

eTEN – eHealth Programme



SPEX

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Abstract

This document reports on the review of requirements carried out by the users participating in the SPEX project. The objective of this work is to double check the features of the SPEX services as they were originally envisioned.

The information in this document is provided as is and no guarantee or warranty is given that the information is fit for any particular purpose. The user thereof uses the information at its sole risk and liability.

Key Word List

Health care models, Continuum of care, Shared treatments, Telecollaboration, Teleconsulting, CSCW.

Executive Summary

The SPEX project aims to explore the significance, in terms of business potential, of an innovative model of healthcare service based on the successful experience of franchising networks accumulated in other business areas.

The healthcare market seems particularly suitable for the proposed approach with centres of excellence making strong efforts to build up meaningful collaborative liaisons with peripheral points of care. The three scenarios summarised below illustrate clinical environments where the sharing of knowledge and training can yield an increased range of services and quality for the final client.

The complex Italian healthcare reality is fully represented in the three locations of the pilot (Piemonte, Lazio and Campania). Cardiologico Monzino, as centre of excellence, will produce a set of profiles of care targeting heart diseases. This will constitute the core for the deployment of three major types of relationships among the participating institutions: telemedicine transferral, education and financial management.

The Spanish pilot site conforms to a collaborative scenario in the disease management of heart failure. A centre of excellence (Hospital Clínic de Barcelona) and a general hospital (Hospital General de Vic) join their efforts to provide better services and increase peripheral accessibility for patients. The selected health condition, because of its evolving nature, offers a variety of possibilities for the interaction. This, in turn, provides an excellent setting for analysing and inferring the potential of a franchising business model.

Uppsala also takes advantage of an already existing collaboration between the participating institutions (County Hospital of Uppsala and Eskilstuna County Hospital). By focusing on the management of problem wounds, the pilot tackles a significant clinical situation that is often uncared for. This example is particularly compelling since giving good support to less usual cases constitutes an authoritative argument in the analysis of the potential impact and economic framework.

Globally, the three scenarios, although distinct, have sufficient number of points in common in order to make a combined analysis doable and to draw conclusions that could be extrapolated to similar environments.

Change History

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0.3	1 st Sept 2004	First draft releases
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Version Changes

1 Initial version

Outstanding Issues

None.

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1. Introduction

The present document D3.1 “User Needs” occupies a very early position in the SPEX project time scale. It summarises the outcomes resulting from project Task 3.1 devoted to user needs review. This task is one of the two building blocks of WP3 “User need review and prototype functional specification”. The document compiles essential information needed to underpin further projects activities.

1.1 Purpose of this document

This document reviews the set of features that users have considered for their inclusion in the SPEX system. The document builds on previous experience already existing in the different pilot sites.

Consequently, in producing the document, the participating teams in the different sites have reviewed specific care procedures that could be totally or partially shifted to the business model that SPEX proposes. In the process of choosing the procedure, several points have been considered to facilitate an early adoption and installation of the pilots:

- Good institutional historical track record in dealing with the type of care that the procedure supports.
- Clinical significance with a well defined target group of patients and professionals.
- Well established protocols for the process that could be applied over a collaborative scenario (Centre of excellence – Peripheral point of care).
- Availability of supporting material for training and educational purposes.
- Ease of comparison with the previous procedure in order to establish a good basis for the market validation.

In all the three pilots sites that are described in the following sections, the above mentioned points can be straightforwardly recognised.

The contents of the present document are to be considered a direct input to other project deliverables, notably “ID3.2 – SPEX Draft Prototype Functional Specifications” and “D3.2 – SPEX Prototype Functional Specifications”.

1.2 Glossary

CCM	Cardiology Centre of Monzino
CCU	County Hospital Uppsala
CHF	Congestive Heart Failure
ESH	Eskilstuna County Hospital
GP	General Practitioner
HCPB	Hospital Clínic i Provincial de Barcelona

HGV
OPD

Hospital General de Vic
Outpatient Department

2. Italian pilot site

2.1 Description of the pilot site

The Monzino Cardiology Centre (CCM) is a highly specialised hospital devoted to cardiovascular diseases, with an interest in clinical management of patients and in applied research, belonging to a network ruled and financed by the Italian Health care authority.

Physicians and facilities of CCM are dedicated to providing patients with the best available methods for the prevention and cure of cardiovascular diseases. Patients' medical needs are addressed in reassuring surroundings, where physical and psychological comfort are the highest priority.

As such, CCM is a referral centre in Italy for cardiovascular medicine. Its research and teaching characteristics put it in a very particular position. The last 10 years show a progressive modification of the pattern of care in cardiovascular disease and also in the Italian healthcare system. Cardiac surgery and interventional cardiology now are widespread in Italy, and for this reason it is now necessary to develop different linkages with both the medical environment and the patients to maintain a leading position in the Italian marketplace. In the past it was only necessary to perform cardiovascular procedures, due to very long waiting lists, and lack of alternatives for the patients. The long experience guarantees very good outcomes in CCM, and also a temporal advantage in the usage of new trends and devices. However, this excellence requires a different approach to make this information available to the population and (even if to a lesser extent) for GPs. On the other hand, CCM should avoid being flooded by a huge number of primary care level patients, which would force highly specialised cardiologists to perform primary investigations and consultations, prolong waiting lists and consume skilled resources in an inappropriate, demotivating and expensive way.

The SPEX approach is foreseen as a solution to the search by patients for tertiary level resources such as:

- Arithmology – Electrophysiology.
- Interventional Cardiology.
- 3D CT scan reconstruction of coronary, hearth and arteries.
- 3D Echocardiography.
- Cardiac Surgery.
- Vascular Surgery.

2.2 Objective / purpose of the pilot

The Italian pilot should obtain the following benefits.

A. From the hub (CCM) point of view:

- Expanding the catchment area for the clinical cases that fall in their mission within the healthcare system by focusing all their highly qualified but expensive resources on more complex diagnostic and therapeutic cases.
- Enhancing the financial performance of the Centres of Excellence.

- Filtering patients to avoid the risk of misusing their highly specialised clinical resources by saturating them with relatively ordinary clinical cases.
- B. From the spokes' point of view (peripheral points of care):
- Enhancing the financial performance of the OPD centres, through a better visibility and the possibility to use the brand of a centre of excellence.
 - Improving the professional skill of medical personnel thanks to lessons (both at CCM site and at home with e-Learning applications) and continuous support for difficult cases (teleconsultation approach and follow-up of third level treatments) leading to the fast spread of medical knowledge and early adoption of innovative diagnostic and treatment techniques.
- C. From the patients' point of view:
- Facilitating the access of patients to best practice in cardiology, by providing care to them in accordance with the best international guidelines (CCM approved).
 - Avoiding patients to spend money and time on unnecessary travelling, since primary and secondary level care is provided directly where they live or work presence at CCM site is only required for tertiary level care.
 - Assuring a strict follow-up to tertiary level treatment where they live.
 - Allowing prompt entrance in the tertiary level, due to the guaranteed access to the preferential route.

2.3 Description of the clinical pilot scenario

The Italian pilot will be carried out with a single hub (CCM) connected with three peripheral Points of care. The spokes are located in regions representative of the complex Italian reality (Piemonte, north of Italy, Lazio, at the centre, and Campania, in the south). The different background of the three regions is valuable in order to extract useful information on the business model.

2.3.1 Current process

Current problems:

- strong competition from other hospitals;
- difficulty in reaching patients from the whole country;
- huge numbers of inappropriate primary level consultations at CCM;
- impossibility to filter outside patients before CCM consultation.

It is desirable to move to SPEX because the hub and spoke approach could guarantee a win-win approach to both the centre of excellence and the peripheral outpatient clinic.

2.3.2 Definition of the new process

Type of clinical model: CCM will develop an approach based on Profiles of Care (PoC), with a definition of the tertiary level care. Every PoC will be a formalised and

updated document, published by CCM; the content of the PoC will be tuned for every spoke, in order to optimise it for the local reality.

Type of patients: cardiology patients, belonging to the following pathologies:

- cardiac ischemia;
- cardiac arrhythmias;
- heart failure;
- valvular heart disease;
- peripheral vascular disease;
- systemic hypertension.

Interrelations between providers: the SPEX prototype foresees the integration of clinical activities, and an administrative relationship. The main areas are the following:

- clinical: telemedicine transferral;
- teaching: CCM courses and e-learning;
- financial: contract fees.

List of user requirements

The Outpatient Clinic (spoke) must guarantee primary and secondary level cardiology activities. The rules of the SPEX contract assure a higher standard with regard to the accreditation requirement of the Italian national Health System. Evaluation is performed on:

- professional characteristics (clinical experience of cardiologists);
- the presence and characteristics of instrumental equipment for non invasive cardiology (ECG, dynamic 24 hrs ECG monitoring Holter, cycloergometer Stress test, Dynamic 24 hrs Blood Pressure monitoring, echocardiography, peripheral eco-doppler, etc.);
- technological hardware platform for management of patients records and billing system.

2.3.3 Participating user profiles

The pilot will be made with three participating peripheral centres.

User 1: LARC, Torino.

Private Outpatient Department clinic, accredited with the regional Piemonte Health System (with appointment of A grade, best excellence); L.A.R.C. was created in 1968 as a clinical pathology facility; in time it grew into a big outpatient clinic with multiple specialties, imaging, physical therapy and rehabilitation, sports and occupational medicine.

User 2: Gruppo BIOS, Roma.

Gruppo Bios is a healthcare structure with headquarters in Rome, with multiple outpatient activities; the most important are related to preventive medicine, diagnostic medicine including imaging, physical therapy and rehabilitation, occupational medicine and home care.

User 3: Centro Diagnostico Plinio, Ercolano, Napoli.

The Centro Diagnostico Plinio was created in 1974 in Ercolano (Naples). It is a group of outpatient clinics of high quality (with clinical pathology and imaging), and two structures for physical therapy and rehabilitation. The OPD got a quality certification.

2.3.4 Technological platform

Telemedicina Rizzoli is in charge of the set-up and usage of the technological platform. The tele-consultation infrastructure, already used by TMR in other EU-funded projects, is affordable and viable. The infrastructure is composed of a tele-consultation sub-system (with high quality videoconference system, an outpatient department management module, and an additional component for integration of diagnostic devices for cardiology), an e-learning sub-system (for storage and delivery of training materials and the student-teacher-tutor interaction) and a connectivity sub-system. The server platform will be installed and managed by TMR in Bologna, and the linkage between CCM and the three users will be made by Internet connection.

3. Spanish pilot site

3.1 Description of the pilot site

The Hospital Clínic i Provincial de Barcelona (HCPB) is a tertiary hospital that provides care to an urban area of about 500.000 inhabitants. It is a well-known centre of reference at national and international level with an intense activity in basic and applied medical research. Also, it is a leading centre for pre- and postgraduate medical education.

For the past years and as a part of HCPB's corporate strategy, the development of new models of care provision has been considered a core element to achieve increased levels of quality through cooperation among professionals, levels of care and institutions.

The Hospital General de Vic (HGV), with remarkable similarities in the way to understand healthcare provision and how to advance towards higher levels of service, is outstanding as one of the institutions where collaboration agreements with HCPB have been developed more extensively. It is a general hospital with a high number of medical specialities, which explains a complexity rating slightly above the average for its reference group. It provides health services to a county of 135.871 inhabitants, but also shows an attractive profile in clinical research and education activities.

There is hope in the possibilities of emerging models of care provision. Many see them as a way to partially mitigate some of the challenges that healthcare institutions are facing at present in Western societies. The list is, unfortunately, long, because of the complex variety of scenarios, associated care needs and possible solutions. The reasons that explain this situation are multifaceted, but the following three elements are important when considering the SPEX approach in the Spanish scenario:

- An increased demand for services, triggered by the aging population and the accompanying growth in different health problems.
- The sophistication of modern techniques for diagnose and treatment, that lead to unprecedented levels of survival rates, but, in turn, significantly augment the costs.
- The ethical need to guarantee accessibility to care to all the population in equal terms, and at the same time keep expenditure at an acceptable level from a social perspective.

The example that has been selected for the market validation of the SPEX project in the Spanish pilot is presented in the following sections. In spite of its particularities (such as type of patients, type of shared interventions, information handling or other), the situation is considered illustrative of other sorts of interaction. Therefore, it properly suits the market validation goals of the project that specifically apply a franchising model to the delivery of services in the health domain.

3.2 Objective / purpose of the pilot

The pilot to be validated by HCPB and HGV focuses on the shared management of patients with advanced CHF that are candidates for the heart transplant programme or other types of cardiac surgery.

This corresponds to a highly sophisticated service only available in tertiary care centres that are equipped with the required technology and have properly trained teams that can perform the procedure in accordance to the required standards.

However, this centralisation of the service, beneficial from the perspective of quality, has its drawbacks from the user's viewpoint. Patients treated in this type of scheme cannot receive the treatment locally but, rather, are forced to travel. This has clear implications with regard to time wasted and costs incurred but also, more indirectly, can generate inequalities in treatment opportunities.

The purpose of the current pilot is to shift some elements of the procedure (notably those not dependent on technical equipment) from the centre of excellence (HCPB) to the peripheral structures (HGV). In doing so, it is expected that, overall, there will be a better use of the clinical competences available in the HCPB (here being the centre of excellence) and increase the level of resolution at HGV (as a peripheral centre).

The above mention objective is compliant with the terms stated in the Technical Annex¹:

- Increased capability of peripheral structures.
- Diminish burden on the centres of excellence.
- Improvement in patients' accessibility to high quality services.

The collaborative environment that the proposed pilot assumes depends on the availability of a telematic network. This element, already foreseen in the Technical Annex, should adequately support the interactions to be established between the participating centres.

3.3 Description of the clinical pilot scenario

The selected clinical pilot deals with patients suffering from heart failure. In Appendix A (page 25) a summarised description of the characteristics of the disease is provided for the benefit of non-experts.

In our opinion, heart failure constitutes an ideal scenario for the type of market validation that the SPEX project pursues. The fact that the disease has a progressive nature that worsens over time implies that the applied disease management strategy must be constantly adapted to the patient's required intensity. This calls for the involvement of different professionals and providers covering all levels of care. Therefore, it engenders significant opportunities for professional collaboration schemes.

¹ See page 5 SPEX Technical Annex version 11 (03/04/04)

3.3.1 Current process

The team of professionals working at the HGV cardiology unit is composed of a product manager and four consultants. The unit provides regular services for diagnosis and treatment of heart disease in in-patients and out-patients. Additionally, it supports the thorax-pain functional unit as well as the following diagnostic facilities and procedures:

- ECG.
- Holter.
- Echocardiography (transthoracic and transoesophageal).
- Conventional stress test.
- Hypocycloidal CT Scan.
- NMR Scan.
- Implantation of pacemakers (types: VVI, VDD and DDD).

Additionally, the Intensive Care Unit at HGV can be used as an Intensive Cardiac Care Unit in those patients that require it.

Some complex cardiac conditions cannot be treated at HGV because of the unavailability of the required equipment as well as appropriately trained professionals. In the specific case of heart failure patients, diagnosis and treatment is initially performed at HGV. However, in some patients, the evolution of the disease makes it necessary to refer these patients to HCPB to continue their treatment.

This referral process usually implies a sort of break in the chain of actions in the patient's follow-up until the moment that the patient is sent back again to HGV. Moreover, at present, the opportunities for continuous medical education are only addressed at a local level. Even if the current educational programme in place at HGV can be regarded as an advanced one (based on case-discussion with experts), the opportunity of introducing specialists from the centre of excellence would mean a major step forward.

3.3.2 Definition of the new process

The reviewed process aims at building up a stronger collaboration for the specificities of the disease strategy in heart failure patients. In particular, the following cases are considered:

Patients with severe heart failure, candidates for heart transplant

- Initial assessment of the patient by the specialist at HCPB with the information provided by the specialist at HGV.
- Coordination of both centres in order to reduce visits or the need for the patient to travel to HCPB.
- Booking of the required tests prior to the surgical procedure.
- Continuous information exchange between the specialists managing the patient, thus maximising opportunities for optimal care delivery.

Patients with severe heart failure, post-transplant follow-up

- Application of a control protocol in these patients, under the guidance of HCPB, in order to minimise the need for travelling.

- Improvement of the capabilities of the HGV team in the management of patients in this phase.

Patients undergoing other heart-related surgery

In the case of those patients undergoing heart surgery because of a valve disease or coronary artery disease, the following cases are foreseen:

- Joint pre-surgical assessment of the patient.
- Booking of additional tests and / or visits to HCPB.
- Coordination of the pre-surgical phase and transportation of the patient.
- Post-surgical follow-up at HGV with remote support of HCPB's team.
- Continuous educational strategy in order to increase the range of services to be delivered by HGV and increase the target group of pathologies, procedures or patients.

Pulmonary hypertension

A minor group of these patients, if possible, will also be included in the pilot. The interest in including this is because it is a good example of a rare disease that is almost totally managed at tertiary centres. The disease is characterised by a narrowing of the arteries in the lungs which makes it difficult for blood to flow through the vessels. This provokes an increase in the blood pressure in the pulmonary artery which, in turn, strains the right ventricle of the heart, causing it to expand in size. Overworked and enlarged, the right ventricle gradually becomes weaker and loses its ability to pump enough blood to the lungs. This could lead to the development of right heart failure.

In this specific context, the opportunities for the pilot collaboration primary focus on:

- Early detection of the patient.
- Jointly assessment (HGV and HCPB) of the case.
- Establishing the appropriate treatment strategy and follow-up.

Support and continuous education in transoesophageal echocardiography

This small area of collaboration will address the increase in the capabilities of interpreting some difficult cases of this type of echocardiography.

Support in advanced bacterial endocarditis

Although this condition can generally be managed at general hospitals, in some cases it is necessary to go for surgical procedures, such as in those patients with pacemakers or with concurrent heart valve diseases. In these cases, it is expected to build up a collaboration for:

- Joint assessment of cases and planned course of action.
- Coordination of surgical procedures and patient transportation.

In Table 1, a summary of the main services that are to be considered in the different cases mentioned above is provided.

Table 1: Main services in the Spanish pilot

	Data sharing	Protocols	Booking	Medical education
Pre-transplant	Yes	Yes	Yes	Yes
Post-transplant	Yes	Yes		Yes
Vascular surgery	Yes		Yes	Yes
Pulmonary Hypertension	Yes			
Echocardiography	Yes			Yes
Endocarditis	Yes			

3.3.3 Participating user profiles

In Table 2, the profiles for the Spanish pilot are displayed. UPIT stands for “Projects and Technology Innovation Unit” and it will take care of the communication infrastructure and evaluation activities at the HCPB side.

Table 2: User profiles for the Spanish pilot

Unit	User	Function/profile
HGV	Heart specialist	Responsible for the clinical parts of the pilot.
HGV	Telecommunications engineer	Responsible for the operation of the supporting IT tool.
HGV	Health information manager	Responsible for the assessment of the service and market validation of the approach.
HCPB	Heart specialist	Responsible for the clinical parts of the pilot.
UPIT (HCPB)	Telecommunication engineer	Responsible for the operation of the supporting IT tool.
UPIT (HCPB)	Health Information Manager	Responsible for the assessment of the service and market validation of the approach.

3.3.4 Technological platform

Both HCPB and HGV need a tool in order to allow the exchange of administrative data, patient management data, clinical data and messages with a high level of security to ensure patient data confidentiality.

Different platforms and elements that are already in use both at HGV and HCPB will be key elements in order to achieve the objective of exchanging data between the two hospitals. For example, at HGV, an existing platform called SISO, developed by an enterprise called Thales IS, will be taken into account in order to develop the communication protocol. The same idea will be applied at HCPB where the platform receiving and sending the information will be the already established one; no modifications will be required. Similarly for HGV, however their platform may need some small changes.

The technical specifications of the SISO platform, which is the most important one since this will be the platform that will manage most of the communication tasks, are the following:

- Database: Oracle 9i.
- Operating system: Linux (REDHAT 7.3).
- http server: Apache 1.3.23 with SSL module.
- Application server: Tomcat 4.1.12.
- Programming language: Java (J2EE).
- Web browser: Explorer version 5.5 or higher.
- Message format: XML.
- Digital certificates: CMB.

To get a more accurate idea of the context in which we focus the transmission of information, Figure 1 shows a simple diagram of data interchange:



Figure 1: Data interchange in the Spanish pilot

In order to be able to allow sharing of the necessary information between the two hospitals involved in the project, it is necessary first of all to adapt the information exchange mechanisms inside the SISO platform. This task has to be driven very carefully, since the security level at this kind of healthcare organisation is very strict and not all the possible solutions will be accepted by the network administrators. Therefore, the solution implemented will have to comply with the security rules and with the network limitations given by each of the one of two scenarios available. Specifically, the security functions of the SISO platform are the following:

- User definition.
- Profile definition.
- Access level definition.
- Digital certificates. In order to allow the HCPB professionals to use the application, it is necessary that they have a homologated digital certificate by HGV.

To guarantee data protection, it has been necessary to adapt security in SISO related to the following already existent functions:

- Allow access to restricted functions by professionals from entities not belonging to SISO.
- Access control to SISO functions through a URL that does not go through the application menu.

The technical solution that allows the integration of the different services has been thought to be a common web portal. This portal will provide the necessary virtual space for the interaction between the professionals of both healthcare centres involved in the project. The web portal will be structured depending on the services that need to be supported. This portal will allow managing different tasks, for example:

- Managing the access and security policies.
- Managing the communication between both organisations.
- Data presentation in a common format. Data will come from both HGV and HCPB. This access to the data will be done in a read-only format, at least in a first stage. Only information consulting by both hospitals (no modifications) has been considered.
- Information on the protocol for patient management (patient derivation alert, pending consulting list, ...).

Let us suppose that a patient belonging, geographically speaking, to HGV needs to be referred to HCPB in order to receive a specific high-level treatment. The healthcare team, which performs the treatment, needs to have access to the clinical information of that specific patient located on the SISO platform; it also has to be able to complete that information with other clinical information generated in HCPB. Besides this, the professionals from HGV have to be able to consult the list of patients subjected to the tertiary treatments performed in HCPB; they also need to be informed when a patient follows a treatment in HCPB. In order to allow these actions to be done, some requirements have to be considered related to the existing platforms at both hospitals:

1. First, the professional at HGV will have to indicate in the HGV information system that a patient is referred to HCPB.
2. Second, the healthcare team from HCPB have to know the patient list referred from HGV. From this list they have to have access to the clinical information stored in SISO related to that specific patient.
3. The security of the SISO platform will have to be increased so that HCPB professionals can access only the clinical information of those patients being treated in HCPB.
4. In order to access to SISO system, the professionals will have a digital certificate.
5. The records completed by HCPB professionals will be stored at the SISO system.
6. From the diagnostic screen in SISO it will be possible to see that a patient is following a treatment in HCPB.

In order to fulfil the requirements mentioned above, some considerations have to be taken into account:

- HGV information System: this has to include the information related to the fact that a patient has been referred to HCPB, together with the necessary data (data, hospital, speciality, patient CIP, cause for referral) and, a message with this information has to be sent to SISO.
- SISO:
 - Treatment of the message which was sent before by HGV_IS. This means to insert the information (data) in SISO and also treatment and notification of errors in the messages that were sent by HGV_SI.
 - E-mail notification to the professional or speciality.
 - Increase the professional table indicating speciality /service.
 - Patients referred to HCPB with their specific information.
 - Include in the diagnostic consulting screen an indicator to show if a patient is following a treatment in HCPB.

- Increase security control.

4. Swedish pilot site

4.1 Description of the pilot site

The Sweden pilot site constitutes the two units County Hospital Uppsala (CCU) and Eskilstuna County Hospital (ESH). Both hospitals have prime responsibility for surgical care in their respective counties, but CCU is also a university hospital aimed for referrals of complicated patient problems from other counties, and among others from ESH.

The Department of Surgery of ESH is the hospital department within the western County of Sodermanland to which patients with complicated wounds, defined as wounds that do not heal normally after routine treatment in primary care, are referred. One specialist surgeon has taken special interest in these patients, and there is also a defined outpatient clinic where patients with problem wounds are handled. A nurse with considerable experience in chronic wounds is affiliated to this clinic.

The Department of Plastic Surgery of CCU is a unit to which all patients are referred from other specialists or other hospitals. A considerable number of referrals constitute the subgroup of patients with wounds where appropriate treatment within a surgical department in a county hospital has not lead to healing, or where the referring surgeon suspects that a specialist surgical procedure is required for healing.

There is currently a well functioning collaboration between ESH and CCU, both with respect to technical issues and with respect to cooperation between colleagues.

4.2 Objective / purpose of the pilot

One characteristic of a problem wound is that it has not healed properly. When such a wound is established it has a very high propensity to become chronic. Patients affected normally have a predisposition in the form of age or other associating diseases. The addition of the chronic wound increases the complexity of care and the personal suffering as well as the health economic consequences which are considerable. A central issue in the care of this patient group is that early diagnosis and early appropriate procedures shortens time to heal and decreases costs.

The main objective is to ascertain that individuals with problem wounds are treated similarly in both counties. An extension of the project is to ascertain that patients with problem wounds actually are referred from primary care to hospitals in an early phase of their disease. The purpose is, thus, to optimise the possibilities that patients are adequately assessed and given adequate treatment options early.

4.3 Description of the clinical pilot scenario

Patients with problem wounds seen at the Department of Surgery ESH are selected for this project. The basis for selection is that the patients should be theoretical candidates for referral to CCU. Such patients should either have a complex previous health history and resisted treatment, or present with such wounds that are

expected to require a highly specialised surgical intervention, or represent a low frequency event where there is no previous experience at ESH.

Such patients are handled at a weekly wound clinic. A communication system with on-line connection to CCU is linked to this clinic. Information about patients will be presented on-line, or in the form of stored digital information, e.g. video-sequences or pictures. The ESH clinic is run by the specialist surgeon responsible for the wound patients; at CCU a specialist plastic surgeon participates on a peer-basis. Decisions on treatment are taken immediately during the session in cooperation. The continuous on-line communication between the surgeon at ESH and the plastic surgeon at CCU is the key factor for success of the project.

The clinic is defined in time and is also accessible for students participating in wound healing education.

4.3.1 Current process

The current routine of ESH is to refer patients with problem wounds to CCU with the inconvenience of long transportation and sometimes unnecessary delays. An inherent problem is that the decision to refer or not relies on the interest and perceived knowledge of the surgeon in question. Another problem is that many of the patients are old, and resist cumbersome referrals. This older group of patients actually constitutes the group with highest complexity and where a wide spectrum of variables has to be taken into consideration to optimise resources. The challenge of surgical intervention in this group also requires a broad basis for decision.

The SPEX project enables a cost effective approach to obtain a good decision basis for treatment without transporting patients long distances. It also involves a moment of learning in context, which actually increases the quality of care in ESH. Finally, it liberates resources at CCU for other patient groups that require highly specialised surgery.

4.3.2 Definition of the new process

The new process will be characterised by:

- Effective and safe communication between ESH and CCU without risk of technical failures.
- It is simple, and can be rapidly and simply activated by “average healthcare personnel” not highly experienced in telecommunication.
- It shall enable assessment of a patient wherever he/she is at ESH, with transmission of such data for on-line communication with CCU.

If this is accomplished, and can be generalised, SPEX has succeeded. The process can in such cases be used for any type of patient where a direct on-line communication between ESH and CCU facilitates clinical decision-making.

4.3.2.1 List of user requirements

According to the Technical Annex, the SPEX solution should include services for dissemination, training & accreditation and operational clinical services. The user needs are thus described under these three headings.

Dissemination

The services provided by the SPEX system include dissemination of information. This means that the Hub Centre of Excellence, via use of the network, will provide different levels of information to the staff at the Primary Care. The service will include means to publish information in a structured manner so that the Primary Care staff can easily retrieve it. To facilitate the updating process, the users at the Hub Centre of Excellence will require an easy-to-use tool to publish and update guidelines and any other information made available to the Primary Care staff.

The information presented via this service will have to be presented in a structured way so that users easily can navigate and find what they are looking for. To this end, the system that facilitates this service will have to provide different layouts for different purposes. This includes information structured in a way that is appropriate for online studies, for those pupils taking a course in the clinical area included in the SPEX validation site. It also includes structuring information in a way that is appropriate for publishing guidelines or newsletters. It will have to be possible to update all of these, and maintain them by technically untrained personnel.

The SPEX service will have to include an advanced search engine to provide simple means of finding the right information among all the published documents.

The publishing of guidelines will have to offer a more open structure that allows users publishing information there to add sections, folders and documents as they go along. The guidelines will still have to be organised so that users at the Primary Care can easily find what they are looking for. They will also have to be updated continuously in order to always present the most recent guidelines. The system will have to provide a facility that notifies the Primary Care staff when one of the guidelines has been updated.

Training and accreditation

For the purpose of training the staff at the Primary Care, the SPEX system will have to include a means of distributing lectures and seminars live as well as streaming from a server. The lectures will only need to be distributed from one point, but possibly to be received at multiple points in the network. The seminars however will include discussions and medical examinations, meaning that the picture as well as the sound will have to be distributed from several points to all other points in the network.

The lectures as well as the discussion seminars will have to be recorded and made available on a streaming server for later distribution to any interested participant at any time. The lectures and seminars will have to be ordered by area and date.

The system will also have to provide the possibility to publish material for individual studies by the participants. This will include material separately produced for the individual class as well as links to material already published on other sites. Different teachers will have to be able to prepare and publish their own study material for their classes as well take advantage of material already published by others, inside or outside the SPEX project.

The SPEX system will have to include some way of checking the knowledge of the participants after taking part in the classes and the training activities. The service will thus have to include some kind of electronic exams. This, together with other

means of verifying the level of knowledge will eventually lead to some kind of accreditation of the units and their personnel.

Operational Clinical Services

To be able to support the Primary Care with know-how and skills from the Hub Centre of Excellence, there will have to be a telemedicine video link between the two sites. The service will have to be able to provide both synchronous and asynchronous video links.

The asynchronous part of the service will provide the possibility for physicians at the Primary Care to ask the opinion of the expert or experts at the Hub Centre of Excellence. The experts at the Hub Centre of Excellence will not have to be present at the same time as their support is needed, but will be asked to respond at a later time. Thus the service will require some kind of alert function to tell the experts their help is required within the SPEX service.

The synchronous link will allow the Primary Care to contact the Hub Centre of Excellence experts while interviewing, treating or diagnosing the patient. This requires an interactive video link between the two sites as well as a portable camera to take the pictures. The camera will have to be portable within the hospital as well as within the ward or outpatient clinic.

In addition to the video links described above, the clinical service requires a patient record that can be shared between the parties. The patient record system will have to be easy to use and very self-instructing for the physicians to be able to use the tool without extensive training. There will have to be separate parts for Primary Care and the Hub Centre of Excellence physicians as well as for the Primary Care and Hub Centre of Excellence nurses. The system will have to be secure and guarantee the integrity of the patient and of the physician.

4.3.3 Participating user profiles

The following table lists the user profiles foreseen in the Swedish pilot

Table 3: User profiles for the Swedish pilot

	Unit	User	Function/profile
1	ESH	Specialist surgeon/general surgeon	Running the wound clinic, responsible for the medical process at ESH.
2	ESH	Specially trained nurse	Responsible for practical wound care.
3	ESH	Telecommunication specialist	Supporting communication between ESH-CCU.
4	CCU	Specialist plastic surgeon	Clinical counterpart to 1.
5	CCU	Specially trained nurse	Clinical counterpart to 2, teacher in wound care.
6	CCU	Telecommunication specialist	Technical counterpart to 3.

4.3.4 Technological platform

The service will include at least one video server that hosts the recorded videos and provides the service of streaming video. The communication in the SPEX project will make use of the existing network for healthcare providers in Sweden called SjuNet. The video links will make use of a specific service provided within the network infrastructure for that purpose. There is a need to find a new application for the patient record documentation. The user needs might lead to the point where some existing software will have to be adjusted to fit the needs of this project. The details of the technological platform will be decided during WP 4.

Appendix A – Heart failure

Heart failure is a clinical condition characterised by a weakness in the heart's pumping power. In patients with heart failure, blood moves through the heart and body at a slower rate, and pressure in the heart increases. The result is that the heart cannot pump enough oxygen and nutrients to meet the body's needs. The chambers of the heart respond by stretching to hold more blood to pump through the body. This helps to keep the blood moving for a short while, but then the heart muscle walls weaken and are not able to pump as strongly. The kidneys often respond by causing the body to retain fluid (water) and sodium.

Such retention of fluids can build up in the arms, legs, ankles, feet, lungs or other organs. As a result, the body becomes congested, and congestive heart failure is the term used to describe this condition.

Heart failure can be recognised by a variety of symptoms that correspond to the severity of the condition.

- Congested lungs (caused by fluid backing up in the lungs) - cause shortness of breath with exercise or difficulty breathing at rest or when laying flat at night. Also cause dry, hacking cough or wheezing.
- The fluid and water retention results in swollen ankles, legs and abdomen (called oedema) and weight gain. Symptoms may also include an increased need to urinate during the night.
- Less blood to your major organs and muscles causes fatigue (tiredness) and weakness when exercising.
- Less blood to the brain also causes dizziness or confusion.
- Heart beating faster to pump enough blood to the body causes rapid or irregular heartbeats.

Heart failure is the result of many conditions that damage the heart muscle, including:

- Coronary artery disease (also called coronary atherosclerosis). Coronary artery disease occurs when the normal lining of the arteries breaks down, the walls of the arteries thicken and deposits of fat and plaque block the flow of blood through the arteries.

In coronary heart disease, the arteries that supply blood to the heart become severely narrowed and the heart can no longer respond to increased activity. Extra strain on the heart may result in chest pain (angina pectoris) and other symptoms of heart disease.

- Heart attack occurs when a coronary artery becomes suddenly blocked, stopping the flow of blood to the heart muscle and damaging it. All or part of the heart muscle becomes cut off from its supply of oxygen. A heart attack can damage the heart muscle, resulting in a scarred area which does not function.
- Cardiomyopathy - damage to the heart muscle from causes other than artery or blood flow problems. Causes include infections, alcohol or drug abuse.

Other situation that overwork the heart muscle are important in the development of heart failure, including:

- High blood pressure (hypertension). Blood pressure is the force of blood pushing against blood vessel walls. High blood pressure means the pressure in the arteries is above the normal range.
- Valve disease, a heart valve that is not working properly and is either leaking or blocking the normal flow of blood.
- Heart defects present at birth.
- Diabetes Mellitus.
- Chronic kidney disease.

Stages of heart failure

In 2001, the American Heart Association and American College of Cardiology developed the “Stages of Heart Failure”. This reflects the progressive nature of the condition that worsens over time. These stages are different from the New York Heart Association (NYHA) clinical classifications of heart failure that rank patients as class I-II-III-IV according to the degree of symptomatic or functional limits.

Stage A: Those at high risk for developing heart failure. Includes people with:

- Hypertension
- Diabetes mellitus
- Coronary artery disease (including heart attack)
- History of cardiotoxic drug therapy
- History of alcohol abuse
- History of rheumatic fever
- Family history of cardiomyopathy.

Treatment includes:

- Exercise regularly
- Quit smoking
- Treat hypertension
- Treat lipid disorders
- Discourage alcohol or illicit drug use
- If previous heart attack or current diabetes mellitus or hypertension ® angiotensin converting enzyme inhibitor (ACE-I).

Stage B: Those diagnosed with “systolic” heart failure but have never had symptoms of heart failure (usually by finding an ejection fraction of less than 40% on echocardiogram).

Treatment includes:

- Care measures in Stage A +
- All patients should be on ACE-I
- Beta-blockers should be added
- Surgical consultation for coronary artery revascularization and valve repair/replacement (as appropriate).

Stage C: Patients with known heart failure with current or prior symptoms.

Symptoms include:

- Shortness of breath

- Fatigue
- Reduced exercise tolerance.

Treatment includes

- Care measures from Stage A
- ACE-I and beta-blockers should be used
- Diuretics (water pills)
- Digoxin
- Dietary sodium (salt) restriction
- Weight monitoring
- Fluid restriction (as appropriate)
- Withdrawal of drugs that worsen the condition
- Spironolactone when symptoms remain severe with other therapies.

Stage D: Presence of advanced symptoms, after assuring optimised medical care.

Treatment depends on:

- All therapies under Stages A, B and C

Additionally evaluation for:

- Cardiac transplantation
- Ventricular assist devices
- Surgical options
- Research therapies
- Continuous intravenous inotropic infusions
- End-of-life care.

Surgical treatment:

Heart failure surgeries include the left ventricular assist device, coronary bypass grafting, mitral valve repair, ventricular surgeries and sometimes heart transplantation.

With the right care, the prognosis or outlook for the future will depend on how well heart muscle functions, symptoms, and how well patient responds to treatment plan.