.

3.4.2 Being in control, knowing what to do and how to do it (effectiveness)

5. Navigation – Make it easy for the users to find their way in the system and provide them with directional- and informational signs.
6. Control – Allow the users to take control over the system. It should be clear what a certain type of action will result in when it comes to the real world.
7. Feedback – It is important to give instant feedback to the users of the system within an appropriate time so that they know what is going on and what effect their actions have had. This will also enhance the feeling of control that was mentioned above.

3.4.3 Safety and securely (effectiveness)

8. Recovery – Make it possible for the user to recover from certain actions that have been performed, due to errors or mistakes, in an easy and fast way. Support undo and redo in the system and provide an “emergency exit”. Error messages should be expressed in plain language, explain the problem and suggest a solution.
9. Constraints - To prevent error it is a good idea to eliminate error-prone conditions. For some actions it can be useful to present the user with a confirmation option before the action is executed. Another way is to constrain allowable actions for the user.

3.4.4 Accommodation to the user

10. Flexibility – By making a system flexible it accommodates for different types of users with varied experience. Accelerators can for example be used to speed up the interaction for experienced users. Another thing is to make it possible for the users to personalize the systems to fit their own needs and requirements and so that they can tailor frequent actions.
11. Style – The style used should be attractive to the user.
12. Conviviality – The system developed should be convivial. This means that it should be likeable, polite and friendly. [1]

3.4.5 Additional design aspects

Another one of Nielsen's usability heuristics covers help and documentation. He means that help and information always should be easy to search. Further, the help should focus on the user's task and list concrete steps to be performed. The documentation should not be too large so that the user finds it difficult to locate the appropriate information. [53]

The above mentioned design principles have been made based on evaluations in the industrialized and developed world. During this thesis work I have not been able to find any design guidelines more applicable for the cultural setting in Uganda. Nor have I found a lot of information regarding system design for developing countries in general. Therefore, maybe these principles can be used as a good start that can guide the design of the system, but they should not be seen as an absolute truth and a prototype of the system should be tested by the users in their working environment as soon as possible.

Still, it is possible to find some lists of aspects that can differ when designing for an international environment. These are for example: characters, numerals, ways of reading a text, date and time formats, numeric and currency formats, weights and measures, telephone numbers and addresses, names and titles, national identification, capitalization and punctuation, sorting sequences, icons, buttons and colors, grammar, spelling, etiquette, policies, tone, formality and metaphors. [5]

3.5 Knowledge Management for Clinical Decision Support Systems

In addition to the above mentioned design guidelines, there are also some existing guidelines for the selection and implementation of clinical decision support systems. They suggest that the following aspects should be taken into consideration before developing or purchasing a CDSS.

According to Greenes [9] assure that:

- The users understand the limitations of the system
- The knowledge is from reputable sources
- The system is appropriate for the local site
- The users are properly trained
- The system is being properly utilized after the implementation
- The knowledge base is monitored and maintained

The last point included in these guidelines suggest that knowledge management is something crucial for a well working CDSS. Therefore, this part of the theory section will cover this aspect. When creating a CDSS there is a need to understand the life cycles involved in this process. The challenges and issues connected to CDSS involves many different stages from the general concept and the main idea behind it, to the implementation, maintenance, dissemination and updating of the system.

Further, Greenes [9] has identified three intersecting and interactive life cycles for CDSS, all in a way connected to knowledge:

1. Knowledge generation and validation; is a concept that also includes refinement, representation and updating of the knowledge base in the system.

2. Knowledge management and dissemination; includes dissemination, localization and updating, content management, authoring and editing and tracking of changes in the system.
3. CDSS implementation and evaluation; also includes feedback, modification and updating, decision model and application environment and interface.

How the knowledge basis for the UCG and the IMCI/IMAI protocols has initially been generated and validated is outside the scope of this thesis. However, the life cycle is still mentioned to give the reader a more comprehensive understanding of all the complex processes behind the creation of a CDSS. Further, once the knowledge has been generated, validated, refined and represented in the system it will still need to be updated. This means that the same cycle will start all over again.

The clinical decision support system can be said to consist of both the expert or domain knowledge that has been turned into functions in the system, but also the knowledge about the use and usability of the system itself. Both new and additional domain knowledge and the usability aspects need to be taken into consideration when managing and updating the system. Therefore, when the CDSS have been implemented we need to manage the knowledge and evaluate the impact and usability of the system to improve it. [9]

3.5.1 Aspects that need to be considered regarding knowledge and updating

Below follows some important aspects that Greenes [9] means should be taken into consideration for the management of the clinical decision support system.

- Identify new points and aspects that need to be included in the CDSS. What is currently missing in the system? This is really the identification of knowledge gaps. What is missing in the algorithms? Is it possible to add?
- Ensure that the knowledge being used can be clinically defended, either through review of literature or consensus among appropriate clinical staff or other experts.
- Review existing knowledge at appropriate frequency to find outdated knowledge and information that need to be revised.
- Recognize limited resources, this includes both technology and clinical resources. How should we prioritize when it comes to the modification of knowledge? What is possible to do within the system? What can actually be done in reality?
- Inform the people involved, the users, about the logical thinking behind the knowledge. In this way it is easier to include them in the updating process.
- Evaluate to see whether or not the desired outcomes are being achieved.
- Evaluate to see whether or not the existing strategies improve the effectiveness.
- Is the use of CDSS a hindrance to the workflow? Is the interface working well?

When the tasks that need to be carried out have been identified it is also important to put someone in charge of solving these issues. If we assign knowledge management tasks to a variety of different forums and organizations this can create difficulties regarding decision-making, because it will be difficult for everybody to agree. However, this can

still be the best option since it means that we include many different groups who can offer more specialized expertise within their specific field. But of course these different organizations will need to be coordinated by a single organization with the main responsibility. [9]

There is no single or one way of organizing the knowledge management, but there are guidelines that can help. The following suggestions are made by Glaser and Hongsermeier [8]:

- Leverage existing committees within the fields that the CDSS is covering.
- Use cross-committee representation for a better coverage.
- Identify where the necessary domain expertise exists today.
- Represent the whole overall perspective and not only the clinical discipline, for example include usability and efficiency concerns.
- Include IT cunning personnel in the committees.
- Make sure that all suggestions are examined from an IT-perspective.
- Define an oversight group that is responsible.

When the changes have been made experts must always review and approve the system before they can be implemented on a wide scale. Before implementation the changes would also have to be carefully tested. Even when consensus among experts have been reached, it is also important that the planned changes fit well with the medical policies; both on a national and on a more local level. The changes would also have to be in harmonization with the other information systems that the CDSS is connected to, which in this case can be the EHR, e-Learning and human resource systems. [8]

To make clinical guidelines fit better into clinicians' workflow, there have been attempts to remake them in an algorithmic way with flowcharts. Where gaps exist, expert opinions have been used. However, it has been proven that when using the same guidelines the algorithms may still differ, depending on what type of expert that have been filling in the gaps. If the experts have a lot of domain specific knowledge, then they tend to add more details using their personal experiences and also include organizational aspects. In contrast, computer scientists are more consistent with the guidelines; instead they tend to make some mistakes when interpreting the literature. The best thing is to use a combination of people with knowledge of medicine and of computer science. [10] This section finishes the presentation of the theoretical framework that is used in this thesis. The next chapter will introduce the methodological aspects of this work.

4. Methodology

This chapter of the thesis will cover the methodology that has been the basis for this study. Reviewing of books and articles has been an essential part of this work. The chapter starts with an introduction to the work in the ICT4MPOWER project. This is followed by an introduction to the methods used to gather secondary data and the limitations with this way of working. Finally, the methods behind the collection of primary data will be presented.

By using the Ugandan clinical guidelines on management of common conditions and the WHO and UNICEF published protocols for integrated management of childhood illnesses and integrated management of adolescent and adult illness the aim, within the scope of the ICT4MPOWER project, is in the end to develop a clinical decision support system. The system is meant to be used by the health workers on the different health care levels in Uganda, where a main differentiation of educational groups can be made between clinical officers, nurses and community health workers. However, before this system is developed it is essential to take into consideration previous experiences and lessons learned within this field. This is exactly where this thesis work can play an important part. The lessons learned regard both the use of CDSS in general, as well as the results from the use of the WHO published protocols in developing countries and low resource settings. Yet another aspect to take into consideration is of course the usability and acceptability of the system. This is where the theory from the field of human-computer interaction can be useful. However, the HCI theory available is often based on studies performed in western countries and they are also very general. Therefore, it will be important to discuss these aspects in chapter six, to make sure they are suitable for the conditions in the health care in Uganda.

Before defining the problem at hand there was a need for exploratory research, i.e. to find out more about the specific project, but also about CDSSs and the WHO guidelines. To gather and share information within the ICT4MPOWER project team, the members are using a web-based project management tool called Projectplace. Here it is possible to find most of the project-related documents. All project members have access to this web page, both from the Swedish and the Ugandan side. The information includes the work of other project members here in Sweden, compiled results from field studies in Isingiro and background information concerning health care in general, but also Uganda in particular. Further, the Swedish team at Karolinska has had regular face to face contact in the form of weekly meetings. The purpose of these meetings have been to update other team members about what is going on and future plans within specific areas of the project. Since all of the parts are meant to be perceived as one system by the end-users, collaboration between project members has been vital. The majority of the team members in Sweden have an engineering background within the biomedical field, information technology, human-computer interaction, and energy- and sociotechnical systems. The team also includes medical personnel and people with a background in business studies.

4.1 Literature Studies

Literature studies have been an essential part of the work that I have performed. The studied literature have been concerning clinical decision support systems, computerized clinical guidelines, computerized diagnostics tools in developing countries, the use of clinical guidelines and protocols in low resource settings and human-computer interaction and system usability aspects. The most hands on example of the use of evidence based clinical guidelines in low resource settings, which I have come across, regard the evaluation of the IMCI protocol. Seeing how the protocol was implemented in some countries already in 1995, enough time has passed for it to have been possible to evaluate and even examine the long term effects. WHO has initiated a broad evaluation program of the IMCI protocol called the Multi-Country Evaluation (MCE) of IMCI effectiveness, cost and impact. The evaluation has been performed in five different countries: Bangladesh, Brazil, Peru, Tanzania and Uganda. [30] A lot of this information has been available on the WHO web page. Available at this web page, from the WHO child and adolescent health and development programme, are also the IMCI protocol itself, technical updates, training instructions and additional information. Similar type of information about the IMAI protocol has not been possible to find. This is probably due to the fact that the IMAI was implemented at a later stage and that it is not equally spread and used. However, there might be a risk that the information on the WHO web page is not always completely objective, seeing how they have invested a lot of time and money in developing these diagnostic tools, and therefore they are very interested in finding out how successful their efforts have been. This might result in them emphasizing the benefits with the protocols more than the challenges. Further, criticism can be directed towards the design of the MCE, namely that it is leaving out many important aspects (such as contextual factors or alternative explanations) that might have influenced the end results of the impact studies.

A trip to Uganda has not been possible due to limitations in the project budget. Further, it is probable that it is more beneficial to bring a prototype of a system to Uganda to test it and get feedback rather than to get information regarding CDSS and their experiences, seeing how they to the best of my knowledge do not use these kinds of systems today. However, it would have been valuable to get information concerning their use of IMCI/IMAI and the UCG, how these tools are currently being used and how they are perceived by the health personnel in Uganda. It has been possible to find information about IMCI evaluations carried out in Uganda. However, these evaluations are often more quantitative studies, whereas I would be more interested in qualitative efforts to get the perspective of the actual user and not just compiled data. Another aspect that I have been missing a bit, because of the physical and cultural distance, is the workflow and the work processes within the health care in Uganda. The access to mapped workflow in the health clinics in Uganda has been limited to HC4 settings and it has not been on a very detailed level. This information has been gathered from team members in Uganda that have performed field studies in the Isingiro district. These team members have a background in the field of computer science and are students at the Makerere University. Therefore, it is likely that there might have been cultural and language barriers between the students and the health workers, even though both groups come from, and live, in the

same country. There can be substantial cultural differences between rural and urban areas in developing countries.

One of Uganda's neighboring countries, Tanzania, has on the whole had a very successful implementation of IMCI and can therefore contribute with a lot of information. Since the IMCI implementation has managed to scale-up in the country, it has been possible to carry out a lot of research there. Another beneficial aspect is that Tanzania is situated on the border to Uganda, and there are many cultural aspects that are similar. However, there are of course differences between the two countries, which naturally apply to the health care system as well. Naturally, the same argument applies to the community IMCI experiences that are collected from Kenya.

In Tanzania there has also been efforts made to develop a computerized version of the IMCI protocol, which is called e-IMCI. The technology used within this project was a palm top computer or a Personal Digital Assistant (PDA). [28] Their experiences have been very useful for this thesis and parts of their evaluation can be found in the result chapter of this report. In addition, I have been in contact with one of the members in that project team and therefore we could get access to the code that was used. With some modifications it can hopefully be useful for this project as well. This can be seen as a good example of knowledge shearing between different projects. Instead of redoing everything, it can be valuable to use other people's work and experiences. This is even more important in the cases where the time and other resources are very limited, as it has been for ICT4MPOWER project. Other benefits with this way of working, is that whatever they have tested has been evaluated, hence giving us every possibility to make improvements in our system.

As mentioned, a variety of literature has been studied during this thesis work. There are quite many comprehensive books written on the subject of clinical decision support systems. The two major books that I have been using is *Clinical Decision Support – The Road Ahead* edited by Robert A. Greenes and *Clinical decision support systems: theory and practice* edited by Eta S. Berner. These books cover the history behind CDSS, different case studies, design and implementation issues, ethical and legal issues, mathematical foundations and data mining, and knowledge generation, representation and management. These books provide a background to CDSSs and were mainly useful to increase my understanding of this particular subject. Some of this information can also be found in the introductory and theoretical chapters.

There are also available examples of meta-reviews that have been carried out, where test results from different studies of CDSS have been compiled. These studies provide a very good overview of the benefits and challenges with the use and implementation of CDSS. However, to get a deeper understanding, and more insight into the challenges at hand, it is better to read more in-depth and case specific articles. When studying specific cases it is difficult to make generalizations from the results at hand, but the complexity becomes more apparent than with only using the results from meta-reviews. Therefore these two different types of studies can be said to complement each other. Seeing how the term clinical decision support systems is very wide and covers many different areas and

functions it cannot be seen as fruitful to study the benefits of the use of all different types of systems. Therefore, the focus has been on finding the benefits with the use of IMCI which, if computerized, can be seen as one type of CDSS, or more exactly as a classification and treatment tool.

When searching for research publications I have used the Uppsala University's online library tool where it is possible to find articles in the library's databases and journals. The databases and journals that were searched include: PubMed, Elsevier, SAGE, Oxford Journals and Springer Link. The key-words used include: clinical decision support system, computerized clinical guidelines, telemedicine, IMCI, IMCI evaluation, -development, -update, -management, IMAI, health care developing countries, HCI developing countries and decision support. When reading these articles I have found that a good way to identify additional sources have been to go through their references. These references have then been looked up to get more information and more detailed material.

4.2 Limitations with Using Secondary Material

When mainly using secondary sources it is difficult to get the answers to all of the questions that one might have. Instead the results of this study are limited to the material that I have been able to come across in Sweden. Sometimes it can be difficult to use a critical perspective when reading about studies that have been performed by others. I believe that an important part of research is to be able to observe the things that you are meant to study, to get a feeling of the actual problems at hand. However, this is something that is impossible to do when using secondary sources. Further, I believe that it can sometimes be difficult for researchers that have spent countless hours on trying to achieve a certain objective, to except the fact that maybe their work did not result in all those benefits that they had expected. This might lead them to be biased in the interpretation of their results. In addition, cultural differences between the researchers and the test objects are rarely discussed in the articles that I have read. Cultural differences might have resulted in the researchers sometimes understanding things differently than the local people. However, a great benefit with using secondary sources is that it is possible to get a much wider perspective on things, and to make use of a lot of information that people have put in a great number of hours and effort to collect.

As mentioned earlier in this thesis, a large part of the material that I have covered is coming from the IMCI evaluations and not from IMAI evaluations. The reason for this is that the use of IMAI has started later, and evaluation material is not available at the WHO web page or at the databases or journals mentioned above. This will of course result in a very limited picture of clinical decision support in developing countries. However, these types of decision support have been developed by the WHO in a similar matter and they are adjusted for low-resource settings. Therefore, the conclusions that can be drawn from the IMCI evaluations can hopefully also contribute to improvements in the development of an IMAI application within the system.

Seeing how Uganda is one of the countries that have participated in the MCE of IMCI a majority of the information in the section 5.1 IMCI experiences is coming from Uganda. The aim has been to mainly use material from sub-Saharan Africa, but since the use of

clinical decision support is so limited, experiences from India has also been included. India as an IT country is much more developed than Uganda, but within the health care sector in rural areas there are similarities, especially regarding lack of human as well as other types of resources. To get some even more hands on experiences of the use of CDSSs I have used a lot of information from Sweden. I have chosen to do so because this information has been much more accessible and allowed me to also gather some primary information and data. However, of course even primary information can be influenced by preconceived thoughts on how things work and biased opinions.

4.3 Study Visits, Observations and Interviews

An important part of this thesis work has been study visits combined with interviews and observations. Together with other team members I have visited Medhelp, the Swedish Association of Local Authorities and Regions (SALAR) and a district health care center in Stockholm. Medhelp is a medical care hotline company selling services to organizations and companies. Among their customers are Stockholm county council (Vårdguiden), Värmland county council and Södermanland county council. During the visit to Medhelp it was possible to meet with both the CEO and an experienced nurse working for the medical care hotline. [51]

SALAR is the organization in charge of the national quality registries aiming to improve the quality within the Swedish health care. The registries contain patient specific information regarding treatment and health outcomes. [56] Some of these registries are also being used as CDSSs and are helping clinicians to make decisions in patient specific cases. During my work I have also met with a professor at the Karolinska Institute, who is one of the persons behind the HIV related quality registry/CDSS (also known as InfCareHIV). This system is already in use in Sweden and some other Nordic countries, but they are now implementing it in Tanzania as well. During the visit to the district health care center, we were able to meet with one of the physicians working there and to observe the EHR-system that they are using. It was also possible to ask him some questions regarding the system in use. Further, I have had the possibility to conduct a telephone interview with an employee at the web-based advice service, regarding health related issues, offered by Vårdguiden and Stockholm county council.

The study visits and combined interviews have proven to be very informative. These visits have included a great deal of observations on my behalf, where the observations have given more insight and lead to additional questions being asked at the interviews. When being able to visit professionals in their work setting the observations occur naturally, since it is difficult not to get influenced by the surrounding environment and activities that are being carried out. However, all observations that were made during the visits were confirmed with the people in questions to assure the quality of the material. [3] The interviews carried out were semi-structured. The main reason for this was to get the informant's perspective on the issue and not to be tied to any preconceived assumptions on how things work. Further, it made it possible to ask follow up questions from the observations. [2] Before the meetings with Medhelp and SALAR the members of the ICT4MPOWER team together discussed the topics of the questions that we wanted to be answered. Some questions were pre-determined, while others came up during the

meeting. Since we all were interested in different topics, we divided the responsibility of asking questions between us. During the Medhelp meeting it was possible to start by asking some questions to the management and then to observe the work and ask additional questions to the other members of the staff.

One member of this project is a pediatrician working for Karolinska Institute in Solna. He has been working in Sweden for many years, but he also has some experience from working in African countries. He has not worked in Uganda specifically, but he has had the possibility to visit the project implementation site, Isingiro. No interviews have been carried out with this pediatrician, but his opinions have been influencing my work through the various meetings that have been held within the scope of the ICT4MPOWER project. Among other things, his views include that diagnostics should not be made by lay people such as community health workers. Instead, they should have their focus on prevention. Further, when discussing the tasks of the nurses he is not used to them having the responsibility for diagnostics and prescribing of treatments. However, the situation in Uganda differs a lot from Sweden and his opinions are still influenced by his work here and from being a doctor with many years of experience. It is still difficult for him to understand the situation for nurses working alone on HC2 levels, lacking important tools and with a far shorter educational background than he has. Preferably all diagnostics and treatment issues should be handled by doctors, but this is not possible in Uganda. Nevertheless, his medical experiences have been very valuable for the work of the ICT4MPOWER project, because even though there are dissimilarities between the two countries, there are still things that are the same.

Even though I have not had the possibility to visit Uganda and talk to the potential end-users of the system, I have had some experience from developing countries in general and the east-African region in particular. Among other things, I have worked as a volunteer in Tanzania for three months. During this time I also had the possibility to get a deeper insight into the problems that they have in respect to the health care. This regards for example the lack of resources and diagnostic tools, variation in the quality of the care, the cost burden for patients and their lack of knowledge about health related issues. My experiences from Tanzania have resulted in me making some assumptions about the health care situation in Uganda, which can be said to have influenced the analysis of this thesis. This was a review of the methodology that was used for this work. The next chapter in this thesis will present the results from the study.

5. Clinical Decision Support Systems in Context

The purpose of this chapter is to present a compilation of the information that has been gathered during the work with this thesis. The chapter starts with a section gathering IMCI experiences from different countries, covering benefits and challenges as well as computerized training and community IMCI initiatives. These aspects have been included to cover experiences from the use of clinical decision support in developing countries in general, and Uganda in particular. The section on computerized training of IMCI in Uganda reflects the attitudes and experiences from a computerization within the health care in the country. Further, the community IMCI section is of great interest for the future community health worker CDSS. These sections are followed by a presentation of computerized decision support in India and Tanzania; examples showing similarities with the Ugandan context. Section 5.3 will deal with some usability aspects that are specific for low-literacy users, and that can be useful when developing a CDSS for these settings. This section is followed by an introduction to some clinical decision support systems that are in use in Sweden and England, mainly within the field of telemedicine. These systems are used by nurses in developed countries, but still reflect some of the challenges at hand. Section 5.5 presents some previous results from research on CDSS and the use of clinical guidelines, attempting to provide a broader perspective. The last section in this chapter will cover knowledge management and updating aspects regarding clinical information that are necessary for the future use of the system.

5.1 IMCI Experiences

The multi-country evaluation of IMCI has shown that the protocol can be an effective tool to combat childhood illnesses. However, the results have sometimes been contradictory and there have been problems with the use of IMCI, which naturally affects the end result. Contextual factors and different regional and national prerequisites have also been shown to affect the result from the implementation of IMCI on under-five mortality rates. This includes for example drug availability, the overall cost of care, available supervision and the overall state of the district health management. [20] These sections will present some of the benefits and challenges that a paper-based decision support has encountered in developing countries. The focus will be on Ugandan experiences.

5.1.1 Benefits

No clinical decision support system can cover all diseases and all possible symptoms. As mentioned most systems in the developed world are very specialized. However, in developing countries the diseases and conditions covered by the IMCI protocol such as diarrhea, pneumonia, measles, malaria and malnutrition account for both 70 % of visits to health facilities and deaths of children under five. [17] This is true also in Uganda where the major killing diseases for children under five are malaria, pneumonia and diarrheal diseases. [40]

Experiences from Uganda show that health workers trained in IMCI performed significantly better in assessment and correct classification of the child's illness, than health workers without IMCI training. This meant that they asked the correct health

related questions and ended up with a correct classification of the child's illness in respect to the severity. [20]

The IMCI guidelines have been shown to be very useful in the way that the health workers do not forget important steps in the examination and it is working well as a reminder for the health worker. Further, these guidelines are especially designed for the needs in developing countries and therefore they are, among other things, always recommending the cheapest drugs available. This can save a lot of money for the government, but also for the patients and their families, depending on who it is that stands for the costs. In Uganda they have a system where the government is providing drugs for the dispensaries at the health centers, but the supply is limited and patients are often forced to buy drugs at private pharmacies. Another way, in which the IMCI has been adapted to the conditions in low resource settings, is that the equipment necessary for using the protocol has been limited. Seeing also how IMCI is an integrated strategy it suits well for developing countries, since most patient that come to the clinics are suffering from more than one condition at the same time. [65]

According to another evaluation in Uganda the protocol has been proven to propose less hospital referrals than what health workers not using the protocol would do. This suggests that the protocol is quite restrictive when it comes to giving hospital referrals. This is positive in one way seeing how the hospital's resources are limited and fewer referrals would ease that burden. At the same time it would save the patient and a whole family both time and money if they do not have to go to the hospital. However, it is important to understand that this also means that there is a risk that people that should be referred to the hospital never will get a referral. The same thing applies to the prescription of antibiotic, where less antibiotic is given when using the protocol. This can help to reduce the microbial resistance, but it can also mean that patients needing antibiotics never will get this type of medication. [17] One of the thoughts behind the development of the protocol was that health workers should be encouraged to refer all severe cases and all children showing any danger signs to the hospital urgently. This was not always the case when using the older practice. An additional benefit with using the IMCI protocol is that it can guide the user to prescribe the correct amount of drugs for the patient according to the weight or age of the child. [44]

As mentioned, the multi-country evaluation of the IMCI protocol was also an evaluation of the costs included. According to the WHO the results from this evaluation show that IMCI is worth the investment. If the child is correctly managed, according to the IMCI approach, this strategy costs up to six times less per child than the current care that is provided. However, the costs measured in this case are only on a district level. On this level IMCI could, among other things, help to lower the hospital costs since more patients could be helped at the lower level facilities. On the contrary the costs on a national level will be higher due to the establishment and implementation of IMCI, which can end up being quite expensive. [30]

5.1.2 Challenges

While IMCI in some countries have been shown to give fast results in child survival when it is correctly applied, the use of IMCI is still limited by the expenses of training, the lack of sufficient supervision, the time it takes to follow the whole IMCI booklet and the tendency to make use of the protocol less and less over time. These are some of the reasons why the spread of the protocol is so limited in some developing countries. [28] In Brazil for example, they have not seen any improvement in performance among health workers that have received IMCI training. An additional problem in Brazil is also that 46 % of the children visiting the health facilities in the country suffer from illnesses or conditions that are not included in the IMCI protocol. [11] Therefore, the implementation in Brazil cannot be said to be very successful. In contrast to this specific example, Tanzania has managed to reach very far with their implementation and they have also succeeded in scaling up of the IMCI approach. Uganda also managed very well initially, but they have not succeeded in scaling up and spreading the use of IMCI. [30]

It is now time to further explain some of the problems that have been experienced with the use of the IMCI protocol. First of all the paper format of the IMCI is a bit difficult to use. The users must themselves interpret what should be the next step in the examination. This also means that it is not very time effective, since reading can be a very slow process. Experienced users often find it easier to just follow their own memory of the plan instead of using the actual protocol, which is a risk because they might forget important steps in the process. In Uganda a consultation by a medical assistant using the IMCI protocol took on average 7.2 minutes, this is longer than usual for most African countries and also longer than for a regular examination which takes on average 4.6 minutes. [17]

Second, the use of IMCI requires quite extensive training. This training is also very costly and therefore it is only given to a few individuals. If a person who has received IMCI training then decides to no longer work at a certain clinic, all the knowledge about the IMCI will disappear with this person. In general these countries often have a very high turnover rate at the clinics. This is probably one of the main reasons why IMCI is not so well spread in developing countries. An additional problem connected to the training is that the education provided often is centralized, which means that people have to leave their work for several days to get the education that they need. Since the number of experienced health personnel already is very limited as it is, this only adds to the challenges at the clinic. [41]

Third, when evaluating the use of IMCI in Uganda it was found that in as many as 13 percent of the cases (138 of 1086 completed forms), medical assistants made incorrect classifications of the children's conditions. Many of these mistakes were made by not incorporating the presence of danger signs into the final classifications. Mistakes were also made when for example counting the breaths per minute in the patient. Since the mistakes often lowered the severity of the illness, this can have serious consequences. [17] However, the number of mistakes made in this case was not compared to how many mistakes that were made when not using the protocol.

Fourth, in order to use the IMCI, or any type of clinical decision support systems, correctly the user needs a set of tools to examine the patient. In the case of the IMCI there is a need for a thermometer, a scale and a timer. In some evaluations this was found to be a problem, seeing how all clinics did not have access to these tools. This affected to what extent the clinicians would make use of the protocol for the examination. In some cases it was also found that the clinicians did not have access to the protocol at the workplace, something that will also naturally affect the adherence. [17]

Additional problems that have been experienced, in Uganda in particular, is the overall low utilization of health facilities in rural areas. The consequence of this is that the program has not had a very large impact on the child mortality rates in certain places, because people are not bringing their sick children to the clinics. Further, the referral system in Uganda is not working as expected and there is a big problem with drug availability. [19]

5.1.3 Computerized training of IMCI

As mentioned one of the drawbacks of IMCI is that it is quite expensive and complicated to train a lot of people in the use of the protocol. However, in certain countries there have been attempts to shorten the training time for the IMCI, to save both time and money. There have also been attempts to computerize the training. This has been done by for example the Quality Assurance project sponsored by the United States Agency for International Development. Their efforts can be seen as one example of computer use among health personnel in Uganda and it has therefore been included in this chapter. Further, it is a good example of how some of the drawbacks with the use of IMCI can be handled.

Even with the use of the computerized program the training in Uganda has been centralized to ensure that the health personnel are attaining the appropriate knowledge. Some skill areas, such as recognition of physical signs and counseling techniques, were still lead by a facilitator. The duration of the Quality Assurance project's course was 9 days, compared to the 11 days standard training proposed by the WHO. The number of facilitators could also be decreased to four out of the original six. Certain aspects of the computer-based training were examined: knowledge of IMCI, skill in case management, regular performance of IMCI, costs, and finally comments from the users of the computer program were collected. When the knowledge about IMCI was measured there was only in one test group that the difference was statistically significant ($p < 0.05$), between using a computer as a training tool and the classical course. [39]

Males that had taken the computer course scored 83.6 % on the knowledge score, while male who had taken the normal course only scored 68.4 %, when the knowledge was measured 3-4 months after the initial training. Males who had taken the computer course performed significantly better when it came to the assessment of the child's illness, while women did worse regarding the classification, if they had been trained with computers. The costs proved to be lower when using computer-based training, even if the computers had to be rented. With the use of existing computer the cost was 335 dollars per trainee, for the standard course the corresponding number was 472 dollars. This calculation was

done on the basis of the costs in Uganda year 2000. After the training the research team returned to the sight to ask additional questions to some of the trainees. Everybody who was asked about their satisfaction with the computer-based course gave positive answers. Among the comments from the health workers include satisfaction with how fast it went to revise the work that had been done and the appreciation of the possibility to work in one's own pace. Other things that were appreciated were the feedback that was given by the computer after every task that had been completed, and that computers in contrast to facilitators never forget things. However, in the end it was also discovered that far from everyone was actually making use of IMCI in their workplace, even though they were satisfied with the training. The reasons for this were that IMCI was too time consuming to perform and that many did not have access to the booklet when they worked. Further, some of the nurses that had been trained were actually not allowed to make classifications and give treatment at the clinics where they were working. These tasks were only supposed to be performed by medical assistants. [39]

5.1.4 Community IMCI

As mentioned in the background, IMCI is a broad strategy, the approach is three folded and the aim is to improve case management skills of health-care staff, the overall health systems and family and community health practices. The third part, also known as the community and household module, was the last one to be added to the concept. The content of this module have been discussed at various meetings and the strategies are different from country to country. [64] When Uganda evaluated their own IMCI strategy in the report Implementation of a National Integrated Management of Childhood Illness (IMCI) Program in Uganda the authors concluded that a big flaw in the initial implementation phase was that a community module had not been developed. The aim was therefore to correct this mistake for the future implementation and scale-up of IMCI in the country. [19] This section of the results is meant to provide some insight into the additional challenges that will face the community health workers regarding their use of a CDSS.

In Kenya they were early in developing a well documented community IMCI initiative. A part of this effort has been to develop a simplified version of the IMCI- protocol that can be used by CHWs. Some parts of the original IMCI protocol, that was considered to be too difficult to examine, have been removed. However, when evaluating the performance of the CHWs there were still a lot of mistakes being made. For example, the CHWs only identified 62 % of the cases with fast breathing, which is a quite serious sign that indicates pneumonia. They were also doing poorly when it came to assessing signs for dehydration, such as skin pinch and thirst. However, the good news is that the counseling skills of the CHWs had improved noticeably since the first evaluation, but the main problem was still to remember to advice the caretakers on when to return with the child for a follow-up visit. [25]

When studying the community IMCI protocol that is being used by CHWs in Kenya, it is noticeable that it is formed in a slightly different way when it comes to the recording form for the CHW. Short texts with instructions and advice are added to the recording form as reminders for the CHW. Instead of taking time to go back to the booklet, if they

have forgotten certain things, they will be reminded by looking at the information. However, the protocol follows the IMCI structure in the way that it ends up in classifications. But since the CHWs do not have the education and the experience that nurses have, most of the yellow cases should also be referred to health centers. The main difference between red and yellow is instead that the red cases should be referred immediately, while the yellow cases are not equally urgent. [26]

In Uganda they are currently not using any type of community IMCI protocol that can be handled by CHW. Instead they have developed another strategy. According to national documents, CHW are supposed to use something that is called the Integrated Community Case Management (ICCM). [36] The ICCM program started up with the Home Based Management of Fever program, handled by the Malaria Consortium, and it grew as it became a part of the national village health team strategy. Today it includes the treatment of diarrhea and pneumonia as well. This type of treatment is provided together with health promotion and health education in the villages. However, in order for this to work there is a need for proper supervision and motivation, something that has proven to be a big problem in Uganda and a contributing factor to the limited spread of the program. [50]

5.2 Computerized Decision Support in India and Tanzania

The two most similar examples to what the ICT4MPOWER project is aiming to do regarding the CDSS, are the ones I have found from India and Tanzania. Examples from their evaluations will be presented to the reader below. These are examples of the use of computerized decision support in low resource settings.

5.2.1 The case of India

In India, Peters et al. [22] have tested a computerized clinical decision support system called early diagnosis and prevention system. The results from their evaluations indicate that CDSSs have the potential to increase the quality in care and also to increase the coverage of health care, especially for poor people and where no physicians are available. The system that was developed by a non-profit organization did not have to be used by a health worker; anyone familiar with computers could input the needed information. However, the results that the system provided had to be interpreted by someone with more medical knowledge. Each patient met with a computer operator for 10-15 minutes. The program suggested up to eight possible diagnoses and referral to hospital when necessary. The results were then evaluated by a nurse. The program did not take long for the computer operators to learn. However, they only had to learn the program itself, seeing how the results were evaluated by the nurse. This way of organizing the work have the potential to save time and therefore the health personnel could have the possibility to meet with more patients during a working day. The system algorithms were built on, among other things, the basis of the IMCI protocol and other types of Indian medical references and protocols. The whole objective of the system was similar to the one of the IMCI, which means that it was meant to be used as a screening tool to identify which patients who are in need of medical attention by a doctor. In India patients typically have to see a doctor for getting prescription drugs. [22]

A number of challenges were discovered during the evaluation of the early diagnosis and prevention system in India, many of which can be seen as general recommendations for implementation of CDSSs. First of all, when the system was tested it was discovered that it was not really coherent with the reality. Patients that actually needed medical attention by a physician did not always get this type of recommendation and vice versa. Second, all the key stakeholders involved in the project did not have full confidence in the software, and therefore improvements would have to be made in the system. The authors recommend appointing an authoritative reference body that regularly can review the system and make changes that can improve the credibility of the system. Changes would also have to be made to fit with local conditions. Third, it is important to work with the motivation of the health workers and the system needs to be able to add a value to them. The system that was developed in India was often regarded as additional work by the health workers and therefore they did not want to use the system. Fourth, not only the nurses but also the physicians were pessimistic towards the system. This was mainly due to the fact that they had preferred if the money was used for laboratory equipment instead. It was also their belief that a system such as this was more suitable for nurses working in facilities where no physicians were present. Another of their concerns regarded the patients' expectations on the system and the services it could provide. They feared that using the decision technology would give the patients unrealistic expectations. [22]

The main positive finding during this study was that the patients were really pleased with the use of the system. It even increased the utilization of outpatient services in general. The benefit that was found to be the most appreciated was the extra time that the patient got with the health providers. Normally the average time that a patient gets with a physician is only one minute. However, with the use of the decision support the patient first got some time to talk about their problems with a non-physician and then they got evaluated by a real physician, which increased the patient experienced quality. In their opinion they received a higher level of communication with the health workers, increased technical quality and all in all they were satisfied with the care that they received. [22]

5.2.2 The case of Tanzania

In Tanzania the MoH have chosen to use IMCI as the national policy for treatment of childhood illnesses. The strategy has been shown to lead to fast results regarding improved child survival rates, where the protocol has been correctly applied. However, as mentioned, some of the challenges with the use and spread of IMCI include the expenses of training, the lack of sufficient supervision, the time it takes to follow the whole protocol, and the fact that people tend to use it less rigorously over time. [28]

In an attempt to facilitate the use of IMCI, a collaboration of researchers has developed an electronic version of the protocol that can be used on a PDA. The program, known as e-IMCI, is meant to guide the user through the set of questions that appears in the original protocol. The potential benefits of using an electronic version, instead of the paper-based method, are described by the authors. They expect that the training time can be reduced because the user does not have to learn all the steps in the process; instead the program will interpret what type of actions that should be taken or what the next question should

be. Further, the e-IMCI has the possibility to decrease the number of steps that are skipped and it can also help to avoid logic errors and miscalculations. When the protocol has to be updated it is going to be easier to do when using an e-version. Similarly, it also has the possibility to be further developed and made more complex than a paper version could ever be. [28]

Before the work started, interviews were carried out with clinicians familiar with the IMCI protocol. They stated that the most important factor for success was speed. They themselves rarely followed the recommendations in the IMCI protocol because it took too long time. Further, they pointed out that there were occasions when the protocol did not take all patient specific factors into account, which meant that they needed to be able to override the decisions. One example of a case that appeared during this study was when a girl with a cough came to the clinic. The system classified her as having cough or cold, but no pneumonia. However, the caretaker stated that the child had taken cough syrup, but it had not helped. Therefore, the clinician decided to treat for pneumonia. [28]

The results of the investigation show that when using the e-IMCI the clinicians performed 84.7 % of the investigations, compared to 61 % when using the paper-based version. This means that the adherence increased with the use of the e-IMCI application. Regarding the flexibility, the application was adjusted during the work to allow the users to choose the drugs they wanted and to sometimes put approximate measures as input in the examination. In the end it appeared as the system was almost as fast as the current practice. However, current practice meant that the protocol was not used so often. The clinicians themselves liked to use the system since they experienced it to be faster and easier to use than the paper protocol. Even though there were significant advantages, problems existed as well. [28]

This e-version of the IMCI protocol has been hard coded into the system. Currently the system only covers certain aspects of the original protocol. E-IMCI only covers first visits and not follow-up, children between 2 months and 5 years and only the ones that are not showing any danger signs, nor is it covering immunization, malnutrition or maternal health. Even though the system in this way has several limitations, in addition to the fact that the IMCI protocol in whole only covers certain specific signs and symptoms, the system still seemed to cover most of the cases that were observed. The system starts with a multi-select question asking about the symptoms: cough, diarrhea, fever, and ear problem. This is followed by additional questions that need to be answered. In the end the system suggests a classification, and if any medication is necessary the clinician is presented with a list to choose from. The clinician also have to choose the form of the medicine i.e. child tablets, adult tablets or syrup. Thereafter, the system will calculate the correct dosage according to the child's weight. In Tanzania all the medical records are to be kept in English, therefore the e-IMCI was also developed in English for consistency. However, the researchers believe that a system in Swahili would be easier to use. [28]

During a pre-study with two of the clinicians a lot of changes were made and the whole system was then tested with four clinicians. However, there will be cases when correct usage of the protocol still will lead to an incorrect classification of the patient. This is due

to the fact that algorithms never can take into account all the factors that need to be considered for different patients. Therefore, it is necessary that the system is flexible and allows the clinicians to deviate from it. Further, the system that was built was used in a facility where a laboratory was available, which meant that all suspected cases of malaria could be tested with a blood sample. This meant that not all cases of fever would be treated with malaria drugs, which is normally the case, but only the ones that has a confirmed diagnosis. During the evaluation of the system it became apparent that there were some of the questions that the clinicians forgot to ask the patient, but there were also questions that they left out on purpose. Examples of questions or examinations that were left out were checking for fever, fast breathing and offering the child fluid. These questions were often skipped because they took a lot of time to investigate. [28]

Time is, as mentioned, a critical aspect seeing how there are so many patients waiting outside of the clinic every day to get examined by a clinician. One clinician that was interviewed after the trials mentioned that she experienced the e-IMCI to be much faster than the paper protocol. The reason for this was that there was no need to flip the pages or to think what question that should be next; instead this was automatically provided by the system. Nevertheless, it is still much faster to only use own experience, but the risk of forgetting certain questions and investigations is apparent. [28]

During the evaluation of the e-IMCI system it was found that when the clinicians were working, they liked to do several types of examinations at the same time. One example of this is to check for chest indrawing and stridor at the same time, when presented with a case of cough. This is also something that the researchers think can be useful for speeding up the process, if some of the questions are grouped together. [28]

In the case of this e-IMCI version the protocol and algorithms of the IMCI are in large part hidden from the user. This means that when a case is on a threshold between two classifications, this is not always clear to the user. For example the limit for fast breathing is 40 breaths per minute or more, if the child is between 12 months and 5 years. Fast breathing determines whether or not the classification should be pneumonia or simply a cough or cold. The first case should be treated with antibiotics whereas the second one should not. However, if a child has for example 39 breaths per minute the system would still classify it as normal breathing even though it might be a border line case. According to the authors recommendations, this is something that the system should make the users aware of, so that the users can choose for themselves what type of classification they want to make in that particular case. [28]

The system interface used for the e-IMCI was inspired by another program that was developed for aids care in South Africa. The main idea is that the new question always is presented at the bottom of the screen; similarly to different chat programs (see Figure 4). A short version of the previous questions and the answers are shown above. This allows the user to review the answers, and it also gives a better understanding of the context and the reasoning behind the questions. With the help of arrows it is possible to move up and down between the questions, and to make corrections if any mistakes have been made.

However, the clinicians did not feel that the system was flexible enough; instead they would prefer to use a combination of their own experience and the e-IMCI system. [27]



Figure 4: Examples of the interface.

In order for the system to be used in the long run, it does not only have to be as fast as the current practice, preferably the system should also provide the user with some type of additional value. A typical way of doing this, within the field of health care, is to automatically collect data for different reports that have to be compiled by the health workers and sent to the government on a regular basis. This is a good idea because it can help to decrease the work load for the health workers. [28]

The domain expertise was shown to vary widely between different types of health workers. Therefore, the authors suggest that different types of systems could be developed depending on who the intended user is. They propose to have a tutor mode for training, a guided mode for less educated and uncertain users, and lastly an expert mode for more advanced and experienced users. [27]

5.3 Usability Aspects when Designing for People with Low-literacy Levels and Novice Users

The CDSS being developed is meant to be used by nurses and clinical officers working at the different health care levels in Uganda. However, it has also been proposed that the system should be used by community health workers. One of the criteria for becoming a CHW is that you are able to read and write, meaning that you are literate. However, the educational levels in the villages, where the CHWs are supposed to operate, are in general very low. The consequence of this is that most of the users among the VHTs will have a low-literacy level. For these types of users it can be valuable to take into account previous experiences within this field.

When designing systems for low resource settings and for users with little familiarity with computer devices, it is very important to get to know the local context. Seeing how

there can be very large differences in culture, environment and perspective between the creators of the system and the end-users this might be even more important in this case, than for a system meant to be used in the developed world. [38]

Parikh [38] has been working in the south of India with a banking system for a mobile device meant to be used by Self Help Groups to keep track of their finances. Among these groups there were members that were illiterate, as well as members with low-literacy levels (semi-literate) and well educated people. After studying the local environment and getting feedback from the users, Parikh [38] put together some design recommendations to improve the usability of the system. These recommendations include among other things the importance to follow the original paper formats in the design of the interface. He means that repeated entry into the same format, as was used before, will increase the user's understanding about the organization of the information. [38]

However, the researchers evaluating the e-IMCI system came to the conclusion that there are some cases where the biggest changes can be brought on by changing the original structure, and not by keeping the old format. How well this will work depend on the users of the system and their willingness to adapt to changes. The group behind the e-IMCI suggests that one way of expanding and improve the system is to turn it into a dynamic protocol that can take into account for example statistical data or the patient's history, when coming up with new questions. According to their discussion a system like this will, however, deviate from the user's mental model regarding the structure of the protocol and the work process. Therefore, it is important to understand what type of changes that the users are comfortable with. Especially also seeing how this will end up affecting the training time, maintenance and support, if the system is not so easy to understand. [29]

Other design features that were suggested by Parikh [38], based on his experiences in India, include the use of appropriate icons, audio feedback, guided interactions and colors. The use of icons and pictures that are highly symbolic showed to help the users to navigate more easily in the system. Audio feedback was effectively used to help the users learn the meaning of the icons, with the use of an icon legend. This meant that the users could test and memorize the meaning of each icon, without having to be afraid of the consequences this would have in the system. If this is done in the local language it can help to make the users more familiar with the device, and to make it more appealing to use. The guided interaction means that the number of possible tasks that can be performed in a single window is limited. The sub tasks available should be well organized and thereby helping the user to understand the screen's overall purpose and structure. Another feature that can add to the understanding of the interface is the use of colors. Colors can be used in the background to make separations between different elements, but it can also be used in the foreground to draw attention to some specific data or information. [38]

In the theory section of this thesis, Jakob Nielsen was mentioned as one of the names behind the development of the design heuristics that were presented. The same man has also written texts about the design for low-literacy. As can be understood, low-literacy

means that people can read but they do not do it without difficulties. One particular area where this can cause problems is within the field of health informatics. Therefore, the pharmaceutical company Pfizer has sponsored a lot of research within this field. Their goal is to make their information understandable and actionable for a larger variety of people. To understand health information can be difficult for everyone, but it is even harder if the user has a low-literacy level. The main difference is that people that have difficulties reading cannot only glance at a text to make out what type of information it contains. Instead they read a text word by word and line by line, which gives a very narrow field of view. Further, they often spend a lot of time on understanding multi-syllabic words. [54]

A higher-literacy user can usually scan a text to find the relevant information, and to find the right navigation option. The lower-literacy users must, however, carefully read each option before they can make a decision. If things become too complicated, or if the text is too dense, they usually choose to skip over large amounts, with the risk of missing important information. Further, scrolling is something that breaks the visual concentration for a lower-literacy user, because it takes time to come back to the right place. Finally, something that often creates problems for lower-literacy users is the search function. This problem is two-folded because firstly they can have difficulties spelling the query term; secondly they think it is problematic to process the results. A lower-literacy user will typically pick the first result in the list; it does not matter whether or not it is the most relevant option. [54]

According to Nielsen and his colleagues [54], to design for lower-literacy users does not only improve the usability for this type of users, it also improves the overall usability for all types of users. When making the appropriate changes for low-literacy users in a specific system, the success rate (the number of tasks that could be performed) increased for both low- and high-literacy users. Further, the time it took to perform the tasks decreased for both groups, whereas the overall satisfaction increased. The time it took to complete the tasks decreased by 57 % for the low-literacy users (see Table 2 below). [54]

Success Rate	Original Site	Rewritten Site
Lower-literacy users	46%	82%
Higher-literacy users	68%	93%
Total Task Time	Original Site	Rewritten Site
Lower-literacy users	22.3 min.	9.5 min.
Higher-literacy users	14.3 min.	5.1 min.
Satisfaction (1-5 scale, 5 best)	Original Site	Rewritten Site
Lower-literacy users	3.5	4.4
Higher-literacy users	3.7	4.8

Table 2: Results from Nielsen’s study of design for low-literacy users.

The question is now how the usability can be improved and what they did to get these encouraging numbers.

The first step is to simplify all the text and the words that are being used. But there are also other things that can be done. An important part can be to prioritize the information, so that the most important parts always are displayed at the top of the page where all the users will be able to see it, even the ones that gives up after a few lines of text. Scrolling should be avoided unless the consequences end up being that the text gets divided in an unnatural way. All type of text that moves or changes should be avoided, since static text is much easier to read. The design of the pages should be streamlined and important information should be put in a single main column. Navigation can be simplified by putting the choices in a linear menu. Last, but not least, the search should be optimized i.e. be tolerant for spelling mistake and the first hit should always answer the query. Something else that should be added is easy-to-read summaries for the search results. [54]

It is now time to move on and present some types of CDSSs that are currently in use in Sweden and England.

5.4 Clinical Decision Support Systems in Sweden and England

The below mentioned examples are mainly taken from the field of telemedicine. These examples of decision support systems have been chosen because they are being used by nurses. However, some information regarding the use of CDSS by a doctor in primary care will also be presented.

5.4.1 Sweden

The most similar examples, to what this project is aiming to do, that I have come across in Sweden is the services provided by Medhelp AB and the Inero developed medical decision support system RGS used within the national medical care hotline 1177. The systems have been developed for nurses employed within telemedicine. They do not consist of any medical algorithms; rather they provide searchable information to the nurses in the workplace. [48]

The company Medhelp AB is using their own journal system in combination with other types of help systems such as an external decision support, which is the web based version of the RGS. Basically this system gives the same type of advice as the RGS, but in the RGS you can access all support functions in one window, whereas in the web system you have to go to the web browser to access the decision support. [71]

The RGS-system is developed to give symptom-based support. This means that whatever symptom the caller is describing can be searched in a database. If the symptom is found, the nurse will get presented with certain information. The nurse will also get a list of follow-up questions, with the help of which it is possible to decide the severity of the condition. When the condition has been classified the user is presented with some

classification specific advice. The advice that is chosen by the nurse, and given to the caller, can then easily be copied into the patient journal. [48]

When visiting Medhelp the nurses working within the medical care hotline mentioned that they were rarely using the medical decision support system¹ that was available to them. The reason for this was because they had been working for so long time within the field that they knew most of the things by heart, and therefore they did not need to use the decision support. On the contrary, they had themselves created some support questions to ask certain people that were calling in for specific reasons. This was especially important for parents that were calling for their sick child. These questions were formed as a guide to the nurses, and they were more frequently used than the actual web-based decision support system. They were also presented in the system itself and the nurses did not have to leave the system to visit the web application. For the times when the nurses could not answer the patient's questions, there was always the possibility to send the call to another nurse with more expertise within the specific area. [71]

The difference between the web-based RGS application and the actual RGS system is that the latter is a combined journal system and medical decision support system, whereas the former only is a standalone medical decision support system. The difference results in that the web application is not integrated with the Medhelp journal system. Therefore, the symptom information and the guiding questions will only be presented if the user actively searches for it. Further, the information that is used from the system cannot easily be copied into the patient journal. [71]

During a visit to a district health care center in Stockholm the decision support available for the doctors was, in contrast to the decision support mentioned above, disease or condition based, meaning that the user can search for specific treatment advice and other type of information when a preliminary diagnosis have been made. [73]

The difference between the systems probably depend on the fact that the nurses, on the one hand, only are supposed to give advice to the patient, decide about the severity for a person's condition and to be able to send them to the right place for additional care if necessary. It is the job of the doctor, on the other hand, to make a diagnosis and prescribe treatment accordingly. The web-based decision support application that was sometimes used by the doctor at the district health care center was called Internet Medicine. He stated that these types of applications often are used by medical students lacking of long vocational experience, whereas he himself rarely used the system. The journal system that they were using at the district health care center had one type of inbuilt decision support function regarding what type of medication to choose. The doctor could choose one type of medication when making the prescription, but then the system could suggest something else, depending on what type of medication that is suggested by the Wise list (in Sweden known as Kloka listan)². However, the doctor did not like to use this function

¹ In this case it is called medical decision support system because it is not being used in clinics, but it is still a decision support system for medical use.

² Kloka listan is an evidence-based list of cost-effective drugs that are recommended by Läksak for the Stockholm county council. [59]

because it was not properly updated, i.e. not always recommending the cheapest drug. Further, in his professional opinion it is not always the cheapest drug that is the best drug for the specific patient, because there are a lot of other factors that need to be taken into consideration as well, when prescribing drugs to patients. [73]

Another important difference between the uses of decision support is also that within the district health care center the support was not provided to them by the employer. Instead, they themselves had to find ways of searching for the information they wanted, and decided whether or not the information provided could be trusted. [73]

5.4.2 The CAS-system in England

When visiting the Medhelp office in Stockholm, their company management [70] stated that they preferred to use a very open medical decision support system. This is opposite to what is currently being done in England. Today the average time for a call to the national medical hotline company in England (National Health Service Direct) is 13 minutes. In contrast, the average time for a call to Medhelp is between 3 and 4 minutes. This is, according to Medhelp, due to the fact that the nurses in England are bound to their decision support system and that they have to ask certain questions, when presented with a specific symptom. Instead of working as a look-up tool, it uses an algorithmic approach. The questions have to be answered even if the nurses in their professional opinions believe that they are not necessary, and therefore the use of this type of system is very time consuming. [70]

In England, when using the Clinical Assessment System (CAS), the answers to the questions are always documented and the system will present the nurses with follow-up questions. As mentioned, similar to the e-IMCI application, CAS uses an algorithmic approach. The proposed questions are organized around different symptoms (such as 'dizziness', 'cough', 'chest pain' and 'urinary burning'). While the system is presenting the questions it is also possible for the user to read the on-screen clinical information that is provided to give the reasoning behind the questions that are proposed. When there are no more questions to be answered, the system will present the nurses with some advice. The nurses have the possibility to override (increase the severity of) or underwrite (decrease the severity of) these suggestions based on their own experience, but if doing so the reason has to be clearly expressed in the journal by the nurse. Even the nurses themselves express certain complaints regarding some of the questions that have to be posed. There are occasions when they feel that the questions they have to ask are not significant in the specific case. Another aspect of this is that the nurses working with the system feel that they can learn as much from other colleagues, as they can learn from the system. However, the system is built in such a way that it does not support this kind of collaboration between nurses with different types of expertise and experience. In this evaluation of the CAS-system the authors suggest that by designing the system in this way it is indicated that the algorithms and the technology is more trustworthy than the nurses and their expertise. Another downside with these types of protocols is that they are not designed to be context specific. [14]

The CAS system was developed and implemented to ensure a more uniform approach to the processing of a patient call. This was done to improve the performance at the call center and also to minimize the risk for malpractice. From a managerial perspective it strives to strengthen and standardize the nurse services provided. The nurses are trained for a period of two weeks where they are taught to perform certain tasks. This includes how to use the software, the telephone system, information databases and customer relations. Before they are allowed to handle calls themselves they have a period of preceptorship, as it is called within the field of medicine. [14]

These are very different ways of looking at CDSS and how they should be applied in the day to day work of the health professionals. These results will be further discussed in chapter six. Below follows a presentation of some of the previous research on clinical decision support systems. They are included to give a wider perspective to the implementation issues regarding CDSSs and possible solutions.

5.5 Previous Research on CDSSs

Research has shown that when CDSSs are well designed and effectively used they can very well help to improve the quality of patient care and to help prevent errors and omissions. However, there have been several reports regarding the implementation challenges of these types of decision support. [15]

Findings show, first of all, that there is a need for a substantial amount of resources to be able to develop and maintain a knowledge base for the CDSS. Second, it is difficult to integrate the CDSS into the workflow of the health personnel. Third, clinicians in the developed world have a very strong fear for “cookbook” medicine taking over their practice. Fourth, the business case for developing CDSS is not always clear. Fifth and last, currently there are not that many clinics or hospitals that have implemented EHR-systems. This means that input data cannot automatically be moved from the EHR-system to the CDSS; instead it has to be typed in manually and this increases the workload for the clinicians. CDSSs can work as standalone systems, but it has been proven that the most successful systems are the ones that are connected with EHR-systems. Further, it seems like most of the success stories regarding implementation of CDSS come from sites where the EHR-system has been self-developed rather than commercially bought. This is probably due to the fact that these systems are easier to connect to a CDSS. [23]

Another evaluation, in this case a meta-review, shows that there are four main features of clinical decision support systems that individually increase the likelihood of success.

- Automatic provision of decision support as part of clinician workflow is the first one of these features.
- The second one is provision of recommendations; rather than only a presentation of an assessment of the patient's case.
- The third feature is provision of decision support at the time and location of decision making.

- The fourth and last feature was that the decision support should be computer-based.

Out of the 32 systems that were being tested, and that possessed all of these four features, 30 of these had proven to significantly improve the clinical practice. In excess of these four features it was found that additional characteristics such as the system providing periodic performance feedback, the possibility to share recommendations with patients and the system requesting documentation of reasons for not following the recommendation, also were appreciated by the clinicians. [16]

The authors further claim that there were some features that were found not to affect the effectiveness of the CDSS, even though they were suggested to do so by others. These features include critiques that were worded more strongly, the evidence supporting the critiques was expanded to include institution-specific data, provision of more specific recommendations, local clinicians involved in the system development process and the presence of bibliographic citations to support the recommendation. [16]

Additional features as denominators of success have been suggested by other authors. These features were not, however, tested in this meta-review due to lack of information regarding these particular topics. According to other studies systems should preferably also have these features: the system should be fast, save the clinician time and require minimum time to use, have a clear and intuitive user interface, that the assessments and recommendations given are accurate, that the system is developed through an iterative process, system alignment with organizational priorities and clinician's personal beliefs and financial interests, and involvement of local opinion leaders. [16]

In addition to the above mentioned meta-review regarding CDSSs, another study is covering factors influencing the implementation of clinical guidelines. Their results, gathered from twelve systematic reviews, show that the most successful implementation strategies always included multiple components, in contrast to using single strategies such as only providing reminders or being limited to work as an educational intervention. It was also suggested that the characteristics of the guidelines would affect the use. In this case it meant that guidelines should be easy to understand, easy to try out and they should not require any specific tools or resources in order to be used and accepted by the users. Further, it is important that the existence of the guidelines is well known and that the users are familiar with the content. Finally, environmental factors have been shown to affect the implementation. For example, whether or not the guidelines are supported by the peers and supervisors, and whether or not enough time for using the guidelines is available for the clinicians. [12]

Another issue that has been raised, and that can really be the source of a major implementation challenge, is the vocabulary. The problem can be serious if for example the users and the system do not use the same words for a single concept, or if they use the same word but with different meaning. This problem is difficult to overcome since there are no standards for clinical vocabulary that are agreed upon internationally. [6]

5.6 Knowledge management and updating

Within the field of medicine it is crucial that the information that is displayed in different types of information systems is correct and kept updated. This is valid for CDSSs, as well as for other types of applications. In Sweden we have, for example, several web pages providing non-health educated people with information and advice regarding different health issues. Even for these types of pages it is crucial that the information being displayed is correct. One of these web pages, that provide citizens with health related information, is Vårdguiden. As mentioned above, Vårdguiden does not only provide advice and information to people over the web, they also offer telemedicine services to people within the Stockholm county council. On the web page Vårdguiden provides a collection of articles that they have created themselves. They cover certain medical conditions and give medical advice. The articles are produced by an editor who makes a lot of research within a specific health related area. A draft is written and later reviewed by a medical expert. Once the article has been approved by the expert it can be published. [69]

The medical reviewers for these articles are a part of the Stockholm medical council. The reviewers are chosen because of their medical knowledge and vast experience within a certain field. It is crucial that they are considered as unbiased. The articles on the web page are systematically reviewed once every year. The editor reviews the text in the articles from an editor's perspective i.e. checking the language, spelling mistakes, choice of words, if it is easy to understand, and if they have received a lot of questions regarding certain areas. Then the medical expert also reviews the article. The two of them agree, make the changes and post the article with the new date and year on the web page. The name of the author, the editor and the reviewer is also visible on the web page. If new discoveries have been made during the year, the reviewer or medical expert is responsible for contacting Vårdguiden so that the information can be updated. Since their name is written on the web page it is their vocational pride that is on the line if the information showed is not correct or updated. Therefore they feel a pride in keeping it updated. [69]

However, the editors also keep themselves informed and can contact the medical experts if they hear about new things that are going on or new discoveries that have been made. In some cases they have more than one reviewer for an article. This is common when a subject is more controversial. The editors can be regarded as the users' advocates. They have to make sure that all the information is understandable and easy to find. They also have to keep track of the peoples search behavior so that the information is easy to access. [69]

Similarly as the case with Vårdguiden, the medical information page used by the doctor at the district health care center uses the same kind of system. For every medical topic that is covered a certain expert is in charge of the information displayed. [49]When visiting SALAR they also mention how important it is to get the medical experts on board and involved in the work. Sweden is not a very large country and therefore the real experts within certain fields are well known by others. [72]

5.6.1 Updating and adaptation of IMCI

The WHO suggests that the protocol should be adapted to national conditions before it is implemented in a country. The first steps are to identify the changes needed, to build consensus, to work with national policy makers, to make the changes if possible, and to decide whether or not it should be translated into other languages. Since the protocol already has been adapted to Ugandan conditions it is now only a question of keeping it updated. It is important that the protocol cover the most serious childhood illnesses that their first-level health workers must be able to treat, to make it more efficient.

When adapting the protocol to national conditions the WHO suggests that the nation follows some specific principals. These include providing guidelines that:

- Address the leading causes of mortality and morbidity, without attempting to cover all pediatric conditions that lead a mother to seek care from a health facility.
- Are both safe and effective for all the parties involved.
- Use the minimum number of clinical signs and symptoms to choose the correct classification and treatment plan to reduce the complexity.
- Use the minimum number of essential drugs.
- Take local feeding practices into account and that use local terms to improve communication with mothers and other caretakers. [43]

In Tanzania the IMCI protocol is updated once every year. How often this is done in Uganda is currently not clear. However, it is understandable that to update and distribute a paper copy of the protocol is somewhat of a big project. Especially in countries where the infrastructure is not the same as in developed countries. Making more than one version of the e-IMCI would also require a lot of additional time to keep the protocol updated. In Tanzania they have even suggested that the program should be able to use on different types of devices, depending on the availability and financial resources available at different clinics. In some cases they even suggest to keep the paper copy of the protocol because it might be the most suitable solution. [27] A paper copy of the protocol could probably also be good to have in all clinics because of unexpected technical problems that might occur. There can be problems with the software itself, with the hardware or with the electricity supply.

In the end it is not efficient to have to spend a lot time reprogramming every time the algorithm has to be changed. Instead, the best solution would be if the medical professionals themselves could keep the protocol updated and deploy new functions without any knowledge about programming. The updating of the software and the paper-based protocol should be made into a single process to save time. [27] This section on knowledge management will end the result chapter of this thesis. This chapter will be followed by the analysis of these results.

6. Analysis

In this chapter the theoretical framework of people, activities, context and technology (PACT) will be used as a basis for the discussion. In addition other parts of the theoretical chapter will be covered as well, including the accessibility, usability and acceptability factors. After the initial sections the design aspects will be analyzed. Finally, this chapter of the thesis will discuss some knowledge management aspects. This analysis builds on the background-, theoretical- and result chapters of this thesis, and where my own thoughts on the subject have been added.

6.1 People

As mentioned in the theoretical section, when developing an interactive system there is a need to involve and be considerate towards the end-users of the system, but also to think about the other stakeholders. People can differ from each other in various ways and these differences need to be clarified. It is necessary to identify the abilities of the end-users and how they differ from each other.

In this particular case it has proven to be difficult to test the usability aspects and getting a hold of the end-users themselves. This is mainly due to the physical distance to the test district Isingiro. Naturally, medical personnel in developed countries, such as Sweden and England, work in very different ways and under different conditions than what is being done in Uganda. Even examples from India and Tanzania are not adequate in this case. However, under these circumstances the best that can be done for now is to make use of the experiences that are more easily accessible and available at the moment.

It is clear that different types of users prefer to work with varied sorts of systems. In Sweden doctors always think in the terms of diagnostics, because if you have made a diagnosis, then it is possible to prescribe some sort of medication or to give other types of treatment advice. However, this is not the case for the nurses working in Sweden; instead they provide other kinds of care. Since these people are performing different types of jobs, or various sorts of activities, it is natural to assume that they need different kinds of support in their work. The situation in Uganda is similar seeing how the system that is going to be developed will have different types of users with various educational background and vocational experience. Preferably the developed systems should take these aspects into account. In this respect especially one of the universal design aspects is of great importance, namely flexibility.

In Uganda, the clinical officers are the closest we come to what can be referred to as the “doctors” at the health centers, and it is up to them to make the diagnosis. The nurses at the health centers probably perform different kinds of tasks depending on whether they are working alone at the HC or not, however this is not something that I have been able to confirm. Nonetheless, it is likely that the nurses working on their own, at a HC2 level, perform more tasks than on an HC4 level, because no clinical officer is available and can help them. Further, when studying the work process in an HC4, it became apparent that the work that different actors perform is much interconnected. In other words, there is a need for a system that can adapt to this kind of workflow and is flexible enough for the

user requirements. Preferably three different systems should be developed, to meet the needs of the end-users.

6.1.1 Clinical officers

It is the task of the clinical officer to make diagnosis and to prescribe medicine to the people who need them. In that aspect it is likely that the Ugandan clinical guidelines were developed mostly for clinical officers. In the guidelines it is possible to look up certain diagnosis and use the information to confirm the preliminary diagnosis, or to rethink a decision. In Sweden it is not very common that doctors make use of these types of guidelines in their work. Rather, they are mostly used for an educational purpose. Instead experienced doctors prefer to make use of their own knowledge and experience. However, to computerize the Ugandan clinical guidelines and make them searchable in the system would add to the convenience of the users and thereby according to the theory increase the acceptability of the system. Further, we would remove one of the physical barriers, which would in turn increase the accessibility as well. Instead of having to leave the program to look-up a certain type of information, it should be possible for them to search directly in the system, in which they are working. To be able to search for different diagnosis seems to be very suitable for the way that doctors work and the tasks they perform. However, they would probably be even more useful for the clinical officers, if they were turned into computer interpretable guidelines. These guidelines could be more adapted to their current workflow and therefore they would not interrupt their work process, which is an important aspect of the human-computer interaction. A system like this could also provide reminders and give more patient specific advice. As mentioned in the result section, a system providing more functions is more likely to be used.

Nevertheless, it seems like the more educated people are, and the more experience they have, the stronger their vocational pride will be. Therefore, they might not want to make use of a system like this because pride can be said to be one political factor influencing the acceptability of the system. Similarly, they have very well established routines and ways of doing things that might lead them to object to the use of a computerized system all together, which according to the theory can be referred to as their cultural and social habits that in the end also affect the acceptability. Consequently, it is important that the benefits of using the system are clearly visible to them. This statement is valid for all of our end-users. We have to keep in mind that the use of computers will not be evident to these users, as it is in many places in Sweden today. But even here in Sweden, when the EHR-systems were introduced, it took several years before they were fully implemented. One way to add a value for the end-users is by creating a system that can collect statistical measurements that need to be sent to the ministry. This feature has the possibility to save them a lot of time and thereby increasing the usefulness, and as we know time is a scarce resource that can be used on better things. Usefulness is the fourth out of the five acceptability features mentioned in the theory.

One of the main reasons why the guidelines or CDSSs are rarely used among health personnel in Sweden is because they are not integrated into the EHR-systems. Instead of having to leave one system and go to another, it would be more beneficial if the information is visible in the system that is actually being used by the health worker. Of

course it will then be up to them whether or not they want to make use of it, but at least it will be available. Maybe this is not a bad thing either because we should not forget that, according to the people-centered view, a computer system cannot cover all the aspects of the human thinking. When doctors and nurses make decisions regarding patients they compile all the information available to them, to make an informed decision based on their personal experience. For example, health workers do not only listen to what the patients say; they also listen to how they say it. In addition another important type of information is the patient's health background. As mentioned in the theory, it is people and not computers that can make flexible decisions based on context. Therefore, the use of an algorithmic system might be much too limiting for these types of health professionals. We have also seen from the example in Tanzania that IMCI is not taking all possible patient aspects into account; sometimes it will be necessary to use one's own judgment.

6.1.2 Nurses

It is the nurses, especially on a HC2 level, that would be the main users of a computerized symptom-based clinical decision support system. This is mainly due to the fact that the HC2 nurses do not have access to help from people with a higher type of education, as the nurses on a HC4 level do. Similarly to what is being done in Sweden the nurses are not making diagnosis, rather they make classifications. This is also exactly what the WHO protocols (IMCI and IMAI) is aiming to do. The problem for nurses though, could be that they do not have access to, or are allowed to prescribe, certain drugs. However, according to the essential medicines list for Uganda they are allowed to handle the basic drugs covered in IMCI. For the severe cases they are still encouraged to refer the patients. On a HC4 level, problems that might occur can be connected to the fact that the nurses are not involved in making the diagnosis and prescribing treatment. Therefore only parts of the CDSS system will be useful for them. The system that should be particularly developed for the nurses based on IMCI, and eventually IMAI, will be further discussed below in the activities, context and technology sections. However, these are some of the barriers to access that can be identified for the nurses.

6.1.3 Community health workers

As we know, the fact that the system is meant to be used in a rural setting, means that the medical trained people to the population ratio is even lower than in big cities. Further, the distances to get medical attention can sometimes be very long. This results in people not visiting health centers because of the cost for transportation, but also because of the loss of income due to this time consuming activity. This unwillingness to visit the health centers also depends on the lack of knowledge about health issues and the necessity to seek help for certain conditions, which is a big problem among the rural population in low resource settings. These aspects are more connected to the context aspect of this discussion, but this type of reasoning leads to the suggestion that for the future the ICT4MPOWER project should consider developing a CDSS adopted for use by less educated lay people such as the CHWs. By only creating a system for HC2 levels and above, the system is at the same time supporting the economic barriers, which are mentioned in the theory, that are hindering people from getting help. This is important, because in the end the goal with developing this system is to improve the health care that

is received by the people and therefore they are also an important group of stakeholders that should be taken into consideration.

When developing a system for the CHWs, it is possible to increase their knowledge and support them in their work. These people originate from the villages and they are living in proximity to the other villagers. Without bringing the health care closer to the people, it is not possible to solve any of the above mentioned problems. However, providing a CDSS to less educated people also brings additional challenges. In modern days the main idea behind the CDSS is that it can be used as a tool to support the clinicians in their work. It can never, however, replace the knowledge and experience that the clinicians have themselves. Instead the result from the system should be evaluated by using the knowledge and experience of the clinician, and the results cannot only be followed blindly. Therefore, when creating a system for CHW, without clinical experience, this system has to be adapted to their knowledge level. It is not only that they are not well educated within the field of health care, the problem is also that they lack in computer skills. Nevertheless, this is not only true for the CHWs, but also for the other types of users mentioned. Therefore, when developing this system it is necessary to take into account that the majority of the end-users will be novice users. Further, it is likely that the CHWs will have a lower-literacy level than the other users, because of their lower educational level. However, following the recommendations for low-literacy users have been shown to increase the usability for all types of users. Consequently, the aspects mentioned in section 5.3 should be taken into consideration when designing all the systems.

During this work a lot of time has been spent on trying to come up with a suitable solution for a CDSS that could be used by CHWs. The system should not be too advanced as to avoid mistakes by the CHWs, because as we know this can easily happen. The IMCI and IMAI protocols that have been developed by WHO and UNICEF are mainly meant to be used by medical personnel, with the minimum of a nursing background. Many of the activities that are supposed to be carried out require experience and previous training and education. Tasks in the IMCI such as listen for stridor and wheezing, among others, have proven to be too difficult for less experienced people and mistakes can therefore easily be made. According to the theory, a system's usability can be increased if it is easy to learn, safe to operate and have a high level of utility, in the sense that the system can do the things that the users want it to do. Because the VHT project in Isingiro is currently under development it has not been possible to get information regarding what types of functions that can be useful for CHWs. Therefore, it is at this stage only possible to use our own thoughts and experiences to gather ideas regarding functions that are believed to increase the utility.

However, the results of this thesis show that currently a full scale IMCI system is not useful for CHWs. The reasons for this are first of all that, according to the essential medicines list for Uganda 2007, they are not allowed to give any type of penicillin or even Vitamin A to patients. Instead, they are only allowed to provide certain malaria drugs, Mebendazole for worm treatment, Paracetamol and Oral Rehydration Solution. [33] Therefore, the system that is developed needs to be adapted to these prerequisites.

This is also something that in the end will increase the safety of the system because these drugs are quite harmless, even if they would be given without cause. Safety is an important aspect that has been mentioned in the theory. Second, if the CHWs make too many mistakes when using the system, this can jeopardize the trust and thereby the acceptability for the whole project and in addition people might suffer. Third, it is important that the ICT4MPOWER project is on the same page as the policy makers in Uganda. It is necessary to gather all the stakeholders and involved parties to reach an agreement regarding this subject, because in the end it is rather controversial to let lay people treat patients and there might be important political aspects (power structures, principles and legal issues) to take into consideration. In this case it would be beneficial to include the Malaria Consortium, because of their previous experiences within the field. Fourth, a system developed for CHWs requires a lot more extensive testing before it can actually be implemented. This has to do with the fact that it is not possible to trust the community health workers to use their own experience, if the system has flaws or if there are some gaps.

Further, it will be especially important for CHW to have a system developed after the principles of universal design. The system needs to be intuitive to use, because they are novice users. In addition, the information needs to be even more perceptible than it normally would be, because they have a lower knowledge level than the others users.

What we can learn from previous experience is that it takes time before the CHWs can be expected to reach a certain skill level, and it is not going to happen over a day or just because they have access to a CDSS. Education is still going to be a very central part, not only health education in general, but also education on how to use the system. Hopefully, a computerized protocol will be much easier to follow and will demand less from the user, when it comes to interpreting the next step in the examination and the results, than the paper copy has been. The education of the CHW should be done in steps, meaning that they can learn to tackle one common disease at the time and add functions to the CDSS accordingly. Further, it can be advisable to implement a type of internship for the CHWs at the closest health center. The benefits of this would be that they can test their knowledge in a controlled environment, they can observe and learn new things (for example how an examination should be carried out) and in addition they get a better contact with the HC. This would hopefully ameliorate the collaboration between these two different types of health units and through this also the connection between the HC and the community. This would be a positive outcome since the CHW is meant to be working as the link between the HCs and the rest of the community.

The time limitation for the CHW is maybe not as pressing as for the other health workers at the health clinics, where the cues are very long. But when making a visit to the household they will also be under pressure to carry out their tasks as fast as possible. This is because the CHW will be keeping the household members from their regular tasks and this will probably not be popular, in case it is not directly evident that the visit is very beneficial for the household. The solution here could be to divide the tasks of the CHW. For example, when they visit a family for the first time they only do an initial registration, whereas the next time when they come back they can check on the health

status for the children or adults in the household. Hopefully there will be enough CHWs to make regular visits to the households. From a patient perspective, this is one way of reducing the economic barriers of access to the system.

It is important that the system for the CHWs encourages patients to go and see a nurse, even for less severe cases. A condition that is normally shown as yellow in the IMCI can be treated by a nurse, but should maybe not only be treated by a CHW; if possible they should send this person to an HC2 instead. Further, since the CHW do not have as long vocational experience as the other health workers they need to be especially informed regarding the system's limitations, because they do not have as much experience to compare the results with.

The conceptual barriers mentioned in the theory can typically be a problem for the CHWs, because they might have difficulties understanding the language used within the health care sector. In addition, they have more difficulties in creating a mental model of the examination and how things fit together. For example, they might not know that it is the fast breathing that leads the classification to pneumonia. This means that the systems must support them in creating a correct mental model.

An additional barrier for use can in this case be economic factors. If the CHW do not get paid for the work that he or she performs, this is very likely to affect their motivation. However, this aspect is a bit outside of the scope of this thesis.

6.1.4 Patients

As mentioned previously, all the stakeholders should be considered in the analysis before the development of an interactive system. In this case a major group of stakeholders are the patients. From the patients' perspective the use of a CDSS can make a lot of difference. For example, if the treatment advice is followed by the health worker, they will always be prescribed the cheapest and most effective drugs available (even though this is not true for all individual cases, as was stated by the Swedish physician). Further, we have seen from the case in India that the patients were very satisfied with the use of a computerized decision support, and they experienced that it increased the quality of the care. Another way to increase the patient satisfaction can be by constructing a system that provides additional recommendations for the patients. Seeing how a large part of the population is illiterate, a good idea can be to provide the patient with advice in a video-based format. For the security of the patient it is also important that the system emphasizes the advice on when, or for what reasons, the patient should return for a follow-up visit. However, in the example from India they were worried about the patients' expectations, and that they were too high in comparison to what the system could actually do. This might be a risk seeing how it can result in the patients not questioning the system; instead they trust it blindly.

Trust is a really important political feature that will influence the acceptability of the system. Both too little trust and too much trust can be harmful for all the parties involved and for the system reputation. This is true from a patient perspective as well as from an end-user perspective. If the patients do not trust the system they might go and seek help

elsewhere or maybe not seek help at all. If the end-users do not trust the system they will simply not use it. However, if they trust it too much they will not make the adjustments that might be necessary in specific cases. Another group of stakeholders that need to trust and support the system is the policy makers. If they do not believe in what the system can do they will not invest the financial resources that are necessary for the training and maintenance of the system.

For the system to be trusted the information must come from reputable sources and be updated continuously. Another aspect that has to do with the information in the system is the accountability. In the result chapter some of the risks with using these types of systems were mentioned. Questions such as “who will be the one to blame if mistakes are made?” need to be answered, and legal and ethical issues need to be sorted out. However, this aspect of the use of CDSS has not been dealt with in this thesis work.

6.2 Activities

The element activities in the PACT framework stands for the activities that the above mentioned different groups of people want to carry out. Many aspects can be included in this, such as temporal, cooperation, complexity, task definition and safety.

What types of activities that the health workers are performing, at the different health clinics, is partly explained in the workflow diagram from Isingiro. The problem with this diagram is however, that they only have explained the workflow for HC4 and expressed that the workflow for HC3 and HC2 are similar. However, there is reason to doubt this statement, especially seeing how there are different types of people involved in the different tasks. The workflow can also depend very much on whether or not the clinic has access to a laboratory to test the patients, and this is something that needs to be taken into consideration when creating the system. Instead of posing a lot of questions to a patient with a febrile condition, the health clinic should be able to make some settings in the system so that they are only being asked whether the result from the malaria test was positive or negative.

The workflow has been described to be very important to take into account when developing a system, both in the theory section and from the evaluations of different CDSSs. Something that needs to be taken into account here is that it might be the case that the patient examination is performed by more than one person, and consideration should be given to the cooperation between people. In the HC4 it is the task of the nurse to gather symptoms and assess the child, whereas the clinical officer prescribes the medicine. If we make a system that can also make drug recommendations, in accordance to the paper format of IMCI, then it is more likely that the system can be useful for clinical officers on a HC4 level. An additional benefit would be if it is possible to create a system that can also make medication suggestions for other conditions, which are covered in the Ugandan clinical guidelines. This is one suggestion on how the system can be expanded in the future. However, if this is done, there is a need to carefully control that the information put into the system is correct. When adding the UCG to the CDSS this should be done by using a team of both programmers and medical personnel, because

they will be able to bring different perspectives. Of course the medical personnel should preferably have experiences from rural settings in Uganda.

In this particular case, the best solution might be to start off by making a computerized version of the IMCI protocol, especially seeing how the code from the e-IMCI application is available. Further, the IMCI approach has already been thoroughly evaluated and tested in various countries, and the results have shown to be promising. It has been proven to cover most of the diseases that children visiting health facilities are suffering from. Hopefully, it will also be familiar to some of the health workers. The IMAI approach for adults and adolescents, however, is not so well known and it is a more limited approach than IMCI. The aim of developing IMAI was, according to the WHO, to make it easier for health workers to screen for patients needing to be tested for HIV. This type of support would probably be very useful for health workers. However, it is not clear how accurate it is (since it has not been possible to find any evaluations) and according to the knowledge available it has not yet been implemented in Uganda nor has it been adapted to the Ugandan conditions, which is something that can be a very time consuming process. A good way to bring the IMAI into the system (if the use of IMCI has proven to be successful) is to start with the conditions that are also covered for children in the IMCI, for example respiratory diseases, malaria and diarrhea. They include the same types of examinations and the same type of treatment (only stronger medication) as what should be done with children. Gradually, the system could then be expanded to cover other aspects. It is better to put some functions in the beginning, and test them out, before implementing everything. This should be done from a usability perspective, so that in accordance to the theory the effectiveness, efficiency and satisfaction can be tested, as well as from a learnability perspective. Further, the faster a working prototype can be developed, the sooner it is possible to evaluate it and get feedback from the end-users. As mentioned, prototype, evaluation, feedback and analysis are the basic elements in an iterative user-centered design process.

The use of the CDSS, however, will in the end also depend on how frequently the other systems (electronic health records, e-learning, HR-system) are being used, since they will all be connected and perceived as one system. As described in the theory, the tasks that the users have to perform should be grouped in an appropriate way to suit the needs of the users. In this case it also means that the CDSS have to be connected to the other systems. Information that is being put into the CDSS should be saved and put in the electronic health record of the patient. Similarly, it must be possible for the CDSS system to fetch important data from the patient records. In this case, the type of information that might be important is the weight and age of a child. Even for adult medication, it is sometimes important to know the weight of the patient. Whether all the input from the CDSS should be copied into the EHR-system, or if the users can choose what to put in the records themselves, is a question that can be left for a later stage. The most important thing is that the information does not have to be retyped by the health worker. Further, it can also be of importance that the data is saved for statistical reasons. The data can also be used as a basis for making improvements in the system. Another aspect, why these types of journals can be important is for sorting out responsibility issues in case there are any problems.

In order to create a system that in the end is more coherent with the workflow of the end-users, it would be necessary to gather more detailed information regarding what type of questions the health workers pose to the patients when they come to the clinic, and also in what order this is done. This is important to know, because the system needs to be developed in a similar way. It is not a good solution if the health worker has to go to one page and fill out some general information about the patient only to go back to the CDSS. The workflow analysis from Isingiro has formed the basis for the development of a prototype for the EHR-system. The CDSS that will be developed have to fit well into this system and the EHR-system should be developed with the CDSS in mind.

6.2.1 Organizational aspects

The e-IMCI system that was tested in Tanzania showed to be very welcomed by the users. One very important reason for this is probably because Tanzania is using IMCI as a national strategy for working with childhood illnesses. However, this is not the case in Uganda. We know that it started up as a centralized strategy, but training responsibilities were then more decentralized and the current state of IMCI in Uganda is unclear. Therefore, it is likely that the name IMCI is not so important to make use of, to get support from the users and the policy makers in Uganda. Instead, it is probably more advantageous to refer to the Ugandan clinical guidelines, seeing how it contains a whole section about childhood illness. This section is more or less the Ugandan version of IMCI and in addition the MoH is standing behind it, because it was them who published the guidelines. Another benefit with this is that if the system is regarded as a part of the UCG, then it can also be updated accordingly.

6.3 Context

As mentioned in chapter 3, the context element of the PACT framework is something that is surrounding the activities; it can also be something that is connecting two activities with each other. For example it can represent the social context and the physical environment.

In contrast to most CDSSs used in the developed world that are very specialized, with the exception of the telemedicine systems, the systems that is planned to be developed for Uganda is more general. Since the system is meant to be used in primary care settings, there is no need to develop a very specialized system. People in need of specialized care have to go to the hospitals to get treatment; this is true for Sweden as well as for Uganda. This clarifies the context for which the system is meant to be used. It is a primary care setting in low resource rural parts of Uganda. Because it is going to be used in a primary care setting, the most common diseases and conditions need to be covered by the system, to make it useful. By reading about the health care situation in Uganda, it is likely that IMCI is a very good approach to use for children, because it is covering so many of the illnesses present among the children in the country. Similarly, the UCG was developed to cover the most common conditions among the general public. When covering the most common conditions, this increases the utility of the system because it can be used for more patients.

Another factor, that has been shown to be of great importance both from the theory and the results, is the time it takes to perform tasks and to use the system. This factor is already crucial for success in developed countries, where the health worker to patient ratio is much higher than in Uganda, which leads to the conclusion that it is even more crucial in Uganda. The time factor is also one of the explanations why IMCI is not always well used, and as we know a system that takes too long time cannot be considered to be very efficient thus decreasing the usability. Therefore, it is essential that the system that will be built is not only flexible (allowing for shortcuts); it also has to be fast even if the users choose to go through all of the steps. However, this is something I will return to later.

To reduce the accessibility barriers that might exist, a system like this has to be available at the point of care, i.e. in front of the health worker when he or she meets with the patient. Therefore, every health worker, or every room in the health center, should have a computer. This is important to overcome the physical barrier to use, that has been mentioned to affect the accessibility, which in this case is the location of the equipment. But it is not only the location of the computer in itself that is crucial. The health workers also need access to the other tools that are necessary to use the CDSS. In the case of the IMCI it is necessary to have a thermometer, a scale and a timer to be able to insert correct values. An experienced person would probably be able to see and feel and listen to the child to determine if it has a fever, is malnourished or whether it has a normal breathing or not. However, with less experienced persons, it is of great importance that they have access to these tools to make a correct diagnosis. Further, it is important to limit the number of tools necessary in low resource settings. In the end all tools are important, not only the computer, to enable the health workers to do their job. To take into account that all tools might not be available at all times, it might be necessary to program a system that allows approximate answers or has an option of not available.

In the Ugandan context it is important to take into consideration that there are many things that can lead to the system not being available for the users. Examples of such things can be technical problems regarding the hardware, or issues with the energy solution. Since the physical distance to the cities can be very long in rural areas, the system might end up being down for several days or even longer, when faced with technical problems. This is due to the lack of technical knowledge at the clinics, leading to experts having to come all the way from the cities to solve the problems. This aspect of technology use in rural and low resource settings, together with the assumption that the system will not always be very well used after the initial implementation, leads to the conclusion that the systems being developed should be educational. This means that the reasoning behind the algorithms should always be visible for the users. In this way they can learn how the system is acting and how to connect certain symptoms with a special condition or classification to create a correct mental model, which was mentioned in the theory. This is also extremely important for the times they will go out to meet the patients outside of the health center, because in these cases they will not always have their computers with them.

6.4 Technology

This aspect of the system development is in many ways outside the scope of this thesis, at least when it comes to the hardware issues. Within the ICT4MPOWER project another master student has been working to come up with an appropriate technical device, suitable for the conditions in rural Uganda. Yet another student has been working on the energy solution for this project. These are two very important parts that need to be working in order for the system to be accessible, but as mentioned this is not something that this thesis has been dealing with. However, it is important to accept the fact that, because of the conditions in Uganda, the system will not always be available to the end-users. Now, instead of discussing technology from the hardware perspective, this section will cover some design features and functions that can be important to consider adding when developing this system and the interface. The technology element of the PACT framework can also be said to cover these sorts of issues.

By having a computerized system to support diagnostics and treatment related issues, according to the results studies have shown that it has been possible to reduce the number of errors that are being made by clinicians in their work. One important benefit with using the computer as a tool is that the system can be able to calculate the correct drug dosage according to age or weight, and by doing this it is possible to avoid unnecessary mistakes. This is something that should be done also for this system. Especially for children, it is important that they get the correct drug dosage. By doing this it is possible to increase the safety for the patients.

Further, a computerized decision support system can be easier to learn how to use than a paper-based version, since knowledge about the different steps of the process can be built into the program. In addition, the next step of the examination will not have to be interpreted by the user, since it will automatically be provided by the program. However, as mentioned, it is still advisable that the reasoning of the program is visible for the user for other reasons. An educational part should be built into the program so that they can access important information and help when they need it. The type of help that they might need access to can regard the use of the system itself, but it can also be health related issues. As mentioned in the result chapter, the results from the search function for the help section should be well organized, with the most relevant match displayed first. The help text should be easy to read and always start with the most important information that the user needs. Any search function should also be tolerant against spelling mistakes. In addition it is important to not add too many choices or too much information in the system; this will only confuse the user.

An important part of the IMCI is the advice that is meant to be given to the caregiver, at the time of the examination. With the use of the IMCI protocol it has been shown that advice is given at a more frequent basis. However, the advice to the caregiver is still regularly skipped or forgotten. With a computerized version of IMCI it is possible to add reminders in the program, which will be given to the user at an appropriate time. The advice for the caregiver is an important step in the work process, so that the child gets the drug correctly and for the full period of time that it is needed. Reminders, or maybe text boxes, with important information is also one way of making the information more

perceptible by the user. However, there cannot be too many reminders as this will undermine the importance of the reminders, and resulting in the users not paying any attention to them. Further, as mentioned, another way to put emphasis on certain information is by using colors. With IMCI and IMAI the color red is already being used for representing danger and severity in the illness. The red, yellow and green colors from the original protocol should be kept for the computerized version. The same types of colors can also be useful for the system developed for CHWs, since we should try and be consistent.

Evaluations in developed countries show that doctors often favor, and are more likely to use, clinical decision support systems that are flexible. It is likely that the same thing will show to be true in the Ugandan case. Flexibility is also something that is mentioned as an important design aspect for system design and as one of the aspects of universal design. When computerizing the IMCI-protocol, it will be important to divide it into different functions or tasks, and if possible that the functions can be used regardless of the other functions. This division has two benefits. First, it is possible to increase the usability, especially for low literate users. Because the user only will get presented with the information that is important for a certain task, there is no need to go through a lot of information to identify what it is that is really important. Second, we will not force the users to go through all of the steps and tie them to the system. This will increase the convenience for the user and thereby the acceptability. The IMCI protocol follows a certain type of workflow. As described before, signs and symptoms should be gathered, the condition should be classified, the child should be checked for malnutrition, drugs should be prescribed, the immunization status should be checked, feeding recommendations should be given and the caregiver should be advised. By allowing the user to get treatment advice, without gathering all the symptoms and signs in the system, only by clicking on a certain type of classification that they decide on themselves with the use of their own experience, we have created a more flexible and convenient system.

6.5 Design Aspects

The main focus of this thesis has not been on the design aspects. However, they have been included because they are necessary to take into consideration when discussing implementation of interactive systems. Most importantly it is the users' needs, wants, problems and limitations that will set the grounds for the development of the user interface. As mentioned, the interface will then dominate the design for the rest of the system. It is now time to discuss some of the design aspects that have been covered in this thesis.

6.5.1 Visibility

Especially for low-literate users it is very important to organize the tasks to be done in a very clear and structured matter. The user of the system should also be provided with a clear overview of these tasks. The tasks to be carried out can be displayed in a sort of timeline with arrows displaying the workflow. The tasks can in this case be divided into assessment, classification, treatment, immunization, feeding and caregiver advice. These

tasks should be clearly visible at the top of the page during the entire work process (see Figure 5).



Figure 5: Example of task division.

The assessment part of the child will be the longest part. In this case it is crucial that even the subtasks are divided into different sections. This will increase the understanding as well as the overview for the user. Hopefully this is also a way to avoid scrolling, since this can be disturbing for novice and low-literate users. The assessment can be divided into danger signs, cough or cold, fever, diarrhea and malnutrition. For each section a set of questions will follow. First, the health worker will get asked about the danger signs, because this is the most important part and it should therefore be checked first. Then the system should ask for the presence of any of the main symptoms. Only the questions for the relevant symptoms should then be shown. The questions in each subtask can be arranged in a hierarchical order and the workflow can be displayed similarly to the IMCI-chart (see Figure 2, Chapter 2) so that the user understands how one question can lead to another question.

As mentioned, if the reasoning of the computer is made visible to the user then they can learn the principles, and therefore they will learn the line of thought much better. This will help them to perform a proper examination, even when the system is not available. For a well trained nurse this might mean how to find the right treatment or how to reason regarding treatment issues, referral and severity of the illness, even if the system is not available. Further, instead of only providing the user with the name of a drug it should also display certain information. An example of this can be a text string explaining the reasoning behind the choice of treatment “Because the child is presenting signs of cough and cold, together with fast breathing, the classification of the child's condition is pneumonia. However, signs of stridor or chest indrawing would have indicated severe pneumonia. The first line of drug for treatment of pneumonia is Cotrimoxazole and the second line of drug is Amoxicillin. The caregiver should return for a follow up visit in 2 days. However, if the child is showing any of these signs: not able to drink or breastfeed, becomes more sick or develops fever; the caregiver should return with the child immediately.”

Similar to the e-IMCI program, the answers from the previous questions should always be visible to the users, so they do not have to go back to check for them or remember them. This also makes it easier for the user to detect if any mistakes have been made when they have filled out the answers. This means that all the answers from the assessment part can be summarized and put in a box, at the page where the suggested classification is provided. Further, if the system suggests a yellow classification level, then it should be possible for the user to choose whether or not they believe this is the

right classification. It must be possible to override or underride the result, and this choice must be visible to the user. Similarly experienced users should be able to choose a classification without answering all the questions in the assessment part. As mentioned in the result chapter, when the users are making this kind of decision it is also important that they know about any cases that are on the threshold between two classifications. It might be advisable to let the users explain why they have chosen to deviate from the system's suggestions. This should be done both for the possibility to make improvements and for responsibility issues.

Another aspect regarding visibility is to make sure that all the information the users need to perform the examination is added in the system, and that it is clearly visible to the user. One example is to write "The child must be calm when you examine the breathing". This kind of advice is not something they should have to remember by themselves. By adding this type of information, it is possible to decrease the memory load of the user. Finally, if the system continuously shows the user where in the work process they are, or at least shows them that they are making progress, it can encourage them to go through the whole process and not stop halfway, only because they did not know how many questions they had left. This is similar to when answering a survey online; the user wants to know how far they have left so they do not get discouraged.

6.5.2 Consistency and familiarity

The most important aspect here is that the CDSS is consistent with the other systems that are going to be developed. The same commands should be used in all systems and have the same meaning. But the consistency does not only consider the language, it also regards the design of the interface, which is an important question for the familiarity for the user.

However, consistency can also regard the information that is being displayed. The information should never be contradictive, and it needs to be coherent with the Ugandan clinical guidelines so that to avoid confusion with current practice.

It will be necessary to find out what kind of language the health workers use today in their work and to adjust the language in the system accordingly. This does not only apply to the translation, but also to the meaning of a concept, which might lead to some tasks being renamed to better suit their understanding. The language used should also somewhat be adjusted to the patient and their understanding of health related issues. This is especially important for the feeding and advice section in the system, which is indirect meant to be addressed to the caregiver. Another linguistic aspect is also to avoid too complex or multi-syllabic words, especially for the CHWs.

Further, familiarity can also apply to the system being similar to the IMCI booklet. This regards for example the language as well as the structure. When designing a system for CHWs it will be important to use a combination of symbols and text to represent things and expressions in a more familiar way and if possible to find useful metaphors. Health related information can be very difficult to understand for people that are not well educated in this particular area.

6.5.3 Control and feedback

The users should be able to move around in the system and to go back and forth as they wish. When having completed a certain section the user should get instant feedback so that they know what they have completed and the result of their actions. If a patient is sent home, it should be clear for the user what the consequences of this can be and for which circumstances the patient should immediately return to the health facility. The user should get instant feedback when they have completed a certain section so that they know what they have completed and the result of their actions. Feedback can also be important for training purposes. As mentioned in the case of computerized training, it was appreciated by the users when they received instant feedback from the system. In this respect the use of computers was much better than the use of human facilitators. This can be seen as encouraging for the future use of computers within the health care sector in Uganda.

Naturally a computer-based CDSS should be combined with a computerized training tool. Since a program like this has already been tested in Uganda this facilitates the implementation. Further, a benefit with using computerized training is that the health workers themselves can refresh their knowledge whenever they want to or feel like they have the time.

6.5.4 Recovery and constraints

In a system using an algorithmic approach the use of undo will probably have consequences, because one question depends on the answer of the previous question. However, it is necessary to have a system where changes can be made. For example, it is possible that the user makes a mistake when choosing the answer or that the patient ends up changing its mind or that the user rethinks a certain decision. However, if the answers that the user have collected are saved in the system, then only the additional questions that come up, when changing an answer, should have to be posed. A division into different subsections will probably simplify this approach. For the users to be able to discover whether or not mistakes have been made it is always necessary to allow them to review the answers.

Maybe some of the most important steps in the work process should not be possible to skip, and if they are, they should still be encouraged to perform them. Further, it can be advisable to put value limits and acceptable intervals for the values that are being put into the system. For the weight of the children this can be crucial, because this determines the drug dosage that should be used. In the case of HC4 maybe the nurses should not be allowed to use the prescribe treatment function, because this task is meant to be performed by the clinical officers. Additional constraints include the ones that should be put for the CHWs. This is really a matter of safety for the patients.

6.5.5 The style

In this case it can be possible to make use of the colors that was mentioned to be very effective, to increase the understanding for low-literate users. Colors can be effective to increase the understanding as well as increase the appeal of the system. However, to

make use of too many different colors can create somewhat of a chaos for the user. The use of colors should be tasteful and used for a certain purpose. To add a lot of pictures or movies for the counsel the mother section will probably add to the appeal of the system for the patients.

6.6 Knowledge Management

In the theoretical chapter we have learned that knowledge management is an important part of the life cycle for a CDSS. The knowledge base for these systems will build on the WHO protocols and the Ugandan clinical guidelines, developed by the MoH. It is likely that the fact that these guidelines are coming from very high instances, make them more accepted by the end-users in Uganda. The problem though, is that they will not be adapted to the local context. The published documents from the MoH (the UCG and the Uganda IMCI protocol) have been adapted to fit to national conditions. But this does not mean that they are automatically adapted to the needs and wants of the end-users in the different clinics. Not all clinics will have access to the same types of tools, or the same number of people on a certain skill level. Therefore, the users should be able to make certain settings in the system itself. However, the above mentioned documents are based on evidence and should not be able to be changed based on solely personal experiences. This is also a matter of security and responsibility. However, it is necessary that the end-users are involved in the updating and management process of the CDSS, also to avoid cultural exclusion. But their suggestions need to reach a higher instance, and several different organizations need to be involved to build consensus, in order to be able to make the actual changes in the system.

As recommended in the theoretical chapter, the actors in charge of maintaining the system should have an oversight group that has the overall responsibility. In this case this group should come from the MoH in Uganda. Seeing how they are in charge of the paper-based clinical guidelines, the best thing would be if they are directly connected to the system. Both the paper-based guidelines and the system should be updated simultaneously. In this way they will not be contradictive either. Further, it is likely that the involvement of the MoH in Tanzania has been crucial for the success of the implementation process of IMCI in the country. Similarly, it will be necessary to get the MoH in Uganda to stand behind and support this system. This also has to do with the fact that it is not enough with only the access to a CDSS to improve the health outcomes. As has been shown, the implementation of IMCI has failed in many countries because of lack of essential drugs, lack of supervision and the overall cost of the care for the patients. The WHO suggests that the number of essential drugs should be minimized, and this is something that the system needs to take into consideration. This is really important for the development of CDSS in developing countries and rural settings.

Knowledge management is about gathering the knowledge available, transforming it into something that is useful and make the necessary changes. However, we have learned that the types of changes that might be necessary, does not only have to do with the knowledge base itself. Additional aspects to take into consideration are the way in which the content is formed and how the information is expressed. It is important that all involved parties understand the text and choice of words. This might have to be even

more carefully tested for the parts that concern the patients. The question is also connected to the choice regarding which language to use. Similarly to the case in Tanzania, Uganda also has English as the official language in which all health related documents have to be filled out. Therefore it might be easier to use English even for other types of documents to keep consistent. However, when designing a CDSS there is no need to have everything in English, because a system like this can easily translate the statistical parts and documents that the MoH is requesting. Therefore, it is important to do as much as possible to decrease the burden on the health workers, which can be done by creating a system in their first language. This will also increase the speed of use.

The conclusion that can be drawn from this is that it is not only important to involve the end-users in the development process, they are also necessary for the maintenance process. They will know best what is missing in the system, what needs to be changed and how it can be made more useful for them. They will also know what aspects that are slowing them down and what type of local adaptations that have to be made.

Below follow a list of changes that are likely they will have to be able to make in the system without any major effort, based on studies of the IMCI protocol:

- Changing the use of first- and second line antibiotics
- Changing duration of treatment
- Changing other types of treatment recommendations
- Adding conditions and symptoms
- Adding general danger signs and recommendation
- Changing recommendations for severe, non-severe or treat at home conditions
- Changing conditions/treatments for different age categories
- Changing vitamin A directions
- Changes in the national immunization plan
- Change when to return to clinic
- Changing feeding recommendations
- Breastfeeding recommendations
- Policies regarding who receives vitamin A
- HIV-issues

- Usability issues
- Local terms and language

But changes in recommendations can also come from the WHO. For example in 2005 they came out with an updated copy of the IMCI protocol. The WHO recommendations are building on a very strong evidence base and should be taken into consideration when making changes in the system. Further, it is strongly advisable that the system is reviewed on a regular basis, which is something that is mentioned both in the theoretical- and result chapters. We have learned that for all suggested changes there is a need to build consensus, make evaluations and test for usability before implementation. By making regular changes this can also add to the credibility and, through this, increase the

acceptance of the system. A system that is reviewed on a regular basis will also become more efficient if appropriate changes are made.

7. About this Study

Initially, according to the plan of the ICT4MPOWER project, the CDSS would be developed during the time I spent working for this project. In this case it would have been possible to put more emphasis on the design aspects that need to be taken into consideration, when creating an interactive system. However, due to project limitations the development of the CDSS has been put on hold for the time being. Still, some of the design theory has been mentioned, mainly as a support for the future development but also to give the reader an insight into this subject. The development and implementation of interactive systems is really a multidimensional task, the same goes for CDSSs.

When discussing some of these design issues there is a great variation on the detail level. This is due to the fact that the design guidelines themselves are very varied in the details they provide, but partly it also depends on difficulties finding relevant information. As mentioned, many design aspect also have to be discussed with the end-users themselves, which has not been possible in this case.

On the whole the result chapter in this thesis is quite limited to secondary sources. One of the downsides with this is that it has not been possible to discuss or criticize the methods that have been used by these research teams. Naturally, their methodology will in this case also affect the results of my study. However, since the sources are clearly displayed in my thesis it is possible for the reader to look them up and to read more about their results and the methodology they have used. In the end I have of course only used material from what I have believed to be reputable resources that can be trusted.

Seeing how I have not had the possibility to go to Uganda, I have not been able to confirm the assumptions that I have made in the analysis chapter of this thesis. To find sources about CDSS in Uganda has been practically impossible.

In the theory chapter it is clearly stated that the end-users should be involved early in the development process, the earlier the better, to get feedback and to create a system for their needs. If I would have come in contact with the end-users themselves it would have been possible to ask them a lot of questions, regarding for example how they would feel about trusting a system like this, their experienced benefits from the use of clinical guidelines, additional functions they might would like to add, the lingo that is being used at their workplace, their attitude towards IMCI/IMAI and UCG, the users' former computer skills and attitude towards the use of computers. Affordance and other design aspects could also have been possible to investigate. However, this has not been possible, but will hopefully be done at a later stage of this development process. In that case, this thesis can be used as a basis for the investigations to be carried out on sight.

The benefits of using a CDSS in Uganda have also been difficult to investigate due to that fact that systems like this are currently not in use in the country. Further, the benefits from the use of CDSSs varies drastically depending on the functions that the system has; if it is used for diagnostics, treatment, administration etcetera. I believe that the benefits can only be investigated for the one particular case and cannot be seen as general. Therefore, the focus of this thesis has shifted slightly during my work and I have

concentrated on identifying the implementation challenges that have been experienced and to describe some systems and their functions, to give some recommendations for the future development. It is not in any way certain that all of these challenges will be present in the particular case, but these aspects should at least be known by the project management and be taken into account when designing the system.

Before starting my work, it was more or less decided that a CDSS would be developed by using the IMCI and IMAI protocols as a basis. However, I believe that my results show that it is not clear that this is the best solution for the situation in Uganda. Maybe a system like this is not the best way to improve their situation at all. Designing a system that is useful and that is being used is not an easy thing to do. Further, if the system recommends the correct medicine, that the patient should use, it will have no impact what so ever in the end, if this medicine is out of stock or too expensive to buy. Nor can the system make any difference if the majority of the people still do not seek medical attention for their problems.

A system like this cannot be 100 % correct at all times. This means that we still have to trust the users to use their own knowledge and experiences to make decisions in each individual case. But no matter how this system is designed there might be legal and ethical aspects that should be investigated. These aspects have not been covered within the scope of this thesis, but they are proposed to be investigated in future research. Another question for future research can be general advice or guidelines for system design in developing countries, which is an area that is difficult to find information about.

During my work I have found that there is a lot of information and experience available at Karolinska university hospital and Karolinska Institute. There are many projects that include Swedish medical personnel staying in Uganda for some period of time. For the future work of the ICT4MPOWER project I highly recommend the project members to try and contact these people to get some more hands on experience from the field. When designing a CDSS system, it is important that there are not only programmers involved. When programmers and health professionals work together the end result will be much more nuanced.

8. Conclusions

We have seen that the use of clinical decision support systems or guidelines, as a support for diagnostics and treatment issues, can have beneficial effects on the health care services delivered within certain organizations. By the use of these types of system, or simply paper-based guidelines, it is possible to increase the quality of the care delivered, to reduce the number of errors being made, to remind health workers about different important factors, to educate the patients and to help recommend the correct type and dosage of the most cost-effective medicines, which in the end can save money for already financially burdened governments and patients. However, in order for a system like this to work, it is important that it is being used by the health professionals, even after the initial implementation phase. To encourage the health workers to use systems like these, the benefits must be apparent to them. Even more so in Uganda than in developed countries, because nowadays the use of computers is more or less a given within many institutions in industrialized countries. However, this is not the case in Uganda and therefore they must be convinced.

The WHO protocols and the Ugandan clinical guidelines are suitable to use as a knowledge base, when creating CDSSs for these settings. They have already taken into account many of the conditions that need to be included when designing for low resource settings in developing countries, and in this way they are context specific. For example the diseases that are covered, the drugs that are available and the tools needed are suitable for Ugandan conditions. However, these guidelines have still not been adapted to the local contexts and prerequisites at individual clinics. Nor are they adapted to adjust to people with different educational and vocational backgrounds, which is something that the system developers have to accommodate for.

Even if it is possible to create suitable systems for these different types of people, the use of clinical decision support systems alone is not going to solve the problems with the health care that are present in Uganda. It can, however, be an important tool for the health workers, a tool that can help them in their work and guide them in decision making. But a tool like this can never be seen as the absolute truth that must be followed no matter what. Health care is a complex area to work within, and there are too many factors than can be covered by algorithms that are taken into account when health professionals make their decisions.

In the end, whether or not the systems will be used depend on the opinions and attitudes towards the systems from all of the people involved and that will be affected by this implementation, namely the stakeholders. It also depends on how well the developers of the systems manage to understand the needs and wants of these stakeholders, including everyone from the patients to the health workers and the ministry of health, and how well they cover the activities that they need to perform. Seeing how the Ugandan culture is so very different from ours, it is crucial that the end-users and other stakeholders get a say in the design process. Otherwise there is a big risk that very advanced and sophisticated systems are developed, but that the systems are lacking all connection with reality, the reality of the end-users. Systems like these will never be very useful for the end-users nor will they be accepted.

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