

**Large-scale integrating project (IP) proposal**  
**ICT Call 1**  
FP7-ICT-2007-1

**Supporting Participation in Healthcare with Expressive,  
Responsive Environments**

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<b>Participant no. *</b>	<b>Participant organisation name</b>	<b>Part. short name</b>	<b>Country</b>
1 (Coordinator)	Vienna University of Technology	TUW	Austria
2	Graz University of Technology	TUG	Austria
3	Università degli Studi di Milano-Bicocca	UniMiB	Italy
4	University of Trento	UniTN	Italy
5	University of Sussex	UoS	United Kingdom
6	University of Lancaster	ULANC	United Kingdom
7	University of Limerick	UL	Ireland
8	IT University of Copenhagen	ITU	Denmark
9	Roskilde University	RU	Denmark
10	Computers Services and Technologies	CoST	Italy
11	Engineering SPA	ESEL	Italy
12	Medixine Oy	MX	Finnland
13	Visionradio Ltd.	VR	United Kingdom
14	Docobo Ltd.	Docobo	United Kingdom
15	Gruppo Per l'Informatica	GPI	Italy
16	Medical University of Vienna	MUW	Austria
17	Fondazione IRCCS Ospedale Maggiore Policlinico, Mangiagalli e Regina Elena	PoliMI	Italy
18	Azienda Provinciale per i Servizi Sanitari	APSS	Italy
19	Brighton & Sussex University Hospitals, NSH Trust	BSUH	United Kingdom
20	Rigshospitalet	RH	Denmark

**Work programme topics addressed**

ICT-2007.5.1 Personal health systems for monitoring and point-of-care diagnostics

**Name of the coordinating person:** Prof. Dr. Ina Wagner

**E-Mail:** ina.wagner@tuwien.ac.at

**Fax:** +43.1.58801.18799

***Proposal abstract***

SPHERE builds on the notion of integrated care, with an emphasis on patient participation, self-care, and cooperation within distributed networks of carers. This requires to look beyond traditional concepts of EPR and realise that healthcare work is deeply interactive and communicative.

The research aim of SPHERE is to integrate a whole range of sensor technologies and to make them accessible to clinicians, patients, and carers and embedded in clinical practice and in patients' homes. It is the integration element that is unique to the project. It will combine technological with social innovation, with a focus on making highly specialised and disparate technologies work in various clinical and homecare contexts. Integration at the level of technology and of clinical and everyday practice will be probed, demonstrated, and evaluated in a series of showcases in two chronic disease areas.

Technologically, this translates into integrating non-invasive, wearable monitoring devices with context-aware applications; an environment integrating coordination functionalities for distributed cooperation; an integrated framework for interactive representations of multi-media data; mobile, mixed-reality or tangible interfaces and other innovative output devices; on a distributed open-source systems platform.

Methodologically, this calls for moving 'out of the lab' with experimental field work in real settings in the two health care areas in an approach that is explorative, experimental, and interventionist, applying a triangulation of disciplines and methods for evaluation.

To meet these challenges requires close collaboration of researchers from a wide range of areas of RTD, from technologies of multi-parametric monitoring to technologies of dynamic coordination to participatory design. The research will be carried out by (mutually complimentary) teams representing advanced research in all of the required areas as well as a demonstrated record of interdisciplinary collaboration.

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## Proposal

### **1 Section 1: Scientific, technical quality - relevant to topics addressed by the call**

#### **1.1 Concept and objectives**

SPHERE builds on the notion of integrated care, with an emphasis on patient participation and self-care, as well as coordination - facilitating cooperation within distributed and heterogeneous networks of formal and informal carers. Patient empowerment requires that designers of health information systems (HIS) look beyond traditional concepts of electronic patient records (EPR) and realise that healthcare work is highly interactive and communicative in nature. The challenge is to build collaborative health information systems (CHIS) that explicitly support the interdependent roles of patients, carers/parents, and healthcare professionals in achieving healthcare goals.

The research aim of SPHERE is to integrate a whole range of sensor technologies and connected applications and to 'package' physiological, environmental, and activity sensor data so that they become accessible to clinicians, patients, and their informal carers, and embedded in clinical practice as well as in patients' everyday life. It is the integration element that is unique to the project. It will combine technological with social innovation, with a focus on making highly specialised and disparate technologies work in and adaptable to various clinical and homecare contexts. Integration at the level of technology and of clinical and everyday practice will be probed, demonstrated, and evaluated in a series of showcases in two chronic disease areas (cystic fibrosis/CDLS in children and cerebro- and cardio-vascular diseases in adults).

Technologically, this translates into integrating non-invasive, wearable monitoring devices with location- and environment aware applications; an environment integrating coordination functionalities for inter- and intra network cooperation; an integrated multi-media representation framework; configurable, interactive representations of multi-media data; mobile, light-weight mixed reality interfaces, tangible user interfaces and other innovative output devices; on a distributed open source systems platform.

More specifically, the project seeks to

- Embed facilities for the **non-invasive, multi-parametric monitoring** of health, activity and environmental parameters in patients' home environments and integrate them with other suites of applications, with attention to issues of placement, usability, awareness, control, and social/personal acceptability.
- Develop an **integrated multi-media representation framework** (including video and sound) for different output devices, which is configurable by the users, supports different views and representational forms that are aligned with heterogeneous practices, as well as immediate feedback, the assessment of trends and episodes, and so forth.
- Increase **patient participation and self-care** by supporting patients in expressing their needs and experiences in their own language and diverse media (e.g. stories, video clips, drawings) and providing space for active involvement, choice and control.
- Create a **context-aware, flexible and configurable functional environment in support of coordination in distributed care environments** that takes account of the social dimension of coordination, of the distribution of care networks in space and across places, of the temporal aspects of care giving, and of issues such as participation, skills, roles, and accountability.
- Design **new functionalities for existing EPR solutions** in support of innovative representations and coordination within and across heterogeneous networks.
- Improve the **choreography of devices, data fusion and system interfaces** and design in a 'standard aware' way so as to facilitate integration with and across local systems.
- **Design in an ethically aware way** through researching and describing the arising ethical problems related to e.g. privacy and confidentiality, transparency, literacy, and standardisation, and resolving them together with all stakeholders
- To experiment with and implement an **effects-driven IT development methodology** that takes account of clinical, patient-related, economic, and legal criteria

- To design for implementation in real-life contexts, taking **reimbursement schemes and legal frameworks** into account.

Methodologically, this calls for moving ‘out of the lab’ with experimental field work in real settings in the two health care areas the project seeks to cover in a user-collaborative approach that is explorative, experimental, and interventionist, applying a triangulation of disciplines and methods for evaluation. These range from interpretative-ethnographic approaches to medical technology assessment techniques. Research will be organised in a set of workpackages aiming at socio- technical innovation and a set of coordinated, research-intense showcases, in which conceptual and technological development will be grounded. The SPHERE showcases are not just demonstration platforms. All development will ground in showcase research in several prototype deployment-evaluation-feedback cycles.

### *The SPHERE Experimental Stage*

SPHERE makes use of an *Experimental Stage* of integrated showcase projects (WP10). While allowing the project to address the unique qualities of six showcase projects in five countries, with their different legal and organisational frameworks, the *Experimental Stage* provides the glue of the project as a whole, as the main resource for concept development, evaluation and further development of prototypes and social/clinical practice. The objectives are to

- Ground conceptual and technical development of integrated personal health systems in realistic on-site experiments;
- Learn about disease management and the SPHERE approach in different contexts and cultures;
- Demonstrate more robustly the validity of our findings across patient groups and conditions.

To ensure results arising will be more widely generalisable, we have carefully selected a set of contrasting showcases, based on the following criteria:

*A balance between elderly people and children:*

- The focus on elderly people responds to the socio-economic demands of prolonged care for an ageing society;
- The choice of children adds a focus on living with chronic disease from birth to death. Childhood chronic diseases also bring up different issues compared to elderly peoples’ conditions because of the role of the family in the delivery of care and the changing requirements for disease management when children get older.

*Two broad classes of diseases – emergent cardio-vascular diseases/stroke on the one hand, and congenital cystic fibrosis/CDLS (Cornelia De Lange Syndrome) on the other hand:*

- Cardio-vascular diseases and strokes (cerebro-vascular accidents CVAs) are some of the most common health problems affecting elderly people, offering a huge potential for saving lives and costs. They usually require the care of a specialist team. In general, it is harder for elderly people to learn to self-manage their disease and to understand and accept the need for a change in life style.
- Cystic fibrosis (CF) and Cornelia de Lange Syndrome (CDLS) are key examples of multi-problem congenital diseases. Both conditions affect multiple organs in the body. Children with CF or CDLS have a shorter life expectancy and there is a need for life-long intervention and disease management that changes as the children grow older, often involving different social, educational, and care teams, as well as a strong commitment and involvement of parents in the delivery of care.

The purpose of such different target groups and disease areas is to explore issues of integration under very different conditions.

We will use cardiac diseases and CF as the prime diseases, with two showcases on each. Additional showcases on stroke and CDLS help to ensure generalisability of the SPHERE approach. Together, these diseases capture a diverse set of personal health monitoring needs that will drive technology development as well as development of supporting care processes.

The showcases will be conducted in close collaboration with local clinical project partners, some associated with existing large-scale initiatives, and will take an iterative participatory design approach to engaging with patients, their families and carers. Field trials will be conducted in real settings, and will employ a multi-discipline, multi-method approach to evaluation.

### ***The SPHERE quality and evaluation framework***

To ensure that integrated care environments for the chronically ill and patients at risk meet the highest quality standards, and to do so in a systematic and accountable way, it is a central and overriding objective of SPHERE to define and develop **quality measures** that are firmly grounded in ethnographic field work and other forms of intense engagement with health care practitioners. At the same time and in the same spirit, SPHERE will institute these quality measures across showcases and technical workpackages in such way that they effectively orient technology development across showcases and technical workpackages. Three workpackages are devoted to this objective, each with a specific focus:

- The work in WP3 is central, in that it develops a **quality framework**, on the basis of the empirical work of the *Experimental Stage*. **Ethics** will be a central research issue and aspect of the quality framework.
- The quality criteria will guide the **evaluation scheme** to be developed in WP4. Evaluations, informed by qualitative ethnographic fieldwork and quantitative measurements, will be based on the concept of **effects-driven IT development**, providing a sustained focus on the effects to be achieved by users through their adoption and use of the SPHERE approach.
- **Social and clinical practice design** (WP9) will ensure that the potential benefits of the envisioned novel technical facilities for monitoring patients in their everyday environments and for making the monitoring data available to patients, informal carers, and clinicians, can be realised. This requires a transformation of organisational and work practices as well as the formal framework in which they are embedded (performance measurement, reimbursement scheme, legal stipulations, etc.).

### ***The SPHERE approach to developing expressive, responsive environments***

SPHERE approaches integrated care and patient participation with the development of expressive and responsive environments that combine multi-parametric monitoring, interactive representations and interfaces, and coordination in heterogeneous networks, each the focus of a technical workpackage (WP5, WP6 and WP7), and brought together in a Development Environment (WP8).

With its user-centred focus, SPHERE builds on the philosophy of designing for **configurability**, with attention to those features of an environment that enable users to adopt and to adapt it, fitting it to their working practices. Central components of an expressive, responsive environment are:

- Multi-parametric monitoring and data recording with unobtrusive and minimally invasive methods over long periods of time to support **analysis of histories, trends, rhythms and routines**;
- **Control, awareness and ‘sense-making’ of patients** as well as configuration of systems by their users, including placement and linking of systems components and self-adaptation of systems to changed configuration (e.g. learning of relative sensor placement for correct interpretation of observations and recorded data);
- Representation tools that are adaptive to user, task and environment, in particular to various screen sizes ranging from a desktop workstation to a cell phone display
- Support of different views and expressions - **clinical representations** that efficiently manage the huge amounts of multi-dimensional, time dependent data and enable expert feedback; **expressive representations** of the more personal and expressive qualitative data (stories, pictures, video) in combination with multimodal interfaces – e.g. tangible user interfaces, auditory displays; **playful and affective representations** designed to motivate and engage;
- Computational support that helps the stakeholders acting in the different care trajectories related to chronic diseases and patients at risk, to define, smoothly use and flexibly adapt **coordination mechanisms to improve their distributed cooperation**;
- A **distributed, dynamically reconfigurable, open service-oriented infrastructure** for integrating various types of healthcare data - structured data (e.g. XML data from patients), context data (e.g. sensor data from medical equipment), and unstructured data (e.g. video blogs, streaming media).

## **1.2 Progress beyond the state-of-the-art**

Barlow et al [5] define three broad objectives of a telecare service: r-mode, i-mode and p-mode.

Response mode (r-mode) is the most common form of telecare and is well served by many commercial

providers; information and advice mode (i-mode) makes use of email, telephone etc. Preventative mode (p-mode) requires much more integrated and ‘intelligent’ devices to monitor and detect abnormal patterns across a range of devices and to initiate additional support. SPHERE seeks to move the state of the art from this response mode care to delivering integrated in-home solutions, making use of off-the-shelf devices as appropriate and providing an integrative and customisable p-mode platform to SPHERE, coupled with innovative representations and coordination and communication support to enable i-mode care.

Table 1.2.a: Comparing state-of-the-art with SPHERE contributions

<b>State-of-the-art</b>	<b>Contributions beyond the state-of-the-art</b>
<p><b>Approaches to telecare:</b> The emphasis in current telecare projects is often on technologies that are conceptualised around a specific single function or purpose or they are still largely research prototypes. Examples are: Assistive technologies, such as gas cooker sensors, and automated bedroom lights, and so on, e.g. see the EU ENABLE project [25]; Remote monitoring and care support, with memory loss and Alzheimer’s Disease receiving particular attention [17, 33, 32]; MIT’s prototype LiveNet, which allows people to receive real-time feedback from their continuously monitored and analyzed health state, and Intel’s CareNet [17], which provides an ambient display (currently with simulated sensors) for monitoring activities of daily living.</p>	<p><i>SPHERE explores how the same underlying sensors and technologies can be re-purposed in different ways, i.e. to become seen as part of the infrastructure and services of the home.</i> <i>While underlining the emphasis on the needs of an aging population SPHERE will also explore opportunities to use the same types of sensors, devices, services, platforms for younger people with congenital chronic conditions.</i></p>
<p><b>Evaluation (WP4):</b> While some of this work on telecare has included some detailed user studies to inform design [17], others tend to be technology-centric and evaluations are conducted post development, thus, incorporating limited insight from every day activity trials by patients. Many telecare projects also report largely on the clinical aspects of the project, talking to a clinical audience [58]. Barlow et al [5] raise a number of issues pointing to the difficulty of conducting a valid Randomised Control Trial (RCT) in telecare; issues include problems around building in a placebo, having too many control variables and the difficulty in calculating number of participants. Morris et al [31] also raise issues involved in evaluating self-monitoring and other assistive technologies for care of elderly people and reject standard medical and social science models.</p>	<p><i>SPHERE will push the state of the art by putting in place methods and processes from the beginning of the project to ensure a concern for the ‘putting to work’ of personal health monitoring solutions. A key aspect of this will be the direct and iterative engagement with clinicians, patients, families carers via participatory design techniques and taking a whole-of-context perspective.</i> <i>SPHERE will develop an effects-driven approach to IT implementation, guided by regular measurements, evaluation and documentation of agreed-upon effects as experienced by patients and/or clinicians using the technology.</i></p>
<p><b>Embedded, responsive, multiparametric monitoring (WP5):</b> Activity and health monitoring beyond specific parameters and events has been approached with computer vision e.g. FP6 CHIL IP (C18). Less invasive monitoring approaches have emerged in wearable computing [20], body-sensor networking [56] and pervasive computing, including tracking of everyday interactions with wireless sensors [49] and with RFID-tagged environments [37]. The predominant focus has been on machine learning of predefined classes of</p>	<p><i>SPHERE will exploit on-going advances in wearable and pervasive sensing to develop a more user-centric approach that takes patients and carers into the loop of design, configuration, control and evolution of personalised in-the-home monitoring.</i> <i>SPHERE will specifically develop</i></p>

<p>activity (e.g. ADLs), mobility and posture, and on context capture (e.g. tagging of data with environmental parameter). Monitoring is generally approached in separation from aspects of representation and interaction, with very limited attention to end-user configuration [8]. The common abstractions provided are events; however there is exploratory work for instance on creation of blogs from captured data [28].</p> <p>Harvard is currently developing “CodeBlue”, exploring applications of wireless sensor network technology to a range of medical applications, including pre-hospital and in-hospital emergency care, disaster response, and stroke patient rehabilitation (C17).</p> <p>In SPHERE, we already know that we can provide longer battery life, higher accuracy and higher reliability. As we have full control over both the hardware and software platforms in SPHERE, we can rapidly adapt the platforms to emerging user needs.</p>	<p><i>novel monitoring devices designed for active engagement, combining monitoring functionality with recreational interaction.</i></p> <p><i>The SPHERE approach will be driven by monitoring needs in the context of chronic illness and hence focus on multi-parametric monitoring over long periods of time, for provision of disease histories annotated with contextual data.</i></p> <p><i>The SPHERE solutions will address issues of data protection connecting to monitoring in focus groups with stakeholders and they will implement mechanisms in support of patients’ awareness and control.</i></p>
<p><b>Interactive representations and interaction design (WP6):</b> Visualisations of medical time dependent data (mTDD) have been mainly studied for desktop contexts. Interaction techniques have been developed to explore and navigate huge amounts of MTDD and their temporal dimensions [1, 2, 24, 38]. Most of these techniques are based on focus+context, pan+zoom and overview+detail methods [46, 29]. Optimised representations for large amounts of hierarchical data can be provided by treemaps, beamtrees or botanical trees [9, 52]. Studies on expressive representations of data collections mostly involve photography [14, 21]. Research on mobile devices visualizing patient data aims to provide more flexibility to specialists and patients. The main challenge is to deal with the small screen size and the limited interaction capabilities of the devices [16, 48].</p>	<p><i>SPHERE explores novel user interfaces and interaction metaphors in support of users creating task-specific views onto multi-dimensional data and it will develop a single configurable software framework to support the diversity of representations and interaction techniques</i></p> <p><i>It will work on synthesizing multi-parametric data into innovative representations that take account of motivational and learning aspects of clinicians and patients and go beyond visual modalities, including interactive, auditory displays.</i></p> <p><i>SPHERE will develop innovative interface solutions for very small screens, investigating e.g. novel iconic representations and potentially 3D glyphs to quickly convey information.</i></p>
<p><b>Inter-network coordination (WP7):</b> Collaborative Virtual Environments are the typical proposed solutions for coordination. They combine information sharing and communication capabilities to support the coordination among the distributed actors using the more successful web technologies, and more recently ubiquitous computing capabilities. Sometimes they are endowed with knowledge models that support inferences so as to build user models, anticipate user actions or information needs, identify erroneous situations, or finally give hints to improve decision oriented reasoning. These functionalities are covered by the range of the research projects developed in previous EU initiatives (e.g., in the Sixth Framework Program (C1): the Care-paths (C2), the Cocoon (C3), the Dicoems (C4), the eu-DOMAIN (C5) , and the Pallianet (C6) projects; in the Fifth Framework Program (C7) : the Asthmaweb (C8), the</p>	<p><i>SPHERE will explore how existing collaborative technologies can be improved to cope with the overall set of requirements and constraints posed by the high heterogeneity characterizing distributed care.</i></p> <p><i>SPHERE aims at constructing a reference technological framework where coordination support can be dynamically and locally constructed by composing and configuring functionalities that are derived from the analysis of current practices in distributed care and can be challenged by the availability of pervasive computing devices.</i></p>



<p>Childcare (C9), the Health Memory (C10), the Telecare (C11), and the WardInHand (C12) projects) and gave rise to a scientific literature that is almost impossible to synthesise here. Also outside Europe the theme has been widely considered as a research issue (see e.g., the USA initiatives: the Aura (C13), the Computer-Supported Coordinated Care (C14), the Intel's Proactive Health (C15), and the Oxygen (C16) projects.</p>	
<p><b>Development Environment (WP8):</b> Different approaches for a complete SOA implementation exist: Enterprise Service Bus (EBS) [15, 27], Java Business Integration (JBI) [40, 50], Service Component Architecture/Service Data Objects for Data Handling (SCA/SDO) [10, 6].</p> <p>In the current day scenario, the industry is divided on their preference for two approaches: JBI and SCA. JBI is a standard for composing service containers into composite applications. SCA/SDO adopt a broader approach to the composition problem and are able to work with multiple language on multiple platforms. It is interesting to note that while JBI is an established standard, SCA has not achieved that status yet. Microsoft developed Windows Communication Foundation (WCF), which is their foundation for building service-oriented applications in 2003, similar to SCA but does not describe any assemblies. It only focuses on service and client development and while it supports multiple languages, it runs on NET alone. It goes without saying that while SCA represents an open standard, WCF does not. It is due for release in 2007.</p>	<p><i>SPHERE will adopt the NESSI vision; it aims to build a SOA platform that supports dynamic reconfiguration, where software can be modified without stopping execution and capable of dynamic reconfiguration allowing systems to evolve and extend without loss of service thus meeting the demands for high availability.</i></p>
<p><b>Social and clinical practice design (WP9):</b> Research traditions like Participatory Design (PD) and Computer Supported Cooperative Work (CSCW) have primarily been carried out in relation to IT supporting work that takes place in an organisational context. Further the main focus has been on IT design rather than on implementation and how to support users in redesigning their practice and organisation. However, the ethnographic approach has generally stopped short of engaging with stakeholders in exploring new ways of working. Furthermore, research traditions like PD and CSCW have primarily been focusing on organisational work settings and do not as yet offer solid methodologies for dealing with widely ramified heterogeneous networks (patients, relatives, clinicians, carers) like the ones target by SPHERE.</p> <p>Research in the area of integrated care examines different practice and organisation models in support of telecare [42] but these models are mostly disconnected from ICT design and implementation and there is little communication and overlap between the different research communities.</p>	<p><i>SPHERE will integrate research and development on social and clinical practices with technology development, implementation and evaluation in the different showcases. SPHERE will engage with clinical practitioners, caregivers, and patients in identifying and articulating as well as negotiating and exploring novel working practice and organisational forms, grounding the evolving care models (and associated reimbursement schemes and legal measures) in concrete cases and experiences.</i></p>

### 1.2.1 Contributions to standards

Included in our activity is the tracking of standards that are relevant to the development of SPHERE. The SPHERE approach builds on existing standards and will attempt to influence the development of standards in emerging areas in which some of its basic research will take place where this is possible. This will involve defining a methodology addressing interoperability, and standards, monitoring standards, and giving input to standards bodies, where appropriate (see 3.2.).

SPHERE project will be concerned with standards on various levels:

- The project will use standardised approaches and technologies wherever possible to ensure widest possible impact. Where existing standards are not appropriate, the project will document new developments with a view on potential contributions to emerging standards.
- The project will ensure awareness of directives, legislation and standards pertaining to technologies for use in the home, and for health care, including standards for safety, data protection, usability, etc.
- The project will actively contribute to advance ethical standards – technologies and systems such as integrated in SPHERE raise important ethical issues regarding networked sensing in the home, and protection of patients and specifically children as a vulnerable segment of the population.

SPHERE will examine various approaches to providing standards in the area of electronic assistive technologies, monitoring and telecare, including the combination of standards as they apply to different components of the system. A selection of attributes that are particularly relevant to care in the home are given below, expressed from the end user's point of view:

- Safety: Can users injure themselves when using it?
- Reliability and availability: Will it always work when a user needs it?
- Maintainability: Can it be changed when users' needs change without introducing new faults?
- Confidentiality and Integrity: Will it make users' health data publicly available?
- Usability and learnability: Will users be able to work with it?
- Fitness for purpose: Does it meet users' real needs?

Annex II gives an overview of a) dependability-related standards applying to Telecare Monitoring Systems; b) the main standards that are used in healthcare with respect to different concerns along the coordination dimension, ranging from the semantic interoperability to the low level interoperability perspective; as well as c) of the main institutions involved in the definition of standards in health care.

## **1.2.2 Reimbursement schemes and legal framework for using new systems**

### ***Reimbursement schemes***

One of the major barriers to the adoption of telemedicine technologies that is widely cited in the literature is the lack of clear reimbursement systems for telecare services. It is deemed necessary to ensure a more equitable level of patient and clinician access to innovative treatments across the EU. Perednia et al. [36] argue: "This view suggests that health care reimbursement should be made technologically neutral. That is, a covered service should produce the best clinical outcome at the lowest possible cost, irrespective of the technology used. "

Reimbursement of new medical technology products and treatment is faced by greatly differing approaches in different European Member States. Medical Device directives contain areas of regulatory uncertainty. The legislative decrees 46/97 and 95/98 implement the European Directive 93/42/EC and the legislative decree 321/00 (updated in February 2007) proposes an univocal classification of medical devices. For example, in Italy, the reimbursement of public and private organisations is regulated by regional rules, according to the typology of medical devices that are procured. In the UK, on the other hand, there are emerging national policies with respect to funding and procurement for telecare such as the NHS PASA National Framework Agreement for Telecare (C19) and the UK Care Services Improvement Partnership (CSIP) "Telecare Implementation Guide" (C20).

SPHERE defines the development of suggestions for reimbursement schemes as a research issue that will be addressed in WP9. Examples of open issues are: some of the medical devices SPHERE will help develop will fall across boundaries of current classification/funding schemes and agencies; some application will co-opt patients' personal devices, such as mobile phones.

### ***Legal frameworks for using new systems***

Use of the SPHERE *Experimental Stage* requires to observe a variety of European, national, and local regulations concerning privacy and confidentiality of patient data, patient monitoring, as well as EPRs. The showcases will allow studying and better understanding the need for extending this legislation with respect to emerging technological possibilities and/or harmonizing some of it.

According to the EC data Protection Directive 95/46/EC and in directive 2002/58/EC on privacy and electronic communications, all data contained in medical documentation and in EPRs should be considered sensitive personal data. They are subject to special rules: explicit consent, vital interest of the data subject, and that the processing of these data is performed by medical staff or other staff subject to professional medical (secrecy) or an equivalent obligation to secrecy.

Other relevant legal aspects covered by the EU directives concerning medical devices are based on the principles of the *New Approach*. They define the essential requirements that devices have to meet when they are put on the market or put into service. Products can only be placed on the market or put into service, if they were subject of a risk assessment, risk management process, and a risk/benefit analysis.

Within SPHERE the Ethical Advisor will, among other things, ensure that each showcase is conducted in compliance with EU and national laws and approved by local ethic committees. But the question of legal frameworks is also a research issue, covered by WP3 and WP9 from different perspectives, and WP3 will ensure that such issues are taken up as attention points by technology developers. As the most important challenge SPHERE sees the fact that multi-parametric monitoring will produce new kinds of sensitive patient data and that these data will be accessible in private homes or eventually also in monitoring centres. SPHERE will deal with these and other upcoming legal issues in focus groups with stakeholders as described in WP3.

### 1.3 S/T methodology and associated work plan

#### 1.3.1 Overall strategy of the workplan

The SPHERE project has 10 workpackages, where WP10 comprises six comparative showcases in five different countries, and 20 partners, with varying engagement and responsibilities. Integration across workpackages will be ensured not only through regular meetings and reports (as described in 2.1.) but also through the project structure.

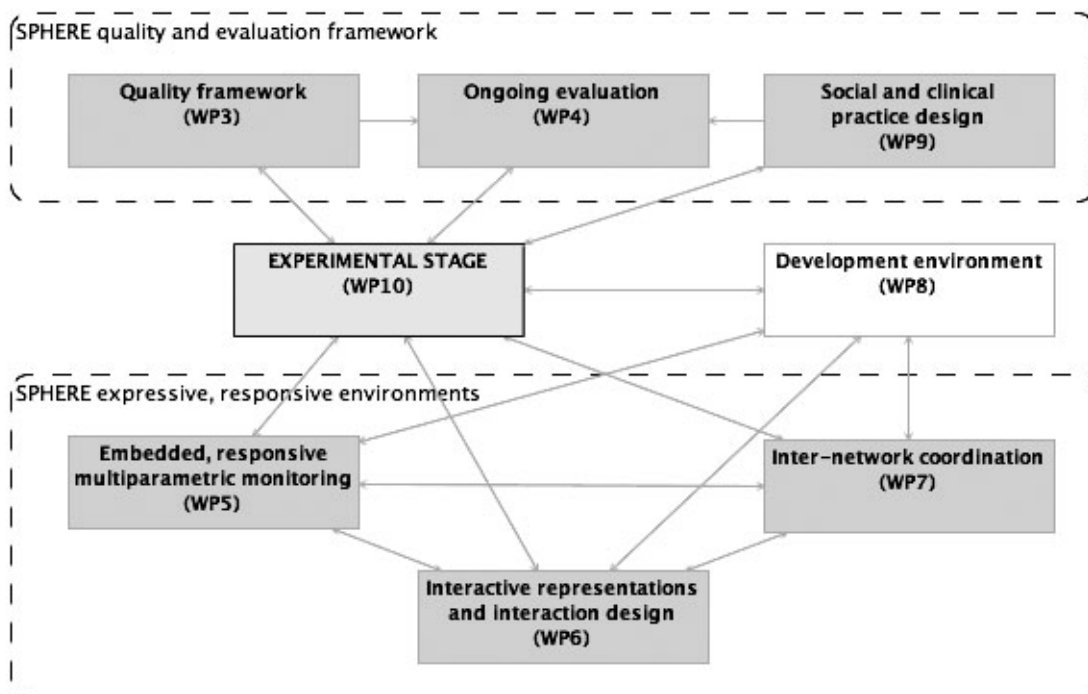


Fig. 1: Overview of relationships between workpackages

SPHERE has a strong research agenda but its ambition is also to contribute to improving the ways in which chronically ill patients can be taken care of at their homes and be more independent of hospital

services. The organisation of the project has been designed so as to ensure an effective combination of research with practical goals.

### ***The SPHERE Experimental Stage***

The *Experimental Stage*, with the support of the showcase integrator, provides the glue of the project as a whole, as the main resource for concept development, evaluation and further development of prototypes and social/clinical practice.

Initial fieldwork carried out in all showcases will provide input to the quality framework (WP3). It will help formulate the first set of requirements for WP5, WP6, WP7, and WP8, as well as scenarios of use. The showcases will provide the sites for **several prototype-deploy-evaluate-feedback cycles**, whose results will shape the further development of the SPHERE approach – the technologies, as well as social and clinical practice design.

Each of the technical workpackages WP5, WP6, and WP7 will concentrate as their main collaborators on one showcase with elderly people and one showcase with children. While taking a holistic case-centric view at the local level, each showcase will also contribute to the overall SPHERE approach by taking a primary concern for a particular technical workpackage at the project level (WP5, 6, 7, 8). Each showcase will also contribute to, and apply the outputs from, non-technical workpackages around qualities (WP3), ongoing evaluation (WP4), and social and clinical practice design (WP9). This necessitates an approach of sharing and integration of information across adult and child showcases to produce a *Focus Area Report* (D10.1.1-D10.6.1) for a relevant technical workpackage, as well as holding workshops with all relevant workpackages to share findings and to ground work. The clinical partners will be responsible for facilitating access to patients and all other actors, defining clinical parameters, helping to identify clinical drivers, and defining and evaluating the health outcomes. The academic partner will drive the conduct of the research and lead the fieldwork, co-design and evaluation phases of the showcases, working closely with relevant technical workpackages.

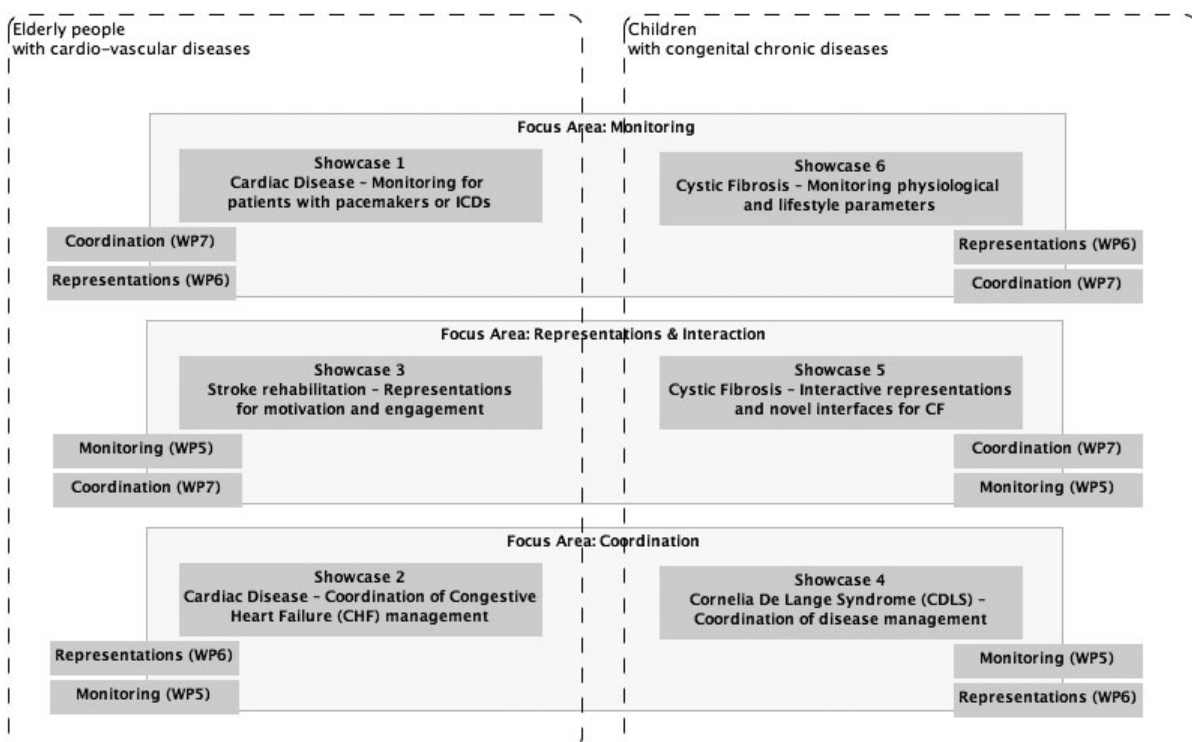


Fig. 2: *Experimental Stage: Overview of showcase-focus area relationships*

### ***Horizontal research topics***

Each of the research workpackages focuses on particular research topics. These topics are fundamental for all types of applications to be developed within SPHERE. Thus while independent of a particular

showcase and aiming at ambitious solutions in their research field, the research workpackages have also to serve the realisation of the individual showcases.

WP5 (Embedded, responsive, multiparametric monitoring) will closely cooperate with WP6 (Interactive representations and interaction design) and WP7 (Inter-network coordination) to design for integration with representation and coordination components. WP7 will be supported by WP6 in the development of visualisations of configurable coordination mechanisms and by WP5 in terms of environmental information affecting coordination. WP8 will provide a Development Environment for SPHERE, which will be iteratively developed in close cooperation with WP5, WP6, and WP7.

#### ***Demonstration activities***

As the showcases (WP10) are research workpackages, SPHERE does not foresee demonstration activities in the traditional sense. A series of public “demonstrations” of the SPHERE approach will be organised as part of academic conferences, trade fairs, etc. (see Dissemination 3.2).

#### ***Training activities***

The SPHERE project will provide training for members of the SPHERE Consortium and for the SPHERE Community (see 3.2.). The training offered to the SPHERE Community of researchers, industry and SMEs, health institutions and organisations, formal and informal caregivers, patient organisations, etc. forms an important part of the SPHERE dissemination activities. Also training provided to members of the SPHERE Consortium is not limited to researchers but includes end-users as participants in the showcases.

#### ***Major milestones over the whole project duration***

The overall project is subdivided into four project phases of 12 months each. Each phase ends with a 2-3 month evaluation, review and re-design period. In each project phase management activities (WP1, WP2), research and innovation activities (WP3, WP4, WP5, WP6, WP7, WP8, WP9) and research and innovation activities within the showcases (WP10) will run in parallel.

All development will be grounded in showcase research and deployment in several prototype-deploy-evaluate-feedback cycles, each ending with a release of the SPHERE approach:

- The first release of the SPHERE approach (**M3**) will be based on concept/model/methods development and first design explorations with technology probes or mock-ups (isolated implementations), combined with the quality framework and guidelines for social/clinical practice design;
- The second release of the SPHERE approach (**M5**) consists of the initial core prototype for each showcase and initial prototype evaluations, as well as refined design principles and guidelines;
- The third release of the SPHERE approach (**M7**) consist of extended/enriched prototypes and their integration with the Development Environment, their evaluations, and of a report on key issues concerning social/clinical practices as well as ethics;
- The final release of the SPHERE approach (**M8**) consists of the final enriched prototypes and their integration with the Development Environment, a summative longitudinal evaluation of the ‘integrated showcase’, as well as conceptual and methodological schemes and design principles for an integrated care environment.
- **M4** and **M6** mark the specific evaluation plan for the showcases guiding iterative development, as well as the detailed evaluation plan for the final release of the SPHERE approach.

### **1.3.2 Research, technological development and innovation activities**

This part describes the RDT workpackages of SPHERE, their objectives, the research issues to be addressed, as well as potential risks and contingency plans.

#### ***WP3 (RTD): Quality framework***

**Partners:** TUW (WP leader), TUG, UniMiB, UniTN, UoS, ULANC, UL, ITU, CoST

**Effort:** 61PM

**Objectives:** The aim of WP3 is to make the ICT-2007.5.1 objectives operational; and to ensure the commitment of all actors to them.

**Research issues:** The quality framework will be developed on the basis of ethnographic fieldwork in the selected health care areas; it will be used for developing operational design principles and for applying them in technology development and social/clinical practice design. This framework will define qualities of an integrated care environment for the chronically ill and patients at risk in ways that effectively orients technology development across showcases and technical workpackages. SPHERE starts out from a set of design principles that will be explored and detailed in the form of examples and scenarios, and operationalised in the course of the project on the basis of intense ethnographic fieldwork (video-supported observation, open and semi-structured interviews). Among the design principles this research will address in particular are: *spatiality*, e.g. to incorporate the technical facilities in a patient's home, to determine how to use space to support privacy and patient's control over monitoring; *transparency*, e.g. to provide users with a valid and simple model of what the system does and to make them aware when their activity has an effect on the system; *reliability* of life critical devices and applications; *availability/readability*, e.g. to present information in ways that help formal and informal caretakers and patients to understand the problems and to make choices; *expressiveness*, e.g. to provide representation languages that allow multiple heterogeneous users to express their views and communicate them effectively; *integration/configurability*, e.g. to support end-users in configuring and orchestrating the diversity of devices, coordination modalities, and views that are provided.

The catalogue of principles to be developed and substantiated reflects the plurality of perspectives and the complexity and specificity of modern technology and health. We expect the descriptions of qualities that emerge from this research to act as powerful guidelines throughout the project, informing notions of use, the design paths taken, the set-up of field trials and their interpretation, and the development of the evaluation framework.

**Ethics** will be a central research issue and inform the quality framework. Based on our initial fieldwork as well as observations and analysis of the field trials we will construct a set of 'vignettes' describing identified ethical issues and address these issues in focus groups that include all the stakeholders. We use the notion of 'situated ethics' which is about bringing everyday conflicts about IT in health care and their moral dimension to the fore. The project will develop field trial protocols for preparing the users (in particular patients and their families) for the field trial situation and guiding them through it.

**Risk assessment and contingency plan:** The main risk for this workpackage is to develop quality criteria and design principles that are understood and shared by all partners and can be translated into the evaluation framework and productively lead technology development so that it meets users' needs. This risk can only be met by intense communication and training sessions with all concerned actors.

#### **WP4 (RTD): Ongoing evaluation**

**Partners:** RU (WP leader), TUW, TUG, UniMiB, UniTN, UoS, ULANC, UL, ITU

**Effort:** 78PM

**Objectives:** The aim of WP4 is to evaluate each showcase with regard to the objectives of ICT-2007.5.1, hence the SPHERE objectives, as operationalised in the quality framework (WP3) that constitutes the fundamental and mandatory quality measures that all showcases must address. Measurements and evaluations include quantitative indicators of the added value and potential impact of the proposed technologies.

**Research issues:** The complexity of the healthcare system as well as the need to focus on productivity, cost stabilisation, and higher patient safety calls for a sophisticated evaluation framework that combines qualitative data, based on ethnographic fieldwork and video observations, with quantitative indicators and assessment techniques. Evaluations, informed by qualitative ethnographic fieldwork and quantitative measurements, will be based on the concept of effects-driven IT development, providing a sustained focus on the effects to be achieved by users through their adoption and use of the technologies.

The basic idea behind the approach to evaluation in SPHERE is that on-going evaluations of iterative development cycles (formative evaluations) as well as longitudinal real-world evaluations of proposed technologies (summative evaluations) will play a guiding role. Thus, the project will be driven by ethnographic fieldwork providing a solid contextual grounding in parallel with regular measurements,

evaluation, and documentation of agreed-upon effects as experienced by patients, relatives, informal carers and/or other clinicians using the technologies.

A comprehensive and generic evaluation scheme will be produced during the first year and will be developed, refined, communicated, taught, and facilitated with regard to the showcases throughout the project. For each showcase, the evaluation scheme will be specified and tailored. This includes identification and specification of the evaluation criteria, i.e., the effects to be obtained by using the envisioned technologies. For each showcase these effects will be identified, specified, and prioritised in collaboration with the users and other core stakeholders. Subsequently, the showcases will be evaluated with respect to how the prototypes of the showcase technologies provide the agreed-upon effects.

The ongoing evaluation work will align with the work on social and clinical practice design (WP9), as that the identification and articulation of local ordering principles and performance criteria are of fundamental importance to both. The mutual alignment will also ensure that general issues arising in the showcases (with regard to, e.g., appropriation and technical support for decision-making and coordination) will be identified and applied as part of the evaluation scheme.

**Risk assessment and contingency plan:** The overall risks for this workpackage are that the showcases do not produce the conditions necessary for realistic evaluations to be made. This includes that the generic evaluation framework is not sufficiently integrated into the showcases; the showcase technologies are not developed to a state mature enough for them to be used under real-world conditions; clinical staff is insufficiently involved and contributes too little to the specification of effects and/or uses the showcase technologies too little for valid measurements to be made; lack of relevant patients and/or inability to reasonably replace real patients with other users.

Countermeasures to these risks are to make shorter, more narrowly scoped, and/or laboratory-type evaluations. This will reduce the real-worldness and validity of the evaluations of the technologies in their totality but will retain possibilities of evaluating selected aspects of the technologies.

#### ***WP5 (RTD): Embedded, responsive multi-parametric monitoring***

**Partners:** ULANC (WP leader), TUG, UniMiB, UL, ESEL, Docobo, GPI

**Effort:** 128PM

**Objectives:** The main objective of WP5 is to move from stand-alone concepts to networked systems for monitoring of a wide range of biomedical and contextual parameters, and from ‘surveillance-style’ infrastructures and devices solely targeting professionals to systems that bring monitoring back into the control of patients, involving issues of usability, interaction design, customizability and social/personal acceptability.

**Research issues:** Multi-parametric monitoring of a patient’s health and activity status and capture of environmental and contextual data will be achieved with integration of a diversity of sensing and monitoring concepts and technologies, to underpin monitoring needs of and for different patient groups and to feed creation of rich accounts and histories of patient health and well being. The project will experiment with devices, systems and approaches ‘across the board’, including wearable monitoring devices, sensors integrated in garments, and implants (specifically pacemakers) with monitoring support, as well as wireless sensors for deployment in the environment, augmentation of objects of daily interaction, and ‘harvesting’ of relevant data that is increasingly pervasive in everyday environments (e.g. indicators for activity, mobility and social interactivity).

More specifically, WP5 will develop and study prototypes of systems and devices that support

- multi-parametric monitoring and data recording with unobtrusive and minimally invasive methods over long periods of time to support **analysis of histories, trends, rhythms and routines**, and to facilitate novel forms of representation (as investigated in WP6, cf. below)
- **control, awareness and ‘sense-making’ of patients** as well as configuration of systems by their users, including placement and linking of systems components and self-adaptation of systems to changed configuration (e.g. learning of relative sensor placement for correct interpretation of observations and recorded data)
- **active participation of patients** through embedding of monitoring in interactive and engaging form factors, including devices designed for recreational interaction and toys and robotic characters with tangible and affective interfaces.

**Risk assessment and contingency plan:** The main risks associated with this WP are related to our approach of integrating a diversity of sensing and monitoring technologies and approaches. Relevant technologies and emerging developments tend to use proprietary protocols and provide non-standard APIs with a risk of increased adaptation and integration effort. Another risk is the emergence of related developments and standards over the duration of the project.

Our strategy to respond to such developments is early adoption and compliance to ensure maximum impact of the SPHERE approach. Some risks can be addressed by resorting to fallback technological alternatives.

**WP6 (RTD): Interactive representations and novel interfaces**

**Partners:** TUG (WP leader), TUW, UoS, UL, CoST, ESEL, MX, VR, Docobo, GPI

**Effort:** 149,6PM

**Objectives:** The main objective of WP6 is to support clinicians, patients and informal carers in exploring and understanding collected data of a different nature through rich, multi-medial, configurable, interactive representations and novel interfaces. The challenge is to optimise and further develop exploration tools so as to enable end-users to configure different views on the collected data, depending on their professional needs and level of understanding, and on a diversity of output devices (mobile phones, PDAs, TV).

**Research issues:** Intelligent combinations of multi-parametric monitoring with expert feedback and care in 'closed-loop systems' will be achieved through rich, multi-medial, configurable, interactive representations and novel interfaces (WP6). These visualisations will support health professionals in understanding and monitoring risk factors or the history of a chronic disease on the one hand, communicating with individual patients about risk factors and therapies and their implications on the other hand. Patients will be supported in their own understanding and self-management of their disease and in producing rich media accounts of their health situation or perceived difficulties in the day-to-day management of their disease and in expressing moods and emotions.

More specifically, WP6 will develop and adapt to the different needs exploration tools in support of

- **clinical representations** that efficiently manage the huge amounts of multi-dimensional, time dependent data and enable expert feedback
- **expressive representations** of the more personal and expressive qualitative data (stories, pictures, video) in combination with multimodal interfaces – e.g. tangible user interfaces, interactive sonification, auditory displays
- **playful and affective representations** designed to motivate and engage.

WP6 will also support WP7 in creating visualisations of coordination mechanisms. An important focus of WP6 will be the development of interface solutions that are realised across distributed devices (e.g. pervasive small displays) and different output modalities, requiring new approaches to presentation and navigation.

**Risk assessment and contingency plan:** It is very challenging to design information visualisation techniques and user interfaces that scale from untrained users to expert users and from very small, low-powered devices to high-end medical workstations, while providing a reasonable service to each use situation from the same underlying representation. There is a risk that the resulting solutions will either be fragmented or become a patchwork, or that they are too uniform and do not address any use case particularly well.

An efficient countermeasure is to consider scalable and adaptive visualisation techniques from the beginning, which can be used in a variety of "levels of detail". Moreover, software-design patterns such as the well-known model-view-controller pattern allow a separation of concerns which is essential in avoiding adversely affecting one use case when modifying another one.

**WP7 (RTD): Inter-network coordination**

**Partners:** UniMiB (WP leader), TUW, ITU, CoST, ESEL, MX, VR, GPI

**Effort:** 168,5PM

**Objectives:** The main aim of WP7 is the modelling and implementation of coordination mechanisms that support distributed healthcare without disrupting the work practices of the heterogeneous networks of actors.



**Research issues:** The envisioned technologies of monitoring and representation will engender enormous amounts of clinical data, at various levels and stages of aggregation, that will be managed and used in heterogeneous networks of actors (from patients, over informal carers, to clinicians and medical researchers). The data will be used in different ways for different purposes; but in any event, by plugging into the same pools of data, the distributed users of the data will become or become increasingly interdependent in different ways. As a result, the issue of coordination within and among heterogeneous networks becomes increasingly critical to integrated care.

The work on coordination mechanisms will in particular address design issues such as: the web of *social relationships* characterizing the networks involved in distributed healthcare; the *conventions* established within and across them; the need of actors to *switch between environments* without losing the context required for the interpretation and coordination of care-related events; the need to maintain *issues and perspectives over time*; and finally, the *heterogeneity* in terms of skill, role, and accountability of the actors constituting the various networks.

The technology developed in WP7 will support *flexible coordination of distributed activities* and will be *configurable by users* according to their local needs. In undertaking this, WP7 will adopt the approaches developed in the areas of CSCW and context-aware computing and apply them, with the necessary transformations, to the very complex application domain of distributed healthcare.

WP7 will be dealing with complex software development issues since it has to integrate coordination mechanisms fulfilling the functional requirements of different showcases. To this aim, a *multilayered architecture* will be adopted in order to perform this integration at different levels of abstraction: first at the logical level of executable specifications of coordination mechanisms and only then, once specifications are stabilised, at a more technical level. In this way, the gap between users' needs and the development of specialised software modules to meet them, can be bridged by the construction of a computational model that a) expresses high-level executable specifications ("at the semantic level of human coordination") without any reference to the concrete software architecture and its constraints, and b) makes their implementation in a concrete software architecture more controllable and easy, since at this stage only technical issues such as software interoperability and constraints can be considered.

Existing standards will be adopted to support the integration of the implemented coordination mechanisms with monitoring and representation technologies and communication infrastructures. The same applies to the issue of ensuring interoperability with pre-existing Healthcare Information Systems (typically, EPR) or, possibly (for purposes of experimental safety) proxies of such systems.

**Risk assessment and contingency plan:** Risks come from the distributed nature of the design effort that has to be done by the partners and from the continuous interactions with the field work conducted in the showcases.

The work plan envisages a) a significant investment to define a first version of the methodological approach that will lead both the modelling and the implementation activities and b) an iterative process of its tuning. Moreover, the two level approach (modelling and implementation) facilitates the alignment between the different stages of coordination mechanisms development while maintaining their overall consistency.

#### **WP8 (RTD): Development Environment**

**Partners:** ESEL (WP leader), TUW, TUG, UniTN, ULANC, CoST, ESEL, MX, VR, Docobo

**Effort:** 90PM

**Objectives:** The aim of WP8 is to provide a distributed infrastructure for integrating various types of healthcare data and make the data accessible to clinicians, patients and their informal carers, and embedded in clinical practice as well as in patients' everyday life. The SPHERE system aims at aggregating software services, databases, legacy systems and sensors in a pervasive environment to support remote healthcare. Considering the participation of different actors and the availability of rich devices in a pervasive environment, the Development Environment in SPHERE will be able to handle both structured data (e.g. XML data from patients), context data (e.g. sensor data from medical equipment), and unstructured data (e.g. video blogs, streaming media).

**Research issues:** Distributed and remote multi-parametric monitoring of a patient's health and coordination mechanisms in distributed healthcare require a dynamic, flexible, adaptive distributed environment in which both data and control can be manipulated and performed easily.

WP8 will provide technologies that can be used to extract various types of healthcare data provided by different kinds of sensors, medical equipments, and wearable monitoring devices, and deliver the extracted data to the stakeholders. Such technologies will be customizable so that they can be employed in a pervasive, widely distributed environment through which caregivers, clinicians, patients are connected.

The Development Environment will support different actors and applications they use by providing a set of core services, which will be deployed in high-end systems, and be responsible for aggregating and processing the extracted data and routing both processed data and raw events to relevant applications and supporting tools used by clinicians and medical researchers. WP8 will rely on SOA-based technologies to ensure that various applications can easily be integrated into SPHERE healthcare system leveraging on SOA interoperability features. To this end, WP8 will work on **integrated middleware solutions** for distributed healthcare. These solutions will integrate various data sources and will allow disparate applications and supporting tools, such as patient monitoring, services browsing, graphic visualisation of processes, discovery and monitoring of processes instances and visualization of relevant data flow, to seamlessly access different types of healthcare data and conduct operations.

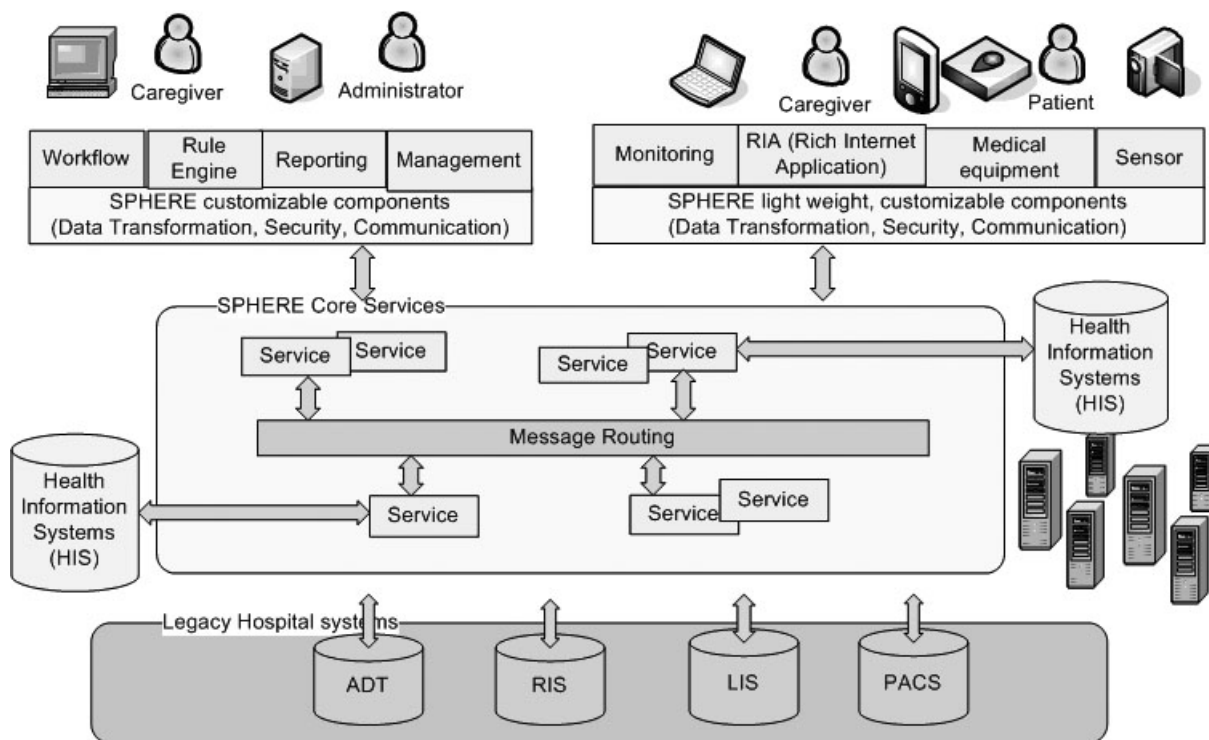


Fig. 3: Development Environment architecture

WP8 infrastructure will be **dynamically reconfigured and open service-oriented**, and will deal with healthcare data. Therefore, WP8 will also address security and data privacy concerns in publishing and accessing medical data. WP8 will work with WP5 in extracting healthcare data from monitoring devices, WP6 in visualizing and representing data, and will support WP7 in its flexible coordination of distributed activities. The figure below outlines the envisioned Development Environment.

**Risk assessment and contingency plan:** Technical problems arising during SPHERE development can be caused by integration problems or by the lack of the use of standards. Also the complexity of integration can compromise the system performance.

The system architecture must be flexible enough to simplify the integration of all available technologies. A first step in the integration phase is foreseen for performing a preliminary integration of some fundamental components and for discussing and evaluating problems.

**WP9 (RTD): Social and clinical practice design**

**Partners:** ITU (WP leader), TUW, UniMiB, UniTN, UoS, ITU, RU

**Effort:** 127PM

**Objectives:** The aim of WP9 is to ensure that the potential benefits of the envisioned novel technical facilities for monitoring patients in their everyday environments and for making the monitoring data available to patients, informal carers, and clinicians, can be realised. This requires a transformation of organisational and work practices as well as the formal framework in which they are embedded (performance measurement, reimbursement scheme, legal stipulations, etc.).

**Research issues:** WP9 addresses the issue that the practices of formal and informal carers and patients, in various ways will have to change in the appropriation of new technical facilities for monitoring, representation, coordination, etc. systematically and accountably as an integral aspect of the overall design process.

In sociological theory [55], work practices, and social practices in general, are conceived of as defined (and hence identified and delimited) by ordering principles, rules, protocols, procedures, techniques, schemes, etc. The work of this WP thus focuses on identifying and articulating the more or less implicit ordering principles etc. underlying extant clinical and care-related practices with a view to uncovering their rationale, so as to be able to systematically develop, contemplate, negotiate, try, etc. possibly alternative practices. This work will draw upon strong research traditions like Participatory Design (PD) and Computer Supported Cooperative Work (CSCW).

WP9 will look beyond local practices and organisational forms and *develop suggestions for reimbursement schemes and legal frameworks*. This work will draw upon sociological theories of how formal organisational constructs are constructed, appropriated, and enacted in actual practice [11, 19, 18, 45, 47], as well as pertinent theoretical contributions from organisation theory on the partly diverging motives and goals of organisational actors [30], high-reliability organisations [44, 54], and organisational networks [39, 41].

Based on the findings of the experimental work in the showcases, WP9 will develop a conceptual scheme of social and clinical practice design. Exemplary practice designs will illustrate how these elements and relations may be combined. Complementary to this, WP9 will develop approaches to the process of social and clinical practice design-

As noted above, the work of WP9 is complementary to WP4, and work in the two WPs will be closely aligned.

**Risk assessment and contingency plan:** Design is here understood in the sense of making plans for others to realise - i.e. close to architects' idea of design. Along that notion, organisational actors are expected to be instrumental in realizing the plans. However, clinicians have developed a reputation of being sceptical of the changes being proposed to them.

It is very challenging to design social and clinical practices in ways that are supportive of the work actually going on. Especially time is an issue: It may take longer time to introduce actual changes in the work practices than it takes for management to generate a new business plan.

**WP10 (RTD): Experimental stage**

**Partners:** UoS (Showcase Integrator), TUW, UniMiB, UniTN, UL, ITU

**Effort:** 40PM

**Objectives:** This work package takes an overall concern for the set-up and running of the various showcase activities within the project to ensure integration and coordination across showcases and with related workpackages. The objectives of WP10 are to:

- Define the overall approach the showcases will take throughout the project phases
- Plan, manage, and coordinate showcase activities, focusing on cross-showcase (within WP10) sharing of data, and integration with other workpackages
- Monitor and report showcase progress.

All of the showcases will share an overall participatory approach and set of generic tasks to develop personal health systems that incorporate both social and technical concerns. Showcases have been chosen to enable the greatest diversity of patients (adults and children), conditions and cultural contexts to promote generalisability of outcomes. Each showcase will use participatory user-centred methods, including intensive ethnographic fieldwork at the locations where care and daily life happen. Each showcase will work with as many participants (patients and informal and formal care networks) as practical in the fieldwork and with at least 10 participants in more focussed design explorations, deployments and evaluations.

**Risk assessment and contingency plan:** Risks are that insufficient patients agree to participate; patients and/or informal carers withdraw from participation in the course of the project; clinicians are too busy to engage in the project; conflicts between stakeholders arise; services and representations given to patients and clinicians are not useable or useful and are not appropriated; policy and/or administrative changes happen during the course of the project that change the priorities of national health agendas and/or project partners; showcase cases and prototype implementation are delayed or not a success.

Countermeasures are: effective initial engagements to promote buy-in; identify alternative sources of patient involvement e.g. via patient organisations; identify alternative sources of clinical expertise eg professional bodies; multi-stakeholder workshops at planning phases to promote buy-in and ensure stakeholder agendas are accommodated where practical; early and repeated user involvement in the design and testing of devices and representations; to include regular and frequent checkpoints in the project to identify changes and facilitate re-planning in a timely way if required; to identify alternative cases with similar characteristics.

#### ***WP10.1: Cardiac Disease: Monitoring for patients with pacemakers or ICDs***

**Partners:** ITU (Showcase leader), RH, ULANC, RU, ESEL, Docobo

**Effort:** 63PM

**Objectives:** This showcase will focus on embedded, responsive, multi-parametric monitoring (WP5). The main objective of this showcase is to evaluate the use of existing new pacemakers/ICDs ((implantable cardioverter-defibrillators) and explore the needs for additional monitoring, with a focus on data management and ‘sense-making’.

**Rationale:** The emphasis in this showcase is on patients with *pacemakers or ICDs*, in cooperation with an existing Danish project involving 100 patients with a new generation of pacemakers. Healthcare providers could save time and money, and the patient could avoid unnecessary stress and anxiety, if distant and periodical monitoring and feedback was possible. The current pacemakers/ICDs are able to monitor the patient’s activity level, amount of fluid in thorax, the therapies given by the device and its battery status. Additional parameters, such as level of oxygen in the blood and certain hormones detectable also in the blood before a cardiac insufficiency strikes, may be monitored. Staff and patients would like to use mobile phones rather than traditional phones for the transmission and sharing of this information and for personalised feedback.

#### ***WP10.2: Cardiac Disease - Coordination of Congestive Heart Failure (CHF) management***

**Partners:** UniTN (Showcase leader), APSS, RU, GPI, ESEL, CoST

**Effort:** 81,8PM

**Objectives:** This showcase will focus on inter-network coordination (WP7). The aims of the showcase are to evaluate the effects of an integrated disease management system in support of guidelines and protocols; to contribute to the further development of this system by implementing configurable coordination mechanisms in support of the network of caregivers involved in the therapy of congestive diseases (physicians, specialists, patients, families, service providers); to help develop supportive social and clinical practices. The showcase will also test the next generation of wearable monitoring integrated in T-shirts.

**Rationale:** The focus here is on patients with congestive heart failure (CHF), a condition that can result from any structural or functional cardiac disorder that impairs the ability of the heart to fill with or pump a sufficient amount of blood throughout the body. It is often undiagnosed, due to a lack of a universally agreed definition and difficulties in diagnosis, particularly when the condition is

considered 'mild'. Mortality rates can be decreased dramatically when clinicians and patients learn to understand and adhere to rather strict protocols. The showcase will cooperate with an existing regional project involving about 1.000 patients in Trentino, run by the regional health agency.

***WP10.3: Stroke rehabilitation – Representations for motivation and engagement***

**Partners:** UL (Showcase leader), TUG, RU, ESEL, VR, MX

**Effort:** 36PM

**Objectives:** This showcase will focus on interactive representations and interaction design (WP6). The main goal of this showcase therefore is to explore the value of playful and engaging interactive representations to motivate appropriate exercise, e.g., in a virtual reality or computer game environment. These representations will be developed in conjunction with the use of a wireless mote system as a system to monitor movement. It also envisages the provision of a low cost implementation of a wearable sensor system for use in in-home rehabilitation.

**Rationale:** For Europe, the number of strokes per year is approximately one million. Based on international data, it is calculated that many who survive stroke have significant ongoing disability. Rehabilitation is essential for the patient to be able to return to everyday life. As a consequence of the reduction in hospital funding and the increasing queues for health care, more of the rehabilitation needs to be moved to the patient's home. The playful monitoring of exercise is seen as having the potential to provide a practice environment that is motivating and holds patients' attention, factors that are key to successful rehabilitation. The showcase will be carried out in collaboration with the Stroke Rehabilitation Unit in the Midwestern Regional Hospital in Limerick, Ireland.

***WP10.4: Cornelia De Lange Syndrome (CDLS) - Coordination of disease management***

**Partners:** UniMiB (Showcase leader), PoliMI, RU, CoST, ESEL, GPI

**Effort:** 90PM

**Objectives:** This showcase will focus on inter-network coordination (WP7). The objectives of the showcase are on one hand, to support this complex network for the care of CDLS with suitable coordination and monitoring technologies. On the other hand, to facilitate a family-centred approach to the care of the patients by supporting family participation within the network of care.

**Rationale:** CDLS is a chronic, rare, disabling, multisystem genetic disease that affects an estimated one in 10.000 children. The choice of this specific syndrome is motivated by the complexity and multi-problematic nature of patients since they are affected by a plethora of different problems and disorders. Most of these problems need timely and ongoing monitoring, particularly gastroesophageal reflux, growth, behaviour, hearing and vision problems, and communication needs. Inside PoliMI two leading excellence centres exist, one for the paediatric diagnosis and care of children with congenital genetic syndromes and one for their neuropsychiatric and rehabilitative care. In the last two years the centre has activated a regional project of research that has delineated the existing structure and problems of the network for caring patients affected by complex disabilities, using CDLS as a model. Since this network is constituted by nodes that are distributed in the Italian territory and whose members own different competencies and expertise, a lot of coordination problems occur. The proposed model of integrated care could be used as a paradigm to support the disease management related to other chronic rare diseases causing disability (affecting 0,5% children in EU population, approx. 45.000 in Italy) requiring the complex management of multiple and intersecting illness trajectories.

***WP10.5: Cystic Fibrosis – Interactive representations and novel interfaces for CF care***

**Partners:** TUW (Showcase leader), MUV, TUG, RU, ESEL, VR, MX

**Effort:** 68PM

**Objectives:** This showcase will focus on interactive representations and interaction design (WP6) for patients with cystic fibrosis (CF). The objective of the showcase is to explore representations and interfaces to both present information in an appropriate way to children and families and clinicians, and also to enable the child and their family to capture their own information about the more expressive elements of the CF experience.

**Rationale:** CF places a significant care burden on parents as the primary people involved in the child's care on a day-to-day basis. They need to very quickly become experts in the management and administration of treatments such as physiotherapy and medications in the home. They also need to play a critical role in the coordination of information among various medical, allied health, social care and education providers involved with the child. As children grow older, it then moves to the child to become experts in their own conditions and start to take more control of their own care. The showcase will be carried out in collaboration with the Paediatric Department at Vienna Medical University.

**WP10.6: Cystic Fibrosis – Monitoring physiological and lifestyle parameters**

**Partners:** UoS (Showcase leader), BSUH, ULANC, TUW, RU, ESEL, Docobo

**Effort:** 73PM

**Objectives:** This showcase will focus on embedded, responsive, multi-parametric monitoring (WP5) for patients with cystic fibrosis (CF). The objective of this showcase is to develop appropriate (playful) in-home monitoring applications for physiological measures (respiratory, digestive, medication) and lifestyle measures (nutrition, exercise) so as to motivate children to participate in the monitoring and to support the child and families interpretation and use of the data for self management as well as the clinicians' use of the data to manage care regimes.

**Rationale:** CF is the most common life threatening inherited chronic disease in Europe. Children with cystic fibrosis have a shorter life expectancy, with the average being around 31 years. The impact of more timely and appropriate intervention for CF sufferers can add up to 5 years to this life expectancy. The main foci for the treatment of CF are to improve nutrition through use of digestive enzymes and dietary supplements, and to reduce the risk of chest infections through multiple daily physiotherapy interventions and proactive antibiotic regimes. Children often also have to deal with frequent antibiotic and other drug regimes, including therapy for diabetes, asthma and liver disease. The showcase will be carried out in collaboration with the CF clinic at the Brighton & Sussex University Hospitals that currently has 36 children in their care, covering a broad age spectrum.

**1.3.3 Assessment of progress and results**

Built into the SPHERE approach is the successive assessment of progress and results; in two ways: ethnographic observations of the deployment of prototypes will provide detailed user feedback at each step of the development; the formative (and finally summative) evaluation of the field trials (WP4) will assess project progress on the basis of quantitative quality measures. A number of quantitative indicators will be used for reporting on progress with the implementation of its research plan by the consortium, to be specified in D1.1. Furthermore, for each workpackage a list of qualitative measures of success has been defined, which will be examined and further operationalised within the first six months of the projects (as part of D1.1) and examined at each milestone.

Table 1.3.a: Summary of success criteria for individual workpackages

WP	Success criteria
WP2	The extent to which the academic community as well as relevant end-user organisations are informed about the SPHERE approach; The extent to which public demonstrations (as part of conferences and trade fairs) are able to gather interested people, both academics and industrials; size of audiences reached by this part of the dissemination and exploitation plan; The extent to which the designed exploitation plan and the proposed business model is able to generate SPHERE spin off and new potential costumers and users.
WP3	The extent to which the quality framework is taken up in the individual showcases; Its usefulness in guiding the formulation of design principles and scenarios; Its integration with the evaluation framework; The number and richness of vignettes describing ethical as well as social/clinical practice issues; The translation of the quality framework research into an integrated framework for developing and assessing personal systems for health monitoring.
WP4	The extent to which the evaluation framework is integrated with the quality framework workpackage (WP3);

	<p>The extent to which the evaluation framework is coordinated with the social and clinical practice design workpackage (WP9), its integration into the showcases. Its utility in guiding the evaluation and iterative refinement of the showcase technologies;</p> <p>The ability of patients, clinicians, and other stakeholders to specify their requirements toward the showcase technologies in terms of effects.</p> <p>The ability of valid measurements to be made within the resource constraints of the involved partners.</p>
<b>WP5</b>	<p>Appropriate accuracy and precision of sensing, monitoring and context capture methods with respect to showcase requirements;</p> <p>Comprehensiveness of the monitoring framework in terms of reusability versus custom development needed for different applications;</p> <p>Personal and social acceptance of monitoring technology;</p> <p>Effective support of awareness and sense-making in terms of user understanding and user ability to configure monitoring systems in accordance with their needs</p>
<b>WP6</b>	<p>Usability and efficiency of presentations and interactions for patients, informal carers and clinicians;</p> <p>Suitability of the techniques for the various showcases – how well are application requirements met;</p> <p>Configurability of presentations to needs/perspectives;</p> <p>Comprehensiveness of the toolkit approach – how much of the developed techniques is re- general purpose vs specialised approaches</p>
<b>WP7</b>	<p>The quality of the modelled coordination mechanisms according to the dimensions identified in WP3;</p> <p>The identification and prototypical implementation of a set of integrated functionalities supporting distributed coordination that constitutes a reference application for the distributed care domain and that can be specialised to local situations, first of all to the showcases;</p> <p>The interoperability of these functionalities with the technology developed by other WPs of the project.</p>
<b>WP8</b>	<p>Comprehensiveness and flexibility of healthcare data extraction and aggregation for multiple types of data from different sources;</p> <p>Comprehensiveness and usefulness of customizable components and healthcare applications for patients, informal carers and clinicians in multiple types of devices (Smartphone, PDAs, laptops, PC, etc.);</p> <p>Sustainability, scalability, interoperability, and extensibility of distributed development environment, including services, techniques and tools, supporting aggregation and propagation of healthcare data and distributed healthcare.</p>
<b>WP9</b>	<p>The extent to which the social and clinical practice design is coordinated with the quality framework (WP 3);</p> <p>The extent to which the social and clinical practice design is coordinated with the ongoing evaluation framework (WP 4);</p> <p>Its usefulness in guiding the work in the showcases (WP10);</p> <p>Its ability to act as a “home” for reflection and generalisation based on the showcases (WP10).</p>
<b>WP10</b>	<p>Effective collaborative relationships with formal and informal care networks and patients as key informants underpinning showcases;</p> <p>The extent to which ethnographic studies of domains inform the design of quality/evaluation/practice workpackages (WP 3, 4, 9) and technical workpackages (WP 5, 6, 7, 8);</p> <p>The extent of involvement of clinical, patient, and informal carers in iterative formative evaluation;</p> <p>The effective functional deployment of prototypes into patient and clinical settings</p> <p>Delivery of identified outcomes to patients, families/informal carers, and formal carers.</p>

Table 1.3 a: **Work package list**

Work package No <sup>1</sup>	Work package title	Type of activity <sup>2</sup>	Lead partic no. <sup>3</sup>	Lead partic. short name	Person-months <sup>4</sup>	Start month <sup>5</sup>	End month <sup>5</sup>
1	Consortium management	MGT	1	TUW	70	1	48
2	Dissemination and exploitation	OTHER	4	UniTN	81	1	48
3	Quality framework	RTD	1	TUW	61	1	48
4	Ongoing evaluation	RTD	9	RU	78	1	48
5	Embedded, responsive multi-parametric monitoring	RTD	6	ULANC	128	1	48
6	Interactive representations and interaction design	RTD	2	TUG	149	1	48
7	Inter-network coordination	RTD	3	UniMiB	168,5	1	48
8	Development environment	RTD		ESEL	90	1	48
9	Social and clinical practice design	RTD	8	ITU	127	1	48
10	Experimental Stage – SPHERE Showcases	RTD	5	UoS	40	1	48
10.1	Showcase 1: Cardiac Disease – Monitoring for patients with <i>pacemakers or ICDs</i>	RTD	8	ITU	63	2	46
10.2	Showcase 2: Cardiac Disease – Coordination of Congestive Heart Failure (CHF) management	RTD	4	UniTN	81,8	2	46

<sup>1</sup> Workpackage number: WP 1 – WP n.

<sup>2</sup> Please indicate one activity per workpackage:

RTD = Research and technological development (including any activities to prepare for the dissemination and/or exploitation of project results, and coordination activities); DEM = Demonstration; MGT = Management of the consortium; OTHER = Other specific activities, if applicable in this call.

<sup>3</sup> Number of the participant leading the work in this workpackage.

<sup>4</sup> The total number of person-months allocated to each workpackage.

<sup>5</sup> Measured in months from the project start date (month 1).



10.3	Showcase 3: Stroke rehabilitation – Representations for motivation and engagement	RTD	7	UL	36	2	46
10.4	Showcase 4: Cornelia De Lange Syndrome (CDLS) – Coordination of disease management	RTD	3	UniMiB	90	2	46
10.5	Showcase 5: Cystic Fibrosis – Interactive representations and novel interfaces for CF	RTD	1	TUW	68	2	46
10.6	Showcase 6: Cystic Fibrosis – Monitoring physiological and lifestyle parameters	RTD	5	UoS	73	2	46
<b>16</b>	<b>TOTAL</b>				<b>1404,3</b>		

Table 1.3 b: **List of Deliverables**

<b>Del. no.</b> <sup>6</sup>	<b>Deliverable name</b>	<b>WP no.</b>	<b>Nature</b> <sup>7</sup>	<b>Dissemi-nation level</b> <sup>8</sup>	<b>Delivery date</b> <sup>9</sup> (proj. month)
D1.1	Project execution and quality assurance plan	WP1	R	PU	m3
D1.2	6-month interim activity and management report	WP1	R	PP	m6
D1.3	Annual report / project progress report (as required by the Commission)	WP1	R	PU	m12
D1.4	18-month interim activity and management report	WP1	R	PP	m18
D1.5	Evaluation summary report for Phase I	WP1	R	PU	m18
D1.6	Annual report / project progress report	WP1	R	PU	m24
D1.7	30-month interim activity and management report	WP1	R	PP	m30
D1.8	Annual report / project progress report	WP1	R	PU	m36
D1.9	42-month interim activity and management report	WP1	R	PP	m42
D1.10	Annual report / project progress report	WP1	R	PU	m48
D2.1	Dissemination and exploitation plan for SPHERE	WP2	R	PU	m12
D2.2	Report on first round of dissemination and exploitation activities and improved plans	WP2	R	PU	m24
D2.3	Report on intensified dissemination and exploitation activities, including special events	WP2	R	PU	m36
D2.4	Final report on dissemination and exploitation activities, including special e	WP2	R	PU	m48

<sup>6</sup> Deliverable numbers in order of delivery dates. Please use the numbering convention <WP number>.<number of deliverable within that WP>. For example, deliverable 4.2 would be the second deliverable from workpackage 4.

<sup>7</sup> Please indicate the nature of the deliverable using one of the following codes:

**R** = Report, **P** = Prototype, **D** = Demonstrator, **O** = Other

<sup>8</sup> Please indicate the dissemination level using one of the following codes:

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<sup>9</sup> Measured in months from the project start date (month 1).

<b>Del. no.</b> <sup>10</sup>	<b>Deliverable name</b>	<b>WP no.</b>	<b>Nature</b> <sup>11</sup>	<b>Dissemi-nation level</b> <sup>12</sup>	<b>Delivery date</b> <sup>13</sup> (proj. month)
D3.1	First version of quality framework and scenarios of use	WP3	R	PP	m6
D3.2	Consolidated quality framework with design principles and scenarios of use	WP3	R	PU	m12
D3.3	Report on use of quality framework and on further development of design principles	WP3	R	PU	m24
D3.4	Report on use of ethics vignettes as part of focus groups with stakeholders	WP3	R	PU	m36
D3.5	Handbook with ethics vignettes and design principles for an integrated care environment	WP3	R	PU	m48
D4.1	Generic methodological evaluation framework	WP4	R	PU	m12
D4.2	Specific evaluation framework for all showcases guiding the iterative development	WP4	R	PP	m18
D4.3	Detailed evaluation plan for all showcases	WP4	R	PP	m34
D4.4	Longitudinal, effects-driven and real-world evaluation of showcase prototype for all showcases	WP4	R	PU	m48
D5.1	Initial methodological framework	WP5	R	PU	m6
D5.2	Functional demonstrator of initial monitoring concepts (isolated implementation of probes and mock-ups) for use in showcases	WP5	D	PU	m12
D5.3	Monitoring and data collection components integrated in first core showcase prototypes	WP5	P	PU	m24

<sup>10</sup> Deliverable numbers in order of delivery dates. Please use the numbering convention <WP number>.<number of deliverable within that WP>. For example, deliverable 4.2 would be the second deliverable from workpackage 4.

<sup>11</sup> Please indicate the nature of the deliverable using one of the following codes:

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<sup>13</sup> Measured in months from the project start date (month 1).

<b>Del. no.</b> <sup>14</sup>	<b>Deliverable name</b>	<b>WP no.</b>	<b>Nature</b> <sup>15</sup>	<b>Dissemi- -nation level</b> <sup>16</sup>	<b>Delivery date</b> <sup>17</sup> (proj. month)
D5.4	Complete integration of monitoring components in the Development Environment	WP5	P	PU	m36
D5.5	Final revision of monitoring hardware and software	WP5	P	PU	m48
D6.1	Initial functional demonstrator for use in showcases and report	WP6	D	PU	m12
D6.2	First prototype and report	WP6	R,P	PU	m24
D6.3	Improved prototype and report	WP6	R,P	PU	m36
D6.4	Final prototype and report	WP6	R,P	PU	m48
D7.1	Initial methodological framework	WP7	R	PU	m6
D7.2	Consolidated modelling of the identified coordination mechanisms	WP7	R	PU	m12
D7.3	1 <sup>st</sup> Version of integrated computational model of the identified coordination mechanisms	WP7	P	PU	m24
D7.4	1 <sup>st</sup> Version of the integration of the developed coordination mechanisms into the SPHERE Development Environment	WP7	P	PU	m36
D7.5	2 <sup>nd</sup> Version of integrated computational model of the identified coordination mechanisms	WP7	P	PU	m36
D7.6	Final integration of coordination mechanisms into the SPHERE Development Environment	WP7	P	PU	m48
D7.7	Final integrated computational model of the identified coordination mechanisms	WP7	P	PU	m48

<sup>14</sup> Deliverable numbers in order of delivery dates. Please use the numbering convention <WP number>.<number of deliverable within that WP>. For example, deliverable 4.2 would be the second deliverable from workpackage 4.

<sup>15</sup> Please indicate the nature of the deliverable using one of the following codes:

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<sup>17</sup> Measured in months from the project start date (month 1).

<b>Del. no.</b> <sup>18</sup>	<b>Deliverable name</b>	<b>WP no.</b>	<b>Nature</b> <sup>19</sup>	<b>Dissemi- -nation level</b> <sup>20</sup>	<b>Delivery date</b> <sup>21</sup> ( <b>pr o.month</b> )
D8.1	Specification and design of SPHERE Development Environment	WP8	R	PU	m6
D8.2	1 <sup>st</sup> Version of SPHERE Core Services	WP8	R,P	PU	m12
D8.3	1 <sup>st</sup> Version of SPHERE Client Customisable Components	WP8	R,P	PU	m18
D8.4	Techniques for data integration and extraction	WP8	R,P	PU	m18
D8.5	2 <sup>nd</sup> Version of SPHERE Core Services	WP8	R,P	PU	m36
D8.6	2 <sup>nd</sup> Version of SPHERE Client Customisable Components	WP8	R,P	PU	m36
D8.7	Integrated SPHERE Development Environment	WP8	P	PU	m36
D8.8	Final version of SPHERE Core Services	WP8	R,P	PU	m42
D8.9	Final version of SPHERE Client Customisable Components	WP8	R,P	PU	m42
D8.10	Final version of SPHERE Development Environment	WP8	R,P	PU	m48
D9.1	'Bootstrap' conceptual and methodological scheme for social and clinical practice design	WP9	R	PU	m6
D9.2	Initial comparative analysis of clinical practices and guidelines for clinical practice designs, including report on local/national, and EU initiatives relevant for Personal Health Systems for Monitoring	WP9	R	PU	m12
D9.3	Updated comparative analysis of clinical practices and guidelines for experimental social and clinical practice designs	WP9	R	PU	m24

<sup>18</sup> Deliverable numbers in order of delivery dates. Please use the numbering convention <WP number>.<number of deliverable within that WP>. For example, deliverable 4.2 would be the second deliverable from workpackage 4.

<sup>19</sup> Please indicate the nature of the deliverable using one of the following codes:

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<sup>21</sup> Measured in months from the project start date (month 1).

<b>Del. no.</b> <sup>22</sup>	<b>Deliverable name</b>	<b>WP no.</b>	<b>Nature</b> <sup>23</sup>	<b>Dissemi- -nation level</b> <sup>24</sup>	<b>Delivery date</b> <sup>25</sup> ( <b>pr o.month</b> )
D9.4	Second updated comparative analysis of social and clinical practices	WP9	R	PU	m36
D9.5	Conceptual and methodological scheme for social and clinical practice design	WP9	R	PU	m48
D10.1	Overall showcase execution plan	WP10	R	PU	m6
D10.2	Summary report of key issues across showcases arising from fieldwork	WP10	R	PU	m12
D10.3	Summary report of key issues across showcases arising from initial prototyping evaluations	WP10	R	PU	m24
D10.4	Summary report of key issues across showcases arising from integration deployments and initial evaluations	WP10	R	PU	m36
D10.5	Final report of key issues across integrated showcase evaluations	WP10	R	PU	m48
D10.1.1	Focus Area Report on requirements for monitoring applications and devices in cardiac care, plus stroke care	WP10.1	R	PP	m10
D10.1.2	Focus Area Report on evaluation of monitoring applications and devices	WP10.1	R	PP	m22
D10.1.3	Focus Area Report on evaluation of monitoring applications integrated with representations, interaction and coordination mechanisms	WP10.1	R	PP	m34
D10.1.4	Focus Area Report on summative evaluation of cardiac (pacemaker/ICDs) integrated showcase platform	WP10.1	R	PP	m46
D10.2.1	Focus Area Report on requirements for coordination mechanisms in cardiac care, integrating requirements for stroke care	WP10.2	R	PP	m10

<sup>22</sup> Deliverable numbers in order of delivery dates. Please use the numbering convention <WP number>.<number of deliverable within that WP>. For example, deliverable 4.2 would be the second deliverable from workpackage 4.

<sup>23</sup> Please indicate the nature of the deliverable using one of the following codes:

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<sup>25</sup> Measured in months from the project start date (month 1).

<b>Del. no.</b> <small>26</small>	<b>Deliverable name</b>	<b>WP no.</b>	<b>Nature</b> <small>27</small>	<b>Dissemi- -nation level</b> <sup>28</sup>	<b>Delivery date</b> <sup>29</sup> ( <b>pr o.month</b> )
D10.2.2	Focus Area Report on evaluation of coordination mechanisms	WP10.2	R	PP	m22
D10.2.3	Focus Area Report on evaluation of coordination mechanisms integrated with monitoring, representation and interaction applications and devices	WP10.2	R	PP	m34
D10.2.4	Focus Area Report on summative evaluation of cardiac (CHF) integrated showcase platform	WP10.2	R	PP	m46
D10.3.1	Focus Area Report on requirements for representation and interaction applications and devices in stroke rehabilitation, integrating requirements for cardiac care	WP10.3	R	PP	m10
D10.3.2	Focus Area Report on evaluation of representation and interaction applications and devices	WP10.3	R	PP	m22
D10.3.3	Focus Area Report on evaluation of representation and interaction applications integrated with monitoring applications and devices and coordination mechanisms	WP10.3	R	PP	m34
D10.3.4	Focus Area Report on summative evaluation of stroke rehabilitation integrated showcase platform	WP10.3	R	PP	m46
D10.4.1	Focus Area Report on requirements for coordination mechanisms in CSDL care, integrating requirements for CF	WP10.4	R	PP	m10
D10.4.2	Focus Area Report on evaluation of coordination mechanisms	WP10.4	R	PP	m22
D10.4.3	Focus Area Report on evaluation of coordination mechanisms integrated with monitoring, representation and interaction applications and devices	WP10.4	R	PP	m34

<sup>26</sup> Deliverable numbers in order of delivery dates. Please use the numbering convention <WP number>.<number of deliverable within that WP>. For example, deliverable 4.2 would be the second deliverable from workpackage 4.

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<sup>29</sup> Measured in months from the project start date (month 1).

<b>Del. no.</b> <sup>30</sup>	<b>Deliverable name</b>	<b>WP no.</b>	<b>Nature</b> <sup>31</sup>	<b>Dissemi- -nation level</b> <sup>32</sup>	<b>Delivery date</b> <sup>33</sup> ( <b>pr o.month</b> )
D10.4.4	Focus Area Report on summative evaluation of CSDL integrated showcase platform	WP10.4	R	PP	m46
D10.5.1	Focus Area Report on requirements for representation and interaction applications and devices in CF care, integrating requirements for CDLS	WP10.5	R	PP	m10
D10.5.2	Focus Area Report on evaluation of representation and interaction applications and devices	WP10.5	R	PP	m22
D10.5.3	Focus Area Report on evaluation of representation and interaction applications integrated with coordination mechanisms and monitoring applications and devices	WP10.5	R	PP	m34
D10.5.4	Focus Area Report on summative evaluation of CF integrated showcase platform	WP10.5	R	PP	m46
D10.6.1	Focus Area Report on requirements for monitoring applications and devices in CF care, integrating requirements for CDLS	WP10.6	R	PP	m10
D10.6.2	Focus Area Report on evaluation of monitoring applications and devices	WP10.6	R	PP	m22
D10.6.3	Focus Area Report on evaluation of monitoring applications integrated with representations, interaction and coordination mechanisms	WP10.6	R	PP	m34
D10.6.4	Focus Area Report on summative evaluation of CF integrated showcase platform	WP10.6	R	PP	m46

<sup>30</sup> Deliverable numbers in order of delivery dates. Please use the numbering convention <WP number>.<number of deliverable within that WP>. For example, deliverable 4.2 would be the second deliverable from workpackage 4.

<sup>31</sup> Please indicate the nature of the deliverable using one of the following codes:

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<sup>33</sup> Measured in months from the project start date (month 1).



## 1.4 Work package descriptions

<b>Work package number</b>	1					<b>Start date or starting event:</b>					Month 1 (m1)									
<b>Work package title</b>	Consortium management																			
<b>Activity type</b>	MGT																			
<b>Participant number</b>	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20
<b>Participant short name</b>	TUW	TUG	UniMiB	UniTN	UoS	ULANC	UL	ITU	RU		ESEL	MX	VR	Docobo						
<b>Person-months per participant</b>	53	2	2	2	2	2	2	2	1		1,5	1	0,5	1						

### Objectives

The management workpackage contains all work to set-up and to run the various management activities within the project. It also contains all administrative tasks within the consortium and the European Commission. The objectives of WP1 are to:

- Plan, manage, coordinate and control the project activities, focusing on success criteria, risk minimisation and quality assurance
- Monitor and ensure that the related results are according to the project objectives
- Define early output and impact indicators and monitor them over the entire project duration
- Monitor and report project progress
- Ensure quality in project processes, results and deliverables
- Manage knowledge and Intellectual Property Rights (IPR) of the project outcomes

### Description of work

- T1.1: Establishing the management structures and bodies described in section 2 “Implementation” (m1-m2)
- T1.2: Establishing and running the communication and collaboration infrastructure for management and administration (m1-m3)
- T1.3: Management and administration of the project budget and related tasks (m1-m48)
- T1.4: Management and administration of the reporting to the commission (m6-m48)
- T1.5: Preparation and organisation of commission audit and review meetings (m5-m48)

### Deliverables

- D1.1: Project execution and quality assurance plan (m3)
- D1.2: 6-month interim activity and management report (m6)
- D1.3: Annual report / project progress report (as required by the Commission) (m12)
- D1.4: 18-month interim activity and management report (m18)
- D1.5: Evaluation summary report for Phase I (m18)
- D1.6: Annual report / project progress report (m24)
- D1.7: 30-month interim activity and management report (m30)
- D1.8: Annual report / project progress report (m36)
- D1.9: 42-month interim activity and management report (m42)
- D1.10: Annual report / project progress report (m48)

<b>Work package number</b>	2				<b>Start date or starting event:</b>										Month 1 (m1)					
<b>Work package title</b>	<b>Dissemination and exploitation</b>																			
<b>Activity type</b>	OTHER																			
<b>Participant number</b>	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20
<b>Participant short name</b>	TUW	TUG	UniMiB	UniTN	UoS	ULANC	UL	ITU	RU	CoST	ESEL	MX	VR	Docobo	GPI					
<b>Person-months per participant</b>	8	4	4	24	3	3	3	4	4	4	4	4	2	2	8					

### Objectives

The objectives of this workpackage are

- To identify and organise the activities needed for promoting and disseminating the outcome of the SPHERE project to relevant research communities and other audiences and to ensure that the result will have maximal impact - this includes managing participation at events, promotional activities for dissemination, preparation of the dissemination material (flyers, brochures, posters, web site) and coordination of communication with external organisation, SIGs, networks, conferences and workshops;
- To prepare a business plan addressing joint exploitation by the consortium partners with the aim to enable its industrial partners to extend their portfolios of solutions implementing an innovative disease management methodology featuring participative collaboration; expressive, visual scenes based monitoring; and patient emotions awareness;
- To define and implement a methodology addressing standard and interoperability issues in using SPHERE service and systems, and the monitoring of standards that are relevant to the development of SPHERE
- To design and organise training activities that reach out to end-users, PhD students and other audiences.

### Description of work

- T2.1: **Definition of dissemination and exploitation plan** (m1-m6)
- T2.1.1: Design of website and logo, development of media plan for SPHERE
- T2.1.2: Design of business plan, analysis of market trends and potential competitors
- T2.1.3: Design of methodology for addressing issues of standards and interoperability within SPHERE
- T2.2: **Build SPHERE community** (m6-m12)
- T2.2.1: Identify relevant actors and include them in media plan
- T2.1.2: Design and organise first set of training activities as part of showcases
- T2.3: **First implementation of dissemination and exploitation plan** (m12-m24)
- T2.3.1: Encourage and support publication activity and participation in academic events
- T2.3.2: Define SPHERE products and services, carry out preliminary financial analysis and design first business model
- T2.3.3: Collect relevant information on standards
- T2.3.4: Design and organise second set of training activities as part of showcases
- T2.4: **Evaluation of dissemination and exploitation plan and improvements** (m22-m24)
- T2.4.2: Evaluate academic dissemination activities and efficiency of media plan and make improvements
- T2.4.3: Evaluate business plan and make improvements
- T2.5: **Intensify dissemination and exploitation activities** (m25-m36)
- T2.5.1: Encourage and support publication activity and participation in academic events
- T2.5.2: Organise first SPHERE workshop with international participation
- T2.5.3: Organise training (tutorials) for researchers and PhD students as part of relevant conferences
- T2.5.4: Establish and manage of the SPHERE Groups of Interest
- T2.5.5: Develop strategy to generate input to standard bodies
- T2.6: **Rounding off dissemination and exploitation activities** (m37-m48)

- |         |  |
|---------|--|
| T2.6.1: | Encourage and support further publication activity and participation in academic events                |
| T2.6.2: | Organise second SPHERE workshop with international participation                                       |
| T2.6.3: | Organise further training (tutorials) for researchers and PhD students as part of relevant conferences |
| T2.6.4: | Organise seminar for government health policy/strategy people and clinicians about SPHERE approach     |
| T2.6.5: | Organise SPHERE award  |
| T2.6.6: | Organise input to standard bodies  |
| T2.6.7: | Create SPHERE related spin-off and/or strengthen SPHERE Groups of Interest                             |

<b>Deliverables</b>
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- |       |   |
|-------|---|
| D2.1: | Dissemination and exploitation plan for SPHERE (m12)  |
| D2.2: | Report on first round of dissemination and exploitation activities and improved plans (m24)     |
| D2.3: | Report on intensified dissemination and exploitation activities, including special events (m36) |
| D2.4: | Final report on dissemination and exploitation activities, including special events (m48)       |

<b>Work package number</b>	3					<b>Start date or starting event:</b>					Month 1 (m1)									
<b>Work package title</b>	Quality framework																			
<b>Activity type</b>	RTD																			
<b>Participant number</b>	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20
<b>Participant short name</b>	TUW	TUG	UniMiB	UniTN	UoS	ULANC	UL	ITU	RU	CoST										
<b>Person-months per participant</b>	24	2	2	8	2	4	2	10	4	3										

### Objectives

The objective of this workpackage is to define qualities of an integrated care environment for the chronically ill and patients at risk, in ways that effectively orient technology development across showcases and technical workpackages; to operationalise the call objectives and to ensure that all actors are committed to them. Ethics will be a central research issue. WP3 will:

- Define the SPHERE quality framework on the basis of intense ethnographic fieldwork and evaluate and consolidate it in cooperation with the showcases;
- Develop operational design principles, on the basis of the framework, that will be applied in technology development and social/clinical practice design, and in evaluating the developed solutions.

### Description of work

- T3.1: Definition of quality framework and first scenarios of use in support of technology development on the basis of findings from initial ethnographic fieldwork in the showcases (m1-m6)
- T3.2: Consolidation of framework and development of second set of scenarios of use in cooperation with showcases, as well as WP5, WP6, WP7, WP8 and WP9 (m7-m12)
- T3.3: Development of a set of design principles based on quality framework (m7-m12)
- T3.4: Internal training for consortium partners in using quality framework, design principles, and scenarios (m7-m18)
- T3.5: Translating the identified qualities of an integrated care environment into the SPHERE evaluation framework with intense cooperation with WP4 (m13-m24)
- T3.6: Preparing, observing and analysing field trials and the implications of the results for technology re-design in cooperation with WP5, WP6, WP7, WP8, WP9 and WP10 (m7-m42)
- T3.7: Construction of a set of vignettes (case descriptions) describing ethical issues identified in field trials and addressing these issues in focus groups that include all the stakeholders (m13-m48)

### Deliverables

- D3.1: First version of quality framework and scenarios of use (m6)
- D3.2: Consolidated quality framework with design principles and scenarios of use (m12)
- D3.3: Report on use of quality framework and on further development of design principles (m24)
- D3.4: Report on use of ethics vignettes as part of focus groups with stakeholders (m36)
- D3.5: Handbook with ethics vignettes and design principles for an integrated care environment (m48)

<b>Work package number</b>	<b>4</b>									<b>Start date or starting event:</b>					<b>Month 1 (m1)</b>					
<b>Work package title</b>	<b>Ongoing evaluation</b>																			
<b>Activity type</b>	<b>RTD</b>																			
<b>Participant number</b>	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20
<b>Participant short name</b>	TUW	TUG	UniMiB	UniTN	UoS	ULANC	UL	ITU	RU											
<b>Person-months per participant</b>	7	2	4	12	4	2	2	4	41											

### Objectives

The aim of WP4 is to evaluate each showcase with regard to the call objectives and SPHERE objectives, as operationalised as quality measures by the quality framework (WP3). The evaluation scheme will guide iterative development and the evaluation of the showcases.

### Description of work

Evaluations are carried out through qualitative ethnographic fieldwork and quantitative measurements and will be based on the concept of effects-driven IT development, providing a sustained focus on the effects to be achieved by users through their adoption and use of the technology. This includes identification and specification of the effects to be obtained by using the envisioned technologies. For each showcase effects related to the design principles defined in WP3 will be identified, specified and prioritised. Subsequently, the showcases will be evaluated with respect to their achievement of these effects. Evaluations include documenting the utility value of the showcase's technologies as experienced by patients, relatives, and informal carers through (possibly prolonged) use of the technical facilities in the patients' home.

- T4.1: Development of a comprehensive generic evaluation scheme that specifies the methodology to be used in the evaluation of the showcases. This task involves collaboration with WP3 with regard to the operationalisation of quality measures (criteria, indicators). (m1-m12)
- T4.2: Internal training and on-going facilitation of showcase participants with regard to the evaluation framework and effects-driven IT development. This task is done in collaboration with WP9 with regard to the development of approaches to social and clinical practice design. (m7-m42)
- T4.3: Specification and operationalisation of the generic evaluation scheme with each showcase, detailing the effects to be achieved and the methods for measuring the effects (m13-m18)
- T4.4: Development of a detailed plan for the evaluation of prototypes with each showcase (m30-m34)
- T4.5: Conduction of a longitudinal, real-world evaluation of prototypes relative to the specified effects documenting the utility value as experienced by patients, relatives, and informal carers with each showcase (m35-m48)

### Deliverables

- D4.1: Generic methodological evaluation framework (m12)
- D4.2: Specific evaluation framework for all showcases guiding the iterative development (m18)
- D4.3: Detailed evaluation plan for all showcases (m34)
- D4.4: Longitudinal, effects-driven and real-world evaluation of showcase prototype for all showcases (m48)

<b>Work package number</b>	<b>5</b>					<b>Start date or starting event:</b>					Month 1 (m1)									
<b>Work package title</b>	<b>Embedded, responsive multi-parametric monitoring</b>																			
<b>Activity type</b>	RTD																			
<b>Participant number</b>	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20
<b>Participant short name</b>	TUW	TUG	UniMiB			ULANC	UL				ESEL			Docobo	GPI					
<b>Person-months per participant</b>	3	16	9			49	28				5			12	6					

### Objectives

The overall aim of this workpackage is to embed unobtrusive and minimally invasive, multi-parametric monitoring of health, activity and environmental parameters in patients' home environments. The specific objectives are:

- Develop unobtrusive and minimally invasive methods for multi-parametric monitoring long periods of time to support analysis of histories, trends, and routines, and to facilitate novel forms of representation
- Develop control, awareness, 'sense-making', and configuration mechanisms that bring monitoring back into the control of patients
- Design novel devices that embed monitoring in interactive and engaging form factors for active participation of patients, incl. devices designed for recreational, tangible, and affective interaction

### Description of work

- T5.1: Identification of methodological approach for user-centred iterative technology development in cooperation with WP6, WP7 and WP8 (m1-m6)
- T5.2: Initial requirements analysis and concepts for responsive monitoring. Development of technology probes and mock-ups (isolated implementations) (m1-m12)
- T5.3: Iterative assessment of emerging sensing and monitoring technologies, feasibility testing and functional tests of components. Bottom-up provision of building blocks for monitoring (m7-m36)
- T5.4: Development of first working prototypes of sensors, monitoring devices, and data collection software. Liaison with WP6 and WP7 to design for integration with representation and coordination components. Lightweight integration in first core prototypes in coop. with WP8 for facilitation of integrated evaluation in showcases. (m13-m24)
- T5.5: Extension of concepts for responsive monitoring and improvement and refinement of hardware and software components. Full integration in Development Environment and with core services developed in WP8, for release of enriched showcases prototypes. (m25-m36)
- T5.6: Final improvements and extensions specifically to support experimental operation 'beyond the lab' over longer periods of time, and integration and deployment for summative evaluation. Drawing out of design guidelines pertaining to monitoring and sensing issues. (m37-m48)

### Deliverables

- D5.1: Initial methodological framework (m6)
- D5.2: Functional demonstrator of initial monitoring concepts (isolated implementation of probes and mock-ups) for use in showcases (m12)
- D5.3: Monitoring and data collection components integrated in first core showcase prototypes (m24)
- D5.4: Complete integration of monitoring components in the Development Environment (m36)
- D5.5: Final revision of monitoring hardware and software (m48)

<b>Work package Num</b>	<b>6</b>					<b>Start date or starting event:</b>					Month 1 (m1)									
<b>Work package title</b>	<b>Interactive representations and interaction design</b>																			
<b>Activity type</b>	RTD																			
<b>Participant number</b>	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20
<b>Participant short name</b>	TUW	TUG			UoS		UL			CoST	ESEL	MX	VR	Docobo	GPI					
<b>Person-months per participant</b>	25	48			11		20			6	5	8,8	8	11,8	6					

### Objectives

The objective of this work package is to develop a set of tools for creating interactive representations and visualisations of patient-specific data (in cooperation with WP5), as well as visualisations of (configurable) coordination mechanisms (cooperation with WP7). The tools must be adaptive to user, task and environment, in particular to various screen sizes ranging from a desktop workstation to a cell phone display, and they must be customisable to suit the needs and level of understanding of patient users as well as expert physicians or healthcare personnel. Apart from visual representations on screen, WP6 will also consider various forms of *ambient displays* and non-visual (e.g. aural) representations. We will:

- Employ modified versions of existing techniques (e.g. in visualisation, hierarchical methods and focus/context methods are paramount for the objectives at hand)
- Employ novel display and interaction metaphors
- Employ user interfaces, for efficient navigation of the data to support interactive representations
- Make it easy to collect patient specific data, which is not easily or reliably measurable with automatic sensors (e.g. emotions or moods)
- Develop tools in support of ‘closed feedback loops’ with experts (enabling remote communication through interactive representations)
- Combine these tools into a single framework, which will moreover be able to integrate the different hardware specifications from all the targeted showcases

### Description of work

- T6.1: Requirement analysis for representation infrastructure driven by the showcases. Identification of type, frequency, value range etc. of the collected data. Cooperation with WP5 and WP7 to determine how these data can be delivered, and what the operating conditions are. (m1-m6)
- T6.2: First concepts for visual and potentially ambient displays, to be tested with other technical partners and showcase participants. Isolated implementations and mock-ups of representation/interface techniques without real data. (m7-m12)
- T6.3: First limited, but working prototypes of representation/interface software for at least two of the showcases (m13-m18)
- T6.4: Iterative design/development involving end user participation, with the aim of the refinement of the interface (m19-m24)
- T6.5: Second major release of the representation/interface software, for all showcases (m25-m30)
- T6.6: Interactive design/development involving end user participation (m31-m36)
- T6.7: Third major release of the representation/interface software for the final testing (m37-m48)

### Deliverables

- D6.1: Initial functional demonstrator for use in showcases and report (m12)
- D6.2: First prototype and report (m24)
- D6.3: Improved prototype and report (m36)
- D6.4: Final prototype and report (m48)

<b>Work package Num</b>	7					<b>Start date or starting event:</b>					Month 1 (m1)									
<b>Work package title</b>	Inter-network coordination																			
<b>Activity type</b>	RTD																			
<b>Participant number</b>	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20
<b>Participant short name</b>	TUW		UniMib					ITU		CoST	ESEL	MX	VR		GPI					
<b>Person-months per participant</b>	20		65					20		18	7	11	3,5		24					

### Objectives

The objective of this WP is to define, following the qualities indicators defined in WP3, a computational support that helps the stakeholders acting in the different care trajectories related to chronic diseases and patients at risk, to define, smoothly use and flexibly adapt coordination mechanisms to improve their distributed cooperation according to the contingent needs. We will:

- Identify a set of coordination mechanisms supporting distributed care that can be integrated in a comprehensive executable coordination model in order to
- Construct a prototypical implementation of a set of interoperable functionalities supporting distributed coordination that will constitute a reference application for the distributed care domain
- Validation of the coordination model and interoperable functionalities within the showcases

### Description of work

- T7.1: Identification of methodological approach encompassing a set of methods, tools and standards in cooperation with WP3, WP5, WP6 and WP8. They will be adopted during the project to support participatory design and develop the coordination mechanisms identified in showcases (m1-m6)
- T7.2: Training for team members who will develop the reference technology for showcases (m1-m6)
- T7.3: Mock-ups implementation to be validated in the showcases involving identification of coordination mechanisms identified in the showcases to be taken as a test bed for the methodological framework and to transform their requirements into executable models (m4-m12)
- T7.4: Consolidation of the modelling approach and its application to all the coordination mechanisms progressively identified in the showcases in cooperation with WP3 and WP9 (m6-m24)
- T7.5: Isolated implementations of coordination mechanisms to be validated in the showcases by experimenting the development of test bed coordination mechanisms within the Development Environment in cooperation with WP8 (m6-m24)
- T7.6: Iteratively consolidation of the models of the coordination mechanisms according to the outcomes of the showcases activities and the outcomes of WP5, WP6 and WP9 (m6-m36)
- T7.7: Incremental validation of coordination mechanisms within the showcases through iteratively consolidation of the development of coordination mechanisms to be integrated into the Development Environment in cooperation with WP8 (m24-m36)
- T7.8: Integration and final validation of coordination mechanisms within the showcases through consolidation of their integration in the Development Environment and tuning of the methodological approach on the basis of the integration activity (m36-m48)

### Deliverables

- D7.1: Initial methodological framework (m6)
- D7.2: Consolidated modelling of the identified coordination mechanisms (m12)
- D7.3: 1<sup>st</sup> Version of integrated computational model of the identified coordination mechanisms (m24)
- D7.4: 1<sup>st</sup> Version of the integration of the developed coordination mechanisms into the SPHERE Development Environment (m36)
- D7.5: 2<sup>nd</sup> Version of integrated computational model of the identified coordination mechanisms (m36)
- D7.6: Final integration of coordination mechanisms into the SPHERE Development Environment (m48)
- D7.7: Final integrated computational model of the identified coordination mechanisms (m48)



<b>Work package number</b>	<b>8</b>					<b>Start date or starting event:</b>					Month 1 (m1)									
<b>Work package title</b>	<b>Development environment</b>																			
<b>Activity type</b>	RTD																			
<b>Participant number</b>	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20
<b>Participant short name</b>	TUW	TUG		JniTN		JLANC				CoST	ENG	MX	VR	Docobo						
<b>Person-months per participant</b>	22	4		4		4				28	21	2	3	2						

### Objectives

The objective of this WP is to design and implement a development environment that integrates software services, databases, sensors to support clinicians, patients and their informal carers performing distributed healthcare in a pervasive and distributed environment.

- To integrate various types of structured and unstructured data provided by sensors, medical equipments, monitoring devices etc. and users
- To develop core services responsible for processing and propagating healthcare data to relevant applications
- To provide and integrate applications and supporting tools for distributed healthcare
- To address concerns about security, privacy and confidentiality for healthcare data

### Description of work

- T8.1: Requirement analysis and design of the conceptual architecture of the environment (m1-m6)
- T8.2: Implementation of core services defined in T8.1 (m7-m42)
- T8.3: Implementation of customisable components atop which applications and supporting tools (T8.4) will be developed (m7-m42)
- T8.4: Integration of various applications and supporting tools that are built atop of customisable components (m7-m42)
- T8.5: Integration of various types of (multimedia) data and data extraction (m7-m42)
- T8.6: Development of solutions for security, confidentiality and privacy (m7-m42)
- T8.7: Integration of core services, applications and supporting tools into the development environment and integration of the environment into SPHERE Development Environment (m18-m48)

### Deliverables

- D8.1: Specification and design of SPHERE Development Environment (m6)
- D8.2: 1<sup>st</sup> Version of SPHERE Core Services (m12)
- D8.3: 1<sup>st</sup> Version of SPHERE Client Customisable Components (m18)
- D8.4: Techniques for data integration and extraction (m18)
- D8.5: 2<sup>nd</sup> Version of SPHERE Core Services (m36)
- D8.6: 2<sup>nd</sup> Version of SPHERE Client Customisable Components (m36)
- D8.7: Integrated SPHERE Development Environment (m36)
- D8.8: Final version of SPHERE Core Services (m42)
- D8.9: Final version of SPHERE Client Customisable Components (m42)
- D8.10: Final version of SPHERE Development Environment (m48)

<b>Work package number</b>	<b>9</b>							<b>Start date or starting event:</b>	Month 1 (m1)											
<b>Work package title</b>	<b>Social and clinical practice design</b>																			
<b>Activity type</b>	RTD																			
<b>Participant number</b>	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20
<b>Participant short name</b>	TUW		UniMiB	UniTN	UoS			ITU	RU											
<b>Person-months per participant</b>	16		20	32	23			28	8											

### Objectives

The objective of WP9 is to address the issue that the practices of formal and informal carers in various ways will change, and will have to change, in the appropriation of new technical facilities for monitoring, representation, coordination, etc. — and to do so systematically and accountably as an integral aspect of the overall design process. WP9 will develop an analytical and methodological scheme of social and clinical practice design based on the findings from the showcases.

### Description of work

The work of WP9 focuses on identifying and articulating the more or less explicit ordering principles and performance criteria underlying a given set of clinical or care-related practices and on uncovering its rationale, so as to be able to systematically develop and negotiate possibly alternative practices; crudely put, to determine what is essential and what is accidental in the given practice. WP9 will use findings from showcases as raw material for comparative analysis in order to develop a conceptual scheme.

- T9.1: Development of conceptual and methodological foundations of systematic practice design (m1-m6)
- T9.2: Comparative analysis of initial observations (m3-m12)
- T9.3: Document analysis and interviews to gain access to local, national and EU initiatives relevant for „Personal Health Systems for Monitoring”. This includes existing and planned strategies, systems, exchange standards and platforms that the IT-application and services as well as the social and clinical practices under consideration need to take into account in order to be interoperable. (m1-m12)
- T9.4: Initial comparative analysis of experimental findings from showcases (m13-m24)
- T9.5: Comparative analysis of experimental findings from showcases, with a particular focus on social and clinical practices spanning the interaction within heterogeneous networks. (m25-m36)
- T9.6: Assessment of the experiences gained from the showcases. This task will produce a consolidated conceptual framework of social and clinical practice design. (m37-m48)

### Deliverables

- D9.1: ‘Bootstrap’ conceptual and methodological scheme for social and clinical practice design (m6)
- D9.2: Initial comparative analysis of clinical practices and guidelines for clinical practice designs, including report on local/national, and EU initiatives relevant for Personal Health Systems for Monitoring (m12)
- D9.3: Updated comparative analysis of clinical practices and guidelines for experimental social and clinical practice designs (m24)
- D9.4: Second updated comparative analysis of social and clinical practices (m36)
- D9.5: Conceptual and methodological scheme for social and clinical practice design (m48)

<b>Work package Num</b>	<b>10</b>					<b>Start date or starting event:</b>					Month 1 (m1)									
<b>Work package title</b>	<b>Experimental Stage – SPHERE Showcases</b>																			
<b>Activity type</b>	RTD																			
<b>Participant number</b>	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20
<b>Participant short name</b>	TUW		UniMB	UniTN	UoS		UL	ITU												
<b>Person-months per participant</b>	4		4	4	20		4	4												

**Objectives:** This WP takes an overall concern for the set-up and running of the various showcase activities within the project to ensure integration and coordination across showcases and with related workpackages. The objectives of WP10 are to: a) define the overall approach the showcases will take throughout the project phases; b) plan, manage, and coordinate showcase activities, focusing on cross-showcase (within WP10) sharing of data, and integration with other workpackages; c) monitor and report showcase progress.

**Description of work:** Each showcase will use participatory user centred methods, including intensive ethnographic fieldwork at the locations where care and daily life happen. Each showcase will work with as many participants (patients and informal and formal care networks) as practical in the fieldwork and with at least 10 participants in more focussed design explorations, deployments and evaluations. While taking a holistic case-centric view at the local level, each showcase will also contribute to the overall SPHERE approach by taking a primary concern for a particular technical workpackage at the project level (WP5, WP6, WP7, WP8). Each showcase will also contribute to, and apply the outputs from, non-technical workpackages around qualities (WP3), ongoing evaluation (WP4), and social and clinical practice design (WP9). This necessitates an approach of sharing and integration of information across adult and child showcases to produce a Focus Area Report for a relevant technical workpackage, as well as holding workshops with all relevant workpackages to share findings and to ground work. All tasks will be led by UoS in collaboration with the individual showcases – involving partners TUW, UniMB, UniTN, UL, ITU.

- T10.1: Agreement on fieldwork approach and definition of mechanisms for sharing findings across-adult and across-child showcases (m1-m2)
- T10.2: Organisation of internal fieldwork dissemination workshop with WP3, WP4, WP8 and WP9 (all showcases) (m5-m6)
- T10.3: Organisation of internal fieldwork dissemination focus area workshops (WP5 with UoS and ITU, WP6 with UL and TUW, WP7 with UniTN and UniMiB) (m5-m6)
- T10.4: Organisation of cross-workpackage workshops (with new focus area partners) (m5-m6)
- T10.5: Facilitation of cross-showcase comparisons for contrasts/commonalities and organisation of cross-workpackage workshops (with partners as relevant) in preparation of **M3** (m6-m12)
- T10.6: Facilitation of cross-showcase comparisons for contrasts/commonalities and organisation of cross-workpackage workshops (with partners as relevant) in preparation of **M5** (m13-m24)
- T10.7: Facilitation of cross-showcase comparisons for contrasts/commonalities and organisation of cross-workpackage workshops (with partners as relevant) in preparation of **M7** (m25-m36)
- T10.8: Facilitation of cross-showcase comparisons for contrasts and commonalities and integration of findings across final showcase deployments in preparation of **M8** (m37-m48)

#### **Deliverables**

- D10.1: Overall showcase execution plan (m6)
- D10.2: Summary report of key issues across showcases arising from fieldwork (m12)
- D10.3: Summary report of key issues across showcases arising from initial prototyping evaluations (m24)
- D10.4: Summary report of key issues across showcases arising from integration deployments and initial evaluations (m36)
- D10.5: Final report of key issues across integrated showcase evaluations (m48)

<b>Work package number</b>	<b>10.1</b>					<b>Start date or starting event:</b>					Month 2 (m2)									
<b>Work package title</b>	<b>Showcase 1: Cardiac Disease – Monitoring for patients with pacemakers or ICDs</b>																			
<b>Activity type</b>	RTD																			
<b>Participant number</b>	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20
<b>Participant short name</b>						ULANC		ITU	RU		ESEL			Docobo						RH
<b>Person-months per participant</b>						8		24	2		1			4						24

### Objectives

This showcase focuses primarily on monitoring for cardiac patients with pacemakers or ICDs. The approach will be based on non/minimal-invasive, multi-parametric monitoring of patients and their ICDs, and for how this data is interpreted and made sense of to enable individualised expert feed-back meant to increase the participation of the patients in their own recovery processes. Subsequent incremental integration will involve coordination mechanisms and then representation.

- To study and understand the needs and issues around cardiac care for patients with pacemakers/ICDs, their families and informal care network as well as healthcare professionals through local hospitals and GP clinics, paying particular attention to needs and opportunities for personal health monitoring around physiological and lifestyle parameters;
- To collate requirements for personal health monitoring devices for adults, and participate in the co-design of monitoring prototypes in collaboration with WP5 and (child) Showcase 6: a) from the patient's perspective, to provide devices that are easy to wear and/or use and that can be acceptably integrated into their everyday life; b) from the clinicians' perspectives, to monitor the right parameters at the right level of granularity and frequency to support clinical management and responsiveness
- To contribute to the requirements and iterative design of representation, interaction and coordination applications, as well as to quality and evaluation frameworks and social and clinical work practice design
- To deploy and evaluate monitoring applications and devices, incrementally adding and evaluating representation, interaction and coordination mechanisms.

### Description of work

- T10.1.1: Conduct of fieldwork around patients with pacemakers/ICDs (m2-m3)  
T10.1.2: Collation of monitoring needs across adults' showcases (m4-m5)  
T10.1.3: Definition of initial requirements for monitoring applications and devices in cardiac and stroke care (m6-m10)  
T10.1.4: Deployment of monitoring applications and devices for patients with pacemakers/ICDs (m6-m44)  
T10.1.5: Evaluation of and feedback to monitoring applications and devices in form of fieldwork (m6-m44)  
T10.1.6: Local adaptation and incremental deployment of representations, interaction and coordination mechanisms (m6-m44)  
T10.1.7: Evaluation of and feedback to integrated platform in form of fieldwork (m45-m46)

### Deliverables

- D10.1.1: Focus Area Report on requirements for monitoring applications and devices in cardiac care, plus stroke care (m10)  
D10.1.2: Focus Area Report on evaluation of monitoring applications and devices (m22)  
D10.1.3: Focus Area Report on evaluation of monitoring applications integrated with representations, interaction and coordination mechanisms (m34)  
D10.1.4: Focus Area Report on summative evaluation of cardiac (pacemaker/ICDs) integrated showcase platform (m46)

<b>Work package number</b>	<b>10.2</b>				<b>Start date or starting event:</b>										Month 2 (m2)					
<b>Work package title</b>	<b>Showcase 2: Cardiac Disease – Coordination of Congestive Heart Failure (CHF) management</b>																			
<b>Activity type</b>	RTD																			
<b>Participant number</b>	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20
<b>Participant short name</b>				UniTN					RU	CoST	ESEL				GPI			APSS		
<b>Person-months per participant</b>				28,4					2	8,4	1				18			24		

### Objectives

This showcase focuses primarily on coordination of the management of patients with Congestive Heart Failure (CHF), supporting the accountability and participation of all involved actors through adherence to guidelines. Subsequent incremental integration will involve representations and then monitoring.

- To study and understand the needs and issues around cardiac care for CHF: a) understanding the network of caregivers involved in the therapy of CHF (physicians, specialists, patients, families, service providers) and their mutually accountable roles; b) develop new support for coordination between the actors involved in networked care
- To collate requirements for coordination mechanisms for adult disease management, and participate in the co-design of coordination mechanism prototypes in collaboration with WP7 and (child) Showcase 4: a) from the patient's perspective, to provide coordination mechanisms that are easy to use and acceptably configurable; b) from the clinicians' perspectives, to capture assistance paths that improve appropriateness and harmonisation of organisational assets with epidemiologic and clinical priorities through configurable and interactive mechanisms
- To contribute to the requirements and iterative design of monitoring, and representation and interaction mechanisms, as well as to quality and evaluation frameworks and social and clinical work practice design
- To deploy and evaluate coordination mechanisms, incrementally adding and evaluating representation and interaction mechanisms and then monitoring devices.

### Description of work

- T10.2.1: Conduct of fieldwork for CHF management (m2-m3)
- T10.2.2: Collation of coordination needs across adults' showcases (m4-m5)
- T10.2.3: Definition of initial requirements for coordination mechanisms in cardiac care and stroke care (m6-m10)
- T10.2.4: Deployment of coordination mechanisms for CHF care network (m6-m44)
- T10.2.5: Evaluation of and feedback to coordination mechanisms in form of fieldwork (m6-m44)
- T10.2.6: Local adaptation and incremental deployment of monitoring, representation and interaction applications (m6-m44)
- T10.2.7: Evaluation of and feedback to integrated platform in form of fieldwork (m45-m46)

### Deliverables

- D10.2.1: Focus Area Report on requirements for coordination mechanisms in cardiac care, integrating requirements for stroke care (m10)
- D10.2.2: Focus Area Report on evaluation of coordination mechanisms (m22)
- D10.2.3: Focus Area Report on evaluation of coordination mechanisms integrated with monitoring, representation and interaction applications and devices (m34)
- D10.2.4: Focus Area Report on summative evaluation of cardiac (CHF) integrated showcase platform (m46)

<b>Work package number</b>	10.3					<b>Start date or starting event:</b>					Month 2 (m2)									
<b>Work package title</b>	<b>Showcase 3: Stroke rehabilitation – Representations for motivation and engagement</b>																			
<b>Activity type</b>	RTD																			
<b>Participant number</b>	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20
<b>Participant short name</b>		TUG					UL		RU		ESEL	MX	VR							
<b>Person-months per participant</b>		7					18		2		1	5	3							

### Objectives

This showcase focuses primarily on interactive representations, interaction design and novel interfaces to motivate engagement in stroke rehabilitation therapy making use of innovative sensor-based devices. Subsequent incremental integration will involve monitoring and then coordination mechanisms.

- To study and understand the needs and issues around stroke rehabilitation for a) enabling physiotherapists to articulate their domain expertise through technology in order to facilitate the patient's recovery strategy; b) enabling the patient to continue prescribed exercises at home with immediate feedback and increased motivation; c) enabling the data from the patient's work at home to be available to the physiotherapist for analysis and to monitor progress and modify exercises
- To collate requirements for interactive representations and novel interfaces for adults, and participate in the co-design of representation and interface prototypes in collaboration with WP6 and Showcase 5: a) from the patients' perspective, to provide representation environments that are easy to use and acceptably configurable; b) from the clinicians' perspectives, to represent the right parameters at the right level of granularity and frequency to support clinical management by enabling configurable and interactive interfaces
- To contribute to the requirements and iterative design of monitoring and coordination applications, as well as to quality and evaluation frameworks and social and clinical work practice design
- To deploy and evaluate representation applications and devices, incrementally adding and evaluating monitoring devices and coordination mechanisms

### Description of work

- T10.3.1: Conduct of fieldwork for stroke rehabilitation (m2-m3)  
T10.3.2: Collation of representation and interaction needs across adults' showcases (m4-m5)  
T10.3.3: Definition of initial requirements for representation and interaction applications in stroke and cardiac care (m6-m10)  
T10.3.4: Deployment of representation and interaction applications and devices (m6-m44)  
T10.3.5: Evaluation of and feedback to representation and interaction applications and devices in form of fieldwork (m6-m44)  
T10.3.6: Local adaptation and incremental deployment of monitoring applications and devices and coordination mechanisms (m6-m44)  
T10.3.7: Evaluation of and feedback to integrated platform in form of fieldwork (m45-m46)

### Deliverables

- D10.3.1: Focus Area Report on requirements for representation and interaction applications and devices in stroke rehabilitation, integrating requirements for cardiac care (m10)  
D10.3.2: Focus Area Report on evaluation of representation and interaction applications and devices (m22)  
D10.3.3: Focus Area Report on evaluation of representation and interaction applications integrated with monitoring applications and devices and coordination mechanisms (m34)  
D10.3.4: Focus Area Report on summative evaluation of stroke rehabilitation integrated showcase platform (m46)

<b>Work package number</b>	<b>10.4</b>		<b>Start date or starting event:</b>													Month 2 (m2)				
<b>Work package title</b>	<b>Showcase 4: Cornelia De Lange Syndrome (CDLS) – Coordination of disease management</b>																			
<b>Activity type</b>	RTD																			
<b>Participant number</b>	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20
<b>Participant short name</b>			UniMiB						RU	CoST	ESEL				GPI		PoliMi			
<b>Person-months per participant</b>			36						2	15	1				12		24			

### Objectives

This showcase focuses primarily on coordination for Cornelia De Lange Syndrome (CDLS) management and early diagnosis of problems. Subsequent incremental integration will involve monitoring and then representation and interaction mechanisms.

- To study and understand the needs and issues around CDLS for: a) reinforcing the network of care supporting patients of rare diseases with complex communication needs; b) Supporting a family-centered approach to patients care by establishing and fostering network relationships and participation of relatives; c) developing new support to coordination between the actors involved in networked care (clinicians of various disciplines, therapists, educationists, psychologists, patients and their relatives)
- To collate requirements for coordination mechanisms for children, and participate in the co-design of coordination mechanism prototypes in collaboration with WP7 and Showcase 2: a) from the child's and parent's perspective, to provide coordination mechanisms that are easy to use and acceptably configurable; b) from the clinicians' perspectives, to represent the right parameters at the right level of granularity and frequency to support coordination work in clinical management by enabling configurable and interactive interfaces
- To contribute to the requirements and iterative design of monitoring and representation and interaction mechanisms, as well as to quality and evaluation frameworks and social and clinical work practice design
- To deploy and evaluate coordination mechanisms, incrementally adding and evaluating monitoring devices and representation and interaction mechanisms

### Description of work

- T10.4.1: Conduct of fieldwork for CDLS treatment (m2-m3)  
T10.4.2: Collation of coordination needs across children's showcases (m4-m5)  
T10.4.3: Definition of initial requirements for coordination mechanisms in CDLS and CF care (m6-m10)  
T10.4.4: Deployment of coordination mechanisms for the extended CDLS care network (m6-m44)  
T10.4.5: Evaluation of and feedback to coordination mechanisms in form of fieldwork (m6-m44)  
T10.4.6: Local adaptation and incremental deployment of monitoring, representation and interaction applications and devices (m6-m44)  
T10.4.7: Evaluation of and feedback to integrated platform in form of fieldwork (m45-m46)

### Deliverables

- D10.4.1: Focus Area Report on requirements for coordination mechanisms in CSDL care, integrating requirements for CF (m10)  
D10.4.2: Focus Area Report on evaluation of coordination mechanisms (m22)  
D10.4.3: Focus Area Report on evaluation of coordination mechanisms integrated with monitoring, representation and interaction applications and devices (m34)  
D10.4.4: Focus Area Report on summative evaluation of CSDL integrated showcase platform (m46)

<b>Work package Num</b>	<b>10.5</b>										<b>Start date or starting event:</b>					Month 2 (m2)				
<b>Work package title</b>	<b>Showcase 5: Cystic Fibrosis – Interactive representations and novel interfaces for CF care</b>																			
<b>Activity type</b>	RTD																			
<b>Participant number</b>	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20
<b>Participant short name</b>	TUW	TUG							RU		ESEL	MX	VR			MUW				
<b>Person-months per participant</b>	24	10							2		1	4	3			24				

### Objectives

This showcase focuses primarily on interactive representations, interaction design and novel interfaces for Cystic Fibrosis (CF) management and early diagnosis of problems. Challenges arise from diverse representation needs for children, parents and clinicians, and covering expressive as well as clinical information. Subsequent incremental integration will involve coordination mechanisms and then monitoring.

- To study the lived experience of CF and understand the needs and issues around CF for child patients (of different ages), parents and other family members, CF clinicians and teachers, paying particular attention to needs for interactive representations of patient-specific data and novel interfaces for different stakeholders
- To collate requirements for interactive representations and novel interfaces for children, and participate in the co-design of representation and interface prototypes in collaboration with WP6 and Showcase 3: a) from the child's and parent's perspective, to provide representation environments that are easy to use and acceptably configurable; b) from the clinicians' perspectives, to represent the right parameters at the right level of granularity and frequency to support clinical management by enabling configurable and interactive interfaces
- To contribute to the requirements and iterative design of coordination and monitoring applications, as well as to quality and evaluation frameworks and social and clinical work practice design
- To deploy and evaluate representation applications and devices, incrementally adding and evaluating coordination mechanisms and monitoring devices

### Description of work

- T10.5.1: Conduct of fieldwork around living with CF and CF treatment (m2-m3)  
T10.5.2: Collation of representation and interaction needs across children's showcases (m4-m5)  
T10.5.3: Definition of initial requirements for representation & interaction applications in CF & CDLS care (m6-m10)  
T10.5.4: Deployment of representation & interaction appl. & devices for CF management (m6-m44)  
T10.5.5: Evaluation of and feedback to representation and interaction applications and devices in form of fieldwork (m6-m44)  
T10.5.6: Local adaptation and incremental deployment of coordination mechanisms and monitoring applications and devices (m6-m44)  
T10.5.7: Evaluation of and feedback to integrated platform in form of fieldwork (m45-m46)

### Deliverables

- D10.5.1: Focus Area Report on requirements for representation and interaction applications and devices in CF care, integrating requirements for CDLS (m10)  
D10.5.2: Focus Area Report on evaluation of representation and interaction applications and devices (m22)  
D10.5.3: Focus Area Report on evaluation of representation and interaction applications integrated with coordination mechanisms and monitoring applications and devices (m34)  
D10.5.4: Focus Area Report on summative evaluation of CF integrated showcase platform (m46)



<b>Work package Num</b>	<b>10.6</b>					<b>Start date or starting event:</b>					Month 2 (m2)									
<b>Work package title</b>	<b>Showcase 6: Cystic Fibrosis – Monitoring physiological and lifestyle parameters</b>																			
<b>Activity type</b>	RTD																			
<b>Participant number</b>	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20
<b>Participant short name</b>	TUW				UoS	ULANC			RU		ESEL			Docobo					BSUH	
<b>Person-months per participant</b>	3				29	10			2		1			14					24	

### Objectives

This showcase focuses primarily on monitoring mechanisms for Cystic Fibrosis (CF) management and early diagnosis of problems. The approach will seek to address the challenges of needing to design for children from birth to becoming teenagers responsible for their own care. Subsequent incremental integration will involve representations to help motivate children and parents, and coordination mechanisms to manage the extended care network.

- To study the lived experience of CF and understand the needs and issues around CF for child patients (of different ages), parents and other family members, clinicians and teachers, paying particular attention to personal health monitoring needs and opportunities around physiological (respiratory, digestive, medication) and lifestyle (nutrition, exercise)
- To collate requirements for personal health monitoring devices for children, and participate in the co-design of monitoring prototypes in collaboration with WP5 and (Adult) Showcase 1: a) from the child's and parent's perspective, to provide devices that are easy to wear and/or use and that can be acceptably integrated into their everyday life; b) from the clinicians' perspectives, to monitor the right parameters at the right level of granularity and frequency to support clinical management over the child's lifetime
- To contribute to the requirements and iterative design of representation, interaction and coordination applications, as well as to quality and evaluation frameworks and social and clinical work practice design
- To deploy and evaluate monitoring applications and devices, incrementally adding and evaluating representation, interaction and coordination mechanisms

### Description of work

- T10.6.1: Conduct of fieldwork around living with CF and CF treatment (m2-m3)
- T10.6.2: Collation of monitoring needs across children's showcases (m4-m5)
- T10.6.3: Definition of initial requirements for monitoring applications and devices in CF and CDLS care (m6-m10)
- T10.6.4: Deployment of monitoring applications and devices for CF management (m6-m44)
- T10.6.5: Evaluation of and feedback to monitoring applications and devices in form of fieldwork (m6-m44)
- T10.6.6: Local adaptation and incremental deployment of representations, interaction and coordination mechanisms (m6-m44)
- T10.6.7: Evaluation of and feedback to integrated platform in form of fieldwork (m45-m46)

### Deliverables

- D10.6.1: Focus Area Report on requirements for monitoring applications and devices in CF care, integrating requirements for CDLS (m10)
- D10.6.2: Focus Area Report on evaluation of monitoring applications and devices (m22)
- D10.6.3: Focus Area Report on evaluation of monitoring applications integrated with representations, interaction and coordination mechanisms (m34)
- D10.6.4: Focus Area Report on summative evaluation of CF integrated showcase platform (m46)

Table 1.3d **Summary of staff effort**

Partic. no.	Partic. short name	WP 1	WP 2	WP 3	WP 4	WP 5	WP 6	WP 7	WP 8	WP 9	WP 10	WP 10.1	WP 10.2	WP 10.3	WP 10.4	WP 10.5	WP 10.6	Total person month
<b>1</b>	<b>TUW</b>	<b>53</b>	8	<b>24</b>	7	3	25	20	22	16	4					<b>24</b>	3	<b>207</b>
<b>2</b>	<b>TUG</b>	2	4	2	2	16	<b>48</b>		4				7	<b>36</b>	10			<b>95</b>
<b>3</b>	<b>UniMiB</b>	2	4	2	4	9		<b>65</b>		20	4							<b>146</b>
<b>4</b>	<b>UniTN</b>	2	<b>24</b>	8	12				4	32	4		<b>28,4</b>					<b>114,4</b>
<b>5</b>	<b>UoS</b>	2	3	2	4		11			23	<b>20</b>						<b>29</b>	<b>94</b>
<b>6</b>	<b>ULANC</b>	2	3	4	2	<b>49</b>			4			8					10	<b>82</b>
<b>7</b>	<b>UL</b>	2	3	2	2	28	20				4			<b>18</b>				<b>79</b>
<b>8</b>	<b>ITU</b>	2	4	10	4			20		<b>28</b>	4	<b>24</b>						<b>96</b>
<b>9</b>	<b>RU</b>	1	4	4	<b>41</b>					8		2	2	2	2	2	2	<b>70</b>
<b>10</b>	<b>CoST</b>		4	3			6	18	28				8,4		15			<b>82,3</b>
<b>11</b>	<b>ESEL</b>	1,5	4			5	5	7	<b>21</b>			1	1	1	1	1	1	<b>49,5</b>
<b>12</b>	<b>MX</b>	1	4				8,8	11	2					5		4		<b>35,5</b>
<b>13</b>	<b>VR</b>	0,5	2				8	3,5	3					3		3		<b>23</b>
<b>14</b>	<b>Docobo</b>	1	2			12	11,8		2			4					14	<b>36,6</b>
<b>15</b>	<b>GPI</b>		8			6	6	24					18		12			<b>74</b>
<b>16</b>	<b>MUW</b>															24		<b>24</b>
<b>17</b>	<b>PoliMi</b>														24			<b>24</b>
<b>18</b>	<b>APSS</b>												24					<b>24</b>
<b>19</b>	<b>BSUH</b>																24	<b>24</b>
<b>20</b>	<b>RH</b>											24						<b>24</b>
<b>Total</b>		<b>70</b>	<b>81</b>	<b>61</b>	<b>78</b>	<b>128</b>	<b>149</b>	<b>168,5</b>	<b>90</b>	<b>127</b>	<b>40</b>	<b>63</b>	<b>81,8</b>	<b>36</b>	<b>90</b>	<b>68</b>	<b>73</b>	<b>1404,3</b>

Table 1.3e: **Template - List of milestones**

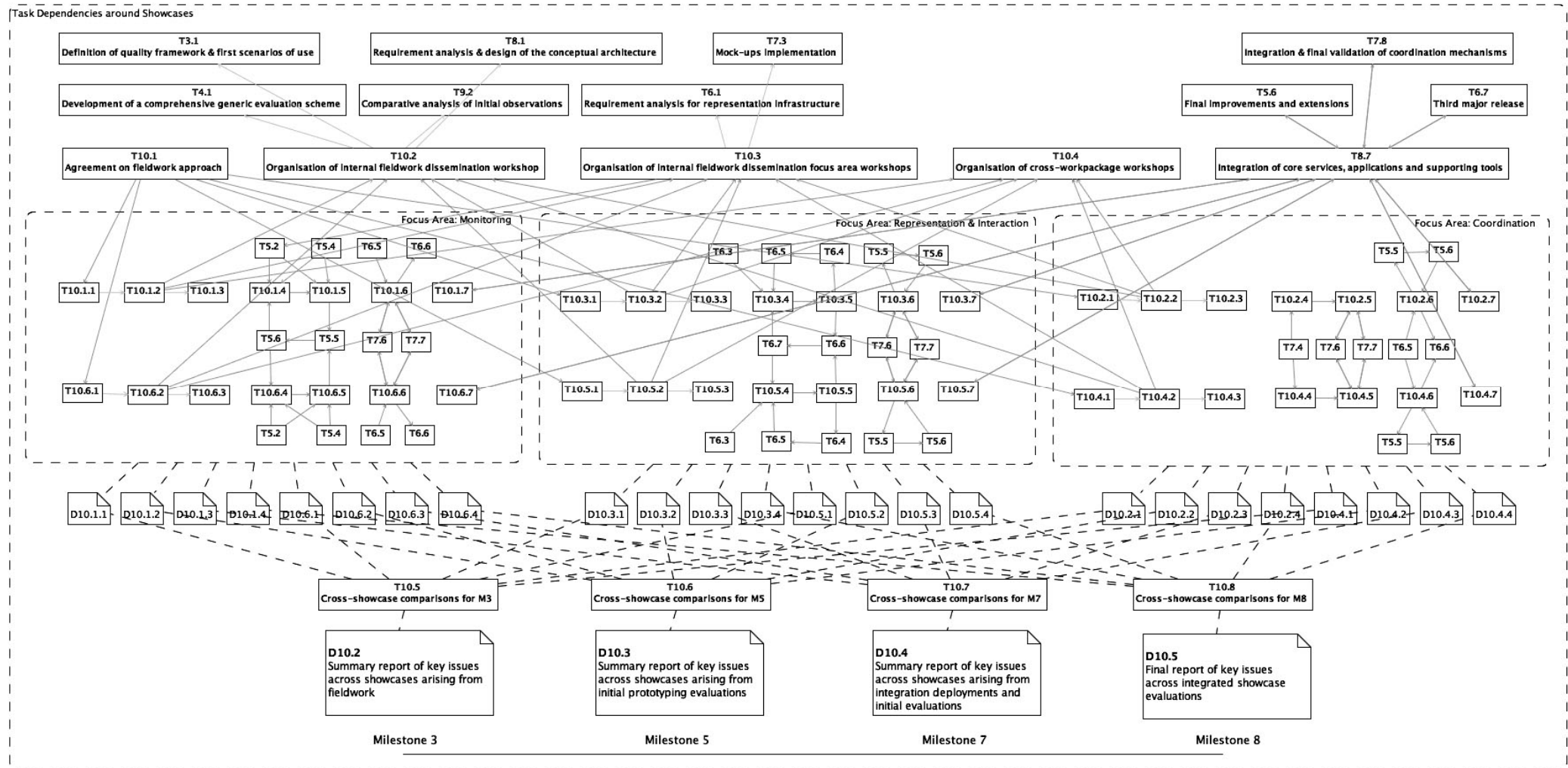
Milestones are control points where decisions are needed with regard to the next stage of the project. For example, a milestone may occur when a major result has been achieved, if its successful attainment is a required for the next phase of work. Another example would be a point when the consortium must decide which of several technologies to adopt for further development.

<b>Milestone number</b>	<b>Milestone name</b>	<b>Work package(s) involved</b>	<b>Expected date</b> <sup>34</sup>	<b>Means of verification</b> <sup>35</sup>
M1	SPHERE Kick-off	All	Month 1	
M2	Identification of initial framework for SPHERE	WP1, WP3, WP5, WP7, WP8, WP9, WP10	Month 6	D1.2, D3.1, D5.1, D7.1, D8.1, D9.1, D10.1
M3	First release of SPHERE approach	WP1, WP2, WP3, WP4, WP5, WP6, WP7, WP8, WP9, WP10	Month 12	D1.3, D2.1, D3.2, D4.1, D5.2, D6.1, D7.2, D8.2, D9.2, D10.2
M4	Specific evaluation plan for showcases	WP1, WP4, WP8	Month 18	D1.4, D1.5, D4.2, D8.3, D8.4
M5	Second release of SPHERE approach	WP1, WP2, Wp3, WP5, WP6, WP7, WP9, WP10	Month 24	D1.6, D2.2, D3.3, D5.3, D6.2, D7.3, D9.3, D10.3
M6	Detailed evaluation plan for showcases	WP4	Month 34	D4.3
M7	Third release of SPHERE approach	WP1, WP2, WP3, WP5, WP6, WP7, WP8, WP9, WP10	Month 36	D1.8, D2.3, D3.4, D5.4, D6.3, D7.4, D7.5, D8.5, D8.6, D8.7, D9.4, D10.4
M8	Release of validated SPHERE approach	WP1, WP2, WP3, WP4, WP5, WP6, WP7, WP8, WP9, WP10	Month 48	D1.10, D2.4, D3.5, D5.5, D4.4, D6.4, D7.6, D7.7, D8.10, D9.5, D10.5

<sup>34</sup> Measured in months from the project start date (month 1).

<sup>35</sup> Show how both the participants and the Commission can check that the milestone has been attained. Refer to indicators if appropriate.

Fig. 4: Task dependencies around SPHERE Showcases

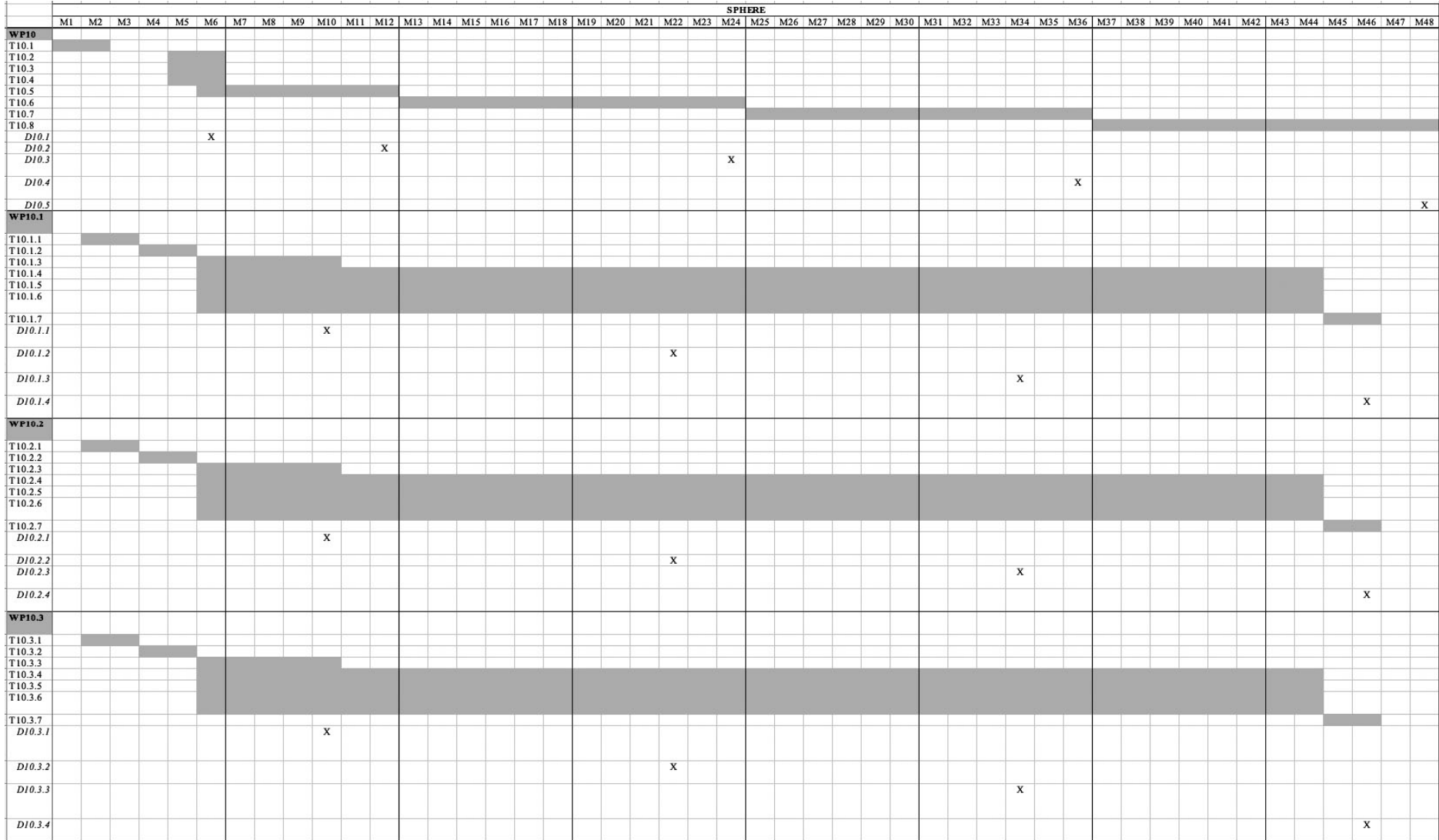


SPHERE Gantt chart – Part 1 (WP1-WP5)

	SPHERE																																																											
	M1	M2	M3	M4	M5	M6	M7	M8	M9	M10	M11	M12	M13	M14	M15	M16	M17	M18	M19	M20	M21	M22	M23	M24	M25	M26	M27	M28	M29	M30	M31	M32	M33	M34	M35	M36	M37	M38	M39	M40	M41	M42	M43	M44	M45	M46	M47	M48												
<b>WP1</b>																																																												
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T1.2																																																												
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D3.3																											X																																	
D3.4																																																												
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SPHERE Gantt chart – Part 3 (WP10-WP10.3)



SPHERE Gantt chart – Part 4 (WP10.4-WP10.6)

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## **2 Section 2: Implementation**

### **2.1 Management structure and procedures**

In this section the management structure and procedures including risk management, different boards and roles in SPHERE, general meetings, communication and collaboration issues and Intellectual Property Rights (IPR) management are described.

The SPHERE project has 10 workpackages and 20 partners. To support integration of the different workpackages, specific directors have been nominated. TUW is the coordinating partner and Ina Wagner of TUW is the Project Director.

Management activities are subdivided into two workpackages, the consortium management Roles and Responsibilities

#### ***Project Director***

The Project Director is responsible for the overall coordination and running of the project. Her duties include strategic and formal management and administrative functions of the project. The Management Board will assist the Project Manager.

#### ***Administrative and Financial Director***

The Administrative and Financial Director will be nominated by the coordinator. The responsibilities of this function are to:

- Receive the entire financial contribution from the Commission. S/he will manage this contribution by allocating it to the Contractors pursuant to the Work Plan and the decisions taken by the appropriate bodies
- Prepare annual accounts
- Provide overall administrative and financial management of the co-ordination
- Keep track of budgets.

#### ***Scientific Project Director***

The Scientific Project Director leads the Scientific Board. S/he must not be the Project Director and is responsible for the scientific excellence and achievements of the project, and the dissemination of the project results. The Scientific Project Director will be nominated during the project kick-off meeting.

#### ***Showcase Integrator***

The task of the Showcase Integrator, who will be appointed at the kick-off meeting, is the management of the showcases, in particular the coordination of showcase activities and the integration of results in summary reports.

#### ***Industry Coordinator***

The task of the Industry Coordinator, who will be appointed at the kick-off meeting, is to support integration of industrial partners in overall R&D effort and to coordinate exploitation plans.

#### ***Technology Integrator***

The task of the Technology Integrator, who will be appointed at the kick-off meeting, is to support alignment of R&D across technical WPs.

#### ***Ethical Advisor***

The task of the Ethical Advisor is to ensure the non-infringement of ethical rules. S/he should be independent, i.e. not directly involved in the SPHERE research activities. This is why this task will be subcontracted (see 2.3.i). His/her responsibilities will be to monitor and assess the following:

- Possible objections against the nature of research raised, e.g. surveillance by machines
- Data protection and privacy of users
- Respect of a code of conduct to be followed by the partners
- Compliance with the existing ethical national and international guidelines for ethics
- State of ethical knowledge among partners, and, in particular, to what extent the consortium members are already sensitive to ethical issues emerging from the development of emotion-oriented systems.

The Ethical Advisor will be aligned with the Showcase Integrator and he/she will be able to control that the progress in the implementation of the showcases will be compliant to the ethical national and international regulations.

The Ethical Advisor will also be in charge of ensuring that ethical issues are included and managed as potential risks. This includes the approach to risk management, including risk identification and analysis, risk mitigation and contingency planning.

#### ***Clinical Advisor***

The main task of the Clinical Advisor, who will be appointed at the kick-off meeting, is to ensure clinical relevance of showcase activities in cooperation with the participating clinicians. S/he will also contribute to the evaluation plans from the clinical perspective.

#### ***Work Package Teams and Work Package Leaders***

Work Package Teams are composed of participants involved in carrying out the work of the relevant workpackage. The workpackage leaders co-ordinate the tasks within their sector of activity, integrate the work of the partners, control and update planning of the tasks, organise thematic meetings as appropriate, and co-ordinate work with other workpackages and stimulate scientific and technical exchange within their workpackage. They report to the Project Director.

The Work package leader's role, which assumes significant project management tasks, is to:

- Drive the implementation of the workpackage and ensure it is reaching its planned milestones and deliverables on time
- Make suggestions on the allocation of workpackage tasks, financial needs and work allocation among the Contractors
- Identify Contractors presenting financial or technical risks within a workpackage, try to find a solution, and inform the Project Director
- Inform the Project Director of any other difficulty arising in connection with the conduct of the workpackage.

#### ***Quality Management***

Quality management (QM) is under the responsibility of TUW. A specific QM System, to be defined D4.1.1 Quality Plan, will be deployed across all project tasks, spanning all activities and involving all partners. This will ensure that there are clear and common views on quality standards, procedures, records and indicators.

### **2.1.1 Boards and Responsibilities**

Within SPHERE, three different boards handle the main management activities:

- The Executive Board
- The Management Board
- The Scientific Board

#### ***The Executive Board***

The Executive Board of the project is responsible for achieving the project objectives by ensuring the integration of the individual tasks and the cooperation of the individual project partners beyond the scope of the individual workpackages. The Executive Board is chaired by the Project Director. Further members are the individual workpackage leaders of currently active workpackages. Work package leaders of showcase workpackages will remain in the Executive Board until all issues regarding this showcase have been finished (which may extend for a certain time beyond the life-time of the particular showcase). On the other hand, if new showcases are initiated, the workpackage leaders for those should participate for a reasonable time even before the actual kick-off for their showcase.

The Executive Board is composed of the Project Director, all workpackage leaders, and Advisors.

The Executive Board will be established at the kick-off meeting of the project. Prior to this date, only the Management Board will exist. The Executive Board will exist beyond the lifetime of the project until all final deliverables and reports have been delivered, the final certificate on financial statements has been passed, and the European commission has accepted the final cost statement.

The Executive Board will be responsible for all issues required to successfully execute the project.

This includes the following tasks:

- Develop the project handbook defining
  - A quality plan including mechanisms for the submission of deliverables, the procedures for the internal deliverable review process, the formats for reports and deliverables
  - Procedures on the preparation, frequency, hosting, and holding of the general project assemblies
- Surveying and enforcing the regulations of the project handbook
- Monitoring the progress within the individual workpackages (including showcases) in relation to the project milestones
- Monitoring the progress and on time delivery of the individual workpackage deliverables
- Monitoring the application of the regulations in the Consortium Agreement and initiating a management board meeting upon violations or problems
- Managing EC certificates on financial statements and adapt the overall project plan according to the reviewer's recommendations
- Managing public presentations at fairs, conferences, or European events in conjunction with the Scientific Board
- Having at least one personal meeting in conjunction with each general project assembly and regular monthly telephone and/or Internet meetings

### ***The Management Board***

While the Executive Board is focused on the operational aspects, the Management Board is formed to handle contractual issues. For this reason the Administrative and Finance Director as well as a representative of each project partner is member of the Management Board. The Project Director chairs the Management Board.

The Management Board is the only management structure, which will exist prior to the start of the project. Initially it will be responsible to prepare and approve the Consortium Agreement. The Consortium Agreement will include the legal frame of the project (partners' rights, duties and formal regulations), handling of intellectual property rights (IPR issues).

Consequently the Management Board will meet to handle violations of the Consortium Agreement as well as additions or changes to the agreement.

The Management Board will assist the coordinator in negotiating the contract with the EC, by providing the appropriate material and participating in negotiation meetings if necessary.

The Management Board will meet at least once a year. Additional meetings will be scheduled

- Upon request from the Executive Board or the Project Director
- Whenever project partners join or leave the project consortium
- For managing issues related to the Consortium Agreement (especially IPR issues)
- For negotiating contracts with third parties
- For negotiating and approving changes to the contract with the EC

### ***The Scientific Board***

The Scientific Board has two major tasks: It is responsible for the scientific excellence and achievements of the project, and the dissemination of the project results. The board will consist of five members, drawn from its senior scientists, who will be elected annually by the management board.

The Scientific Project Director, which must not be the Project Director, chairs the Scientific Board,

The Scientific Board will be constituted and established at the project kick-off meeting. The Project Director will inform the Scientific Board regarding the overall progress and other management issues, which may be relevant.

The Scientific Board is responsible for the following tasks

- Modifying the list of research topics within the individual research workpackages
- Coordinating the strategic objectives of the project
- Establishing internal project reviews
  - Reviewing of the showcase workpackages
  - Defining the critical success factors for each workpackage in the next project phase
  - Appointing internal reviewers for deliverables and reports

- Establishing liaisons with related European projects (FP7), national projects, and research organisations (within and outside of Europe).

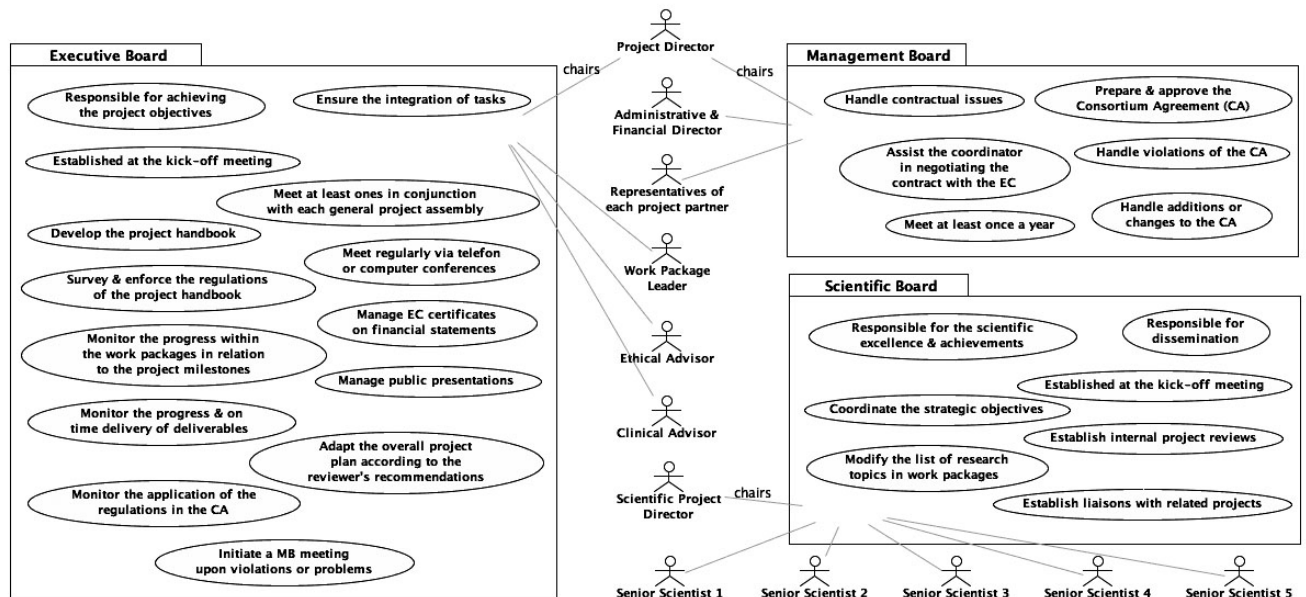


Fig. 5: SPHERE management structure

## 2.1.2 Consortium Agreement

The project organisational structure and decision-making mechanisms of SPHERE are formalised in a Consortium Agreement, which all partners will sign before the start of the project. It includes the following elements that are directly relevant to the management of the project:

- The internal organisation of the consortium, its governance structure, decision-making processes and management arrangements
- IPR regulations (see 3.2.5)
- Arrangements for the distribution of the community contribution among participants and among activities
- Provisions for the settlement of disputes within the partnership

## 2.1.3 General Meetings

In general, meetings will be coordinated so as to reduce travel costs and supplemented by electronic conference tools or phone meetings.

### *Kick-off meeting*

The kick-off meeting will be a four-day meeting hosted by the coordinator. Attendants are all people at the individual project partners involved in the SPHERE project: researchers, developers, designers, managers and administrative people. The kick-off meeting will consist of a series of tutorials and workshops. Within the tutorials the individual technological project partners will present their baseline technologies to the showcase participants so that they get a good understanding of the technologies already available and ready to use; this will also be a starting point for discussing necessary adaptations. Each showcase will have a workshop on the content and goals of the showcase and the initial analysis of the required (technological) components. The Executive Board will meet to take basic general management decisions as well as the specific work plan for the first year. The Scientific Board will be established; and the Showcase Integrator, the Technology Integrator, the Industry Coordinator, the Ethical Advisor, and the Clinical Advisor will be appointed.

### *Project assemblies*

The project will hold general project assemblies approximately every four months. The main objective of these meetings is to monitor the progress of R&D activities and cross-workpackage cooperation.

For this purpose different focus area workshops, cross-workpackage and intra-workpackage workshops will be organized. At each general project assembly an Executive Board meeting and a Scientific Board meeting will be held (see below).

### ***Project workshops***

SPHERE distinguishes between different kinds of workshops:

- *In focus area workshops* showcase partners will collaborate with their focus area technical WP in preparing mock-ups/prototypes for field trials
- *Cross-workpackage workshops* will support integration of technologies and methodologies across technical workpackages and showcases.
- *Intra-workpackage workshops* will ensure integration of development effort and analysis.

### ***Executive board meetings***

The Executive Board will meet at a regular basis at each project assembly and additionally monthly by electronic conference tools or phone meetings. In each meeting the workpackage leaders will report their progress and problems, and necessary adaptations of the work plan will be discussed and decided.

### ***Scientific board meetings***

Similar to the Executive Board, the Scientific Board will meet at each project assembly and, if required, by phone meetings. It will discuss the project progress and advise the Executive Board on necessary changes.

### ***Management board meetings***

The Management Board will meet during the project negotiation period, in order to prepare the negotiations and to agree on the Technical Annex of the project as well as on the Consortium Agreement. It will meet during and after the lifetime of the project if requested by the Executive Board or in case of consortium changes. It will further meet at least once a year to approve the changes and amendments to the contract with the EC for the following working period.

## **2.1.4 Communication and Collaboration Issues**

In order to make communication and collaboration between the individual project partners efficient and easy, a series of services will be set-up. This includes a number of email lists for the individual boards, the overall project, project administration, and the individual workpackages. The TUW infrastructure will provide this service to all project partners.

For simplifying the exchange of documents, to plan meetings and to assemble deliveries, a BSCW shared workspace server and workspace will be hosted and made available to all project partners. This Internet-based shared workspace system, which has already been used successfully to assemble the SPHERE proposal and has been used in a large number of EC funded projects throughout Europe, will also provide the project officer and other EC representatives access to deliverables and other relevant project material. The shared workspace will be hosted by TUW.

## **2.1.5 IPR Management**

In general the SPHERE Management Board will handle all IPR issues. The Management Board is also responsible for defining appropriate IPR regulations to become part of the Consortium Agreement (see 3.2.5). The Management Board will handle new issues arising during the lifetime of the project and not already covered by the Consortium Agreement as well. This proceeding also applies in case any other uncertainties or conflicts about the regulations in the Consortium Agreement occur.

## **2.1.6 Risk Assessment and Control**

Risk assessment is an integral part of the SPHERE management process. The management will identify those factors that are critical to the success of the project and control them. The diagram below shows the main features, which foresees two stages, namely, Risk Assessment and Risk Control:

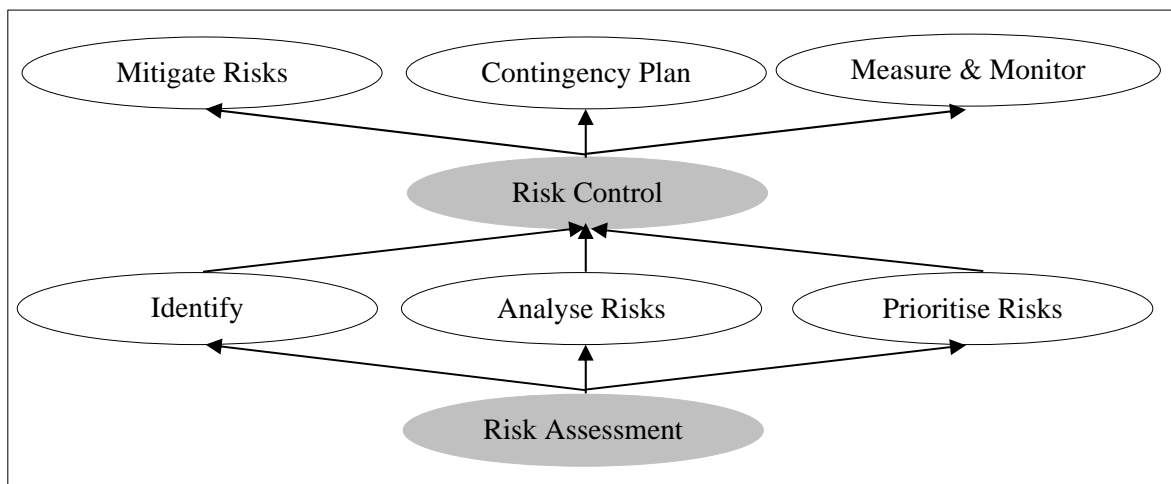


Fig. 6: Risk Management

Risk Assessment can take place at any time during the project. It allows the Executive Board to:

- Explore the entire project plans and identify areas of uncertainty;
- Analyse how those areas of uncertainty can impact the performance of the project, either in duration, cost or meeting the users' requirements;
- Prioritise risks, so as to establish which risks should be eliminated completely (because of potential extreme impact), which should have regular management attention, and which are sufficiently minor to avoid detailed management attention.

Risk Control also has three tasks, as follows:

- Take whatever actions are possible in advance to reduce the effect of risk. It is better to spend money on mitigation than to include contingency in the plan.
- For all those risks which are deemed to be significant, have a contingency plan in place before it happens;
- Measure, monitor and track the effects of the risks identified and manage them to a successful conclusion.

Three kinds of risk will be monitored in SPHERE:

- Management Risk
- Technological Risk - specific risks of the planned R&D activities have already been defined in 1.3.2
- Ethical-legal risks – here the Ethical Advisor will be involved.

As the project develops, the Executive Board will decide which other risks need to be managed, such as market-dependent risks.

Table 2.1.a: Management Risks

<b>Risk description</b>	<b>Evaluation</b>	<b>Resolution</b>
Consortium is too numerous to be easily co-ordinated.	Impact High, Probability Low Should this problem occur, its impact on the project would be significant. However the probability of occurrence is low due to the background of experience in such projects by almost all partners.	The designated Project Director has great experience in co-ordinating research projects. Nevertheless the Management Board is defined to be as representative as possible, maintaining the correct efficiency and operability.
Consortium has no harmony.	Impact High, Probability Low There are many reasons to believe that harmony will be the core of consortium, ranging from personal friendships to company	Previous experience within single partners has been very positive and should be maintained at consortium level. Whole project assemblies and workshops will be held regularly to ensure that good

<b>Risk description</b>	<b>Evaluation</b>	<b>Resolution</b>
	alliances and recent experiences between partners.	communications are established between partners. Electronic, audio and video environments will be used to facilitate continuous communication and cooperation in the consortium.
Too many diverging objectives.	Impact High, Probability Medium The SPHERE management structure has been specifically designed to minimise this risk.	The Executive Board has been especially setup to avoid and manage this kind of risk. It will stress the integrated nature of the project and push the different technical partners to follow the specified directives and focus on workpackage objectives.
One of the major project partners will drop out of the consortium (for various reasons including bankruptcy or liquidation).	Impact High, Probability Medium This results in a situation, where a specific technology can no longer be developed or a particular showcase may not have sufficient resources to be finished as planned.	Regarding the research workpackages the consortium is very strong in the central components, thus the work of this partner could with a reasonable additional effort be covered by other project partners in a way, which will allow the showcases depending on this technology to continue their work. For some highly specialised research topics, the particular partner may not be easily replaced. As a fallback solution, alternative less ambitious technology could be used within the showcases. If this will happen in an early project phase, alternative project partners are available to fill in the gap. In case a major participant of a showcase drops out, this is much less problematic for the project, as it affects the particular showcase only. Depending on the phase of the project, the showcases may be stopped, re-focused, or significantly modified, and optionally an alternative showcase may be defined according to the recommendations of the Scientific Board. This however is a mechanism, which will be applied to the showcases anyway, thus there is no specific additional risk.
A project partner does not contribute to the project according to the work plan.	<i>Impact High, Probability Medium</i> This may lead to significant delays of workpackages or the public demonstrations of showcases and may also result in problems regarding the provision of deliverables to the commission in time.	Due to the overall management structure and the regular progress reports provided by the members of the Executive Board this risk can be minimised as the Management Board will become aware of such a situation within a rather short time period. It may then decide to demand additional regular progress reports from that particular project partner. In case a project partner further faults its obligations under the contract or these faults even cause the withholding of payments by the commission, the Management Board will decide on this issue according to the specific regulations within the Consortium Agreement, which may result in a reduction of the participant's share of the overall project grant or even an exclusion of the specific project partner. Based upon the judgement of the Scientific Board the share of that project partner may be covered by one or several other project partners or if this is not possible, a competitive call may be issued.

Table 2.1.b: Technological Risks

<b>Risk description</b>	<b>Evaluation</b>	<b>Resolution</b>
Technical problems arise during SPHERE development.	<i>Impact Medium, Probability Low</i> Modules could be developed independently by the various partners, without a detailed discussion about their functionality according to the specification document.	The design phase of the project will be led by partners who have significant experience in user-centred design. The system architecture is designed in the light of maximum flexibility to simplify the integration of all technologies available. A first step in the integration phase is foreseen for performing a preliminary integration of some fundamental components and for discussing and evaluating problems.
The complexity of integration compromises system performance.	<i>Impact High, Probability Low</i> The complexity that could arise from the architecture may be a problem. The implementation of the base technology needs to be effective to give an effective response to users.	The experience of the technical partners is essential to solve this problem. Great attention will be given to the proposed solutions and to the base technology that has been used.
The showcases are not of interest to the market.	<i>Impact High, Probability Low</i> The showcases are key in showing that the SPHERE approach is providing true innovation.	The highly qualified partnership will perform continuous technology watch to identify changes in the market.

Table 2.1.c: Ethical-legal risks

<b>Risk description</b>	<b>Evaluation</b>	<b>Resolution</b>
There are risks connected with providing patients with new types of minimally invasive monitoring technologies.	<i>Impact high, Probability low</i>	Partners providing monitoring technologies have to perform a risk assessment and/or demonstrate the safety of their devices.
Another type of risk is connected with the possibility of people other than carers and patients having access to sensitive data.		All persons involved in the field trials have to sign a confidentiality agreement.
Patients may misunderstand or react with fear to some of the situations/information created in field trials.		Clinicians, patients and their families will be involved from the beginning in the project, hence they will be given an opportunity to fully understand the set-up and interventions, have an influence on them, and eventually withdraw.



## 2.2 Individual participants

**Vienna University of Technology (TUW), Multidisciplinary Design Group (mDG) and Distributed Systems Group (DSG), Coordinator, Leader of WP3 and WP10.5**

[www.media.tuwien.ac.at](http://www.media.tuwien.ac.at) , [www.infosys.tuwien.ac.at](http://www.infosys.tuwien.ac.at)

The Multidisciplinary Design Group (MDG), Institute for Technology Design and Assessment at TUW, is characterised by a methodological commitment to participatory design and to situated experimentation with prototype solutions in different media. Main research areas are interaction design and innovative, multimodal interfaces, design research, design methods, CSCW, qualitative methods, as well as gender studies and ethics. MDG performs research in areas as diverse as health care, architecture and urban planning, e-learning, innovative organisations and communities, as well as everyday life. MDG has played a key role in bringing awareness of the implications of information technology for the practice and quality of health care within hospitals to CSCW and HCI.

The Distributed Systems Group (DSG) of the Information Systems Institute at TUW conducts teaching and research in distributed computing with particular emphasis on software architectures, software components and services, and programming languages and paradigms for distributed systems. In the distributed services area, the focus is on development methodologies for software services, worldwide web applications, mobile and ubiquitous collaborative computing, context-aware and autonomic computing and security for distributed (Internet) applications, especially in enterprise computing.

### **Projects**

- The Multidisciplinary Design Group's most recent involvement in health care is as a research partner and consortium member in project Action for Health, financed by the Canadian Social Sciences Research Council (2003-2007). It also acted as a subcontractor for conducting a continuous ethical review in QLRT-2001-00458 Project Friendly Restrooms for Elderly People (2002-2005). Further recent projects of MDG are: IST-2001-34520 Project WWW-ICT (2002-2004); IST-2001-33064 ATELIER (2001-2004); and IST 27571 IPCity (Integrated Project) (2006-2010).
- Recent projects of the Distributed Systems Group are: COST-11-TER (Formal Description Techniques); ISA (Integrated Systems Architecture); ISO-ODP (Open Distributed Processing), inContext (FP6 IST 034718) for context-aware computing and WORKPAD (FP6-2005-IST-5-034749) for complex process adaptation in disaster situations.

### **Key researchers**

**Ina Wagner** is Professor for Multidisciplinary Systems Design and Computer-Supported Co-operative Work (CSCW) and Head of the Institute for Technology Assessment and Design. She has edited and written numerous books and authored over 100 papers on a variety of technology-related issues, amongst them computer-support of hospital work and of architectural design and planning, CSCW and networking, a feminist perspective in science and technology, ethical and political issues in systems design. From 1997 - 2000 she was member of the European Group on Ethics in Science and New Technologies. She is member of the Austrian Bioethics Committee since 2001. She recently joined IST-34800 CALLAS as ethical expert.

**Hilda Tellioglu** is a computer scientist and Assistant Professor at the Institute of Design and Assessment of Technology. She has been involved in research on modelling techniques in software engineering, methodologies for coordination and system design, data security and integrity in databases, gender issues in computer science.

**Schahram Dustdar** is Professor of Computer Science with a focus on Internet Technologies at the Distributed Systems Group, Information Systems Institute, of TUW where he is director of the Vita Lab and Honorary Professor of Information Systems at the Department of Computing Science at the University of Groningen (RuG), The Netherlands.

**Hong-Linh Truong** currently is a post-doctoral research scientist at Distributed Systems Group, Information Systems Institute, Vienna University of Technology (TU Vienna). His research interests focus on performance monitoring and analysis techniques and tools, P2P and Grid computing, Internet technologies, middleware, collaborative computing, workflow systems, and autonomic computing.

**Graz University of Technology, Institute for Computer Graphics and Vision, Leader of WP6**

[www.icg.tu-graz.ac.at](http://www.icg.tu-graz.ac.at)

The Institute of Computer Graphics and Vision (ICG) at Graz University of Technology is the only Austrian academic group with the ability to address both computer vision and computer graphics and is carefully nurturing a culture of digital visual information processing to resolve the artificial boundaries between computer graphics and computer vision. The research at ICG is focused on the following topics: Computer graphics, medical computer vision, object reconstruction and recognition, robotics, virtual reality and augmented reality. The research group of Prof. Schmalstieg focuses on computer graphics and interactive systems.

**Projects**

- **Genopticum:** Visual Data Mining for Genetic Data. A joint project with Graz Medical University. (Funded by FIT-IT Visual Computing, 2007)
- **IPCity** ([www.ipcity.eu](http://www.ipcity.eu)): An EU Integrated Project for the development of mobile AR technology to support presence and participation of ordinary people in urban reconstruction procedures and urban events.
- **GenView:** Analysis of Genetical and Clinical Data with Information Visualisation and Multimodal User Interfaces" (Funded by Zukunftsfonds Steiermark, 2005)
- **ARISER** ([ariser.info](http://ariser.info)): An EU MRTN project for the development of Augmented Reality support during minimally invasive surgery. (European Union MRTN-CT-2004-512400, 2004)
- **Virtual Liver Surgery Planning** is addressing obstacles associated with surgical planning of planning liver tumor resections based on CT image data. [www.icg.tu-graz.ac.at/research/interdisciplinary/liverplanner](http://www.icg.tu-graz.ac.at/research/interdisciplinary/liverplanner)

**Key researchers**

**Dieter Schmalstieg** is professor of virtual reality and computer graphics. He is author and co-author of more than 100 peer-reviewed scientific publications and serves the scientific community in a number of functions: Among others, he was the organising chair of the 1999 Eurographics Workshop on Virtual Environments and general chair (2002) as well as programme chair (2003 and 2006) of the International Symposium on Mixed and Augmented Reality ISMAR, the field's most prestigious conference. He is a member of the scientific advisory board of the VRVis Research Center in Vienna, is in the editorial advisory board of "Computers & Graphics" and in numerous programme committees. In 2002, he received the FWF START award. His current research focuses on virtual reality, augmented reality, ubiquitous computing and information visualisation.

**Ernst Kruijff** is Senior Researcher at the Institute for Computer Graphics and Vision at the Graz University of Technology, and is an expert in the field of spatial user interfaces. His research focuses at the investigation, design and development of 3D user interfaces, aural and haptic interfaces. He is the author of the standard book on three-dimensional user interfaces, "3D User Interfaces – Theory and Practice" (Addison-Wesley, 2004). He holds a Dr. techn. degree from Graz University of Technology and Master's degree from Utrecht University, Netherlands. Previously to his occupation in Graz, he was a researcher at the Fraunhofer Institute of Media Communication (St. Augustin, Germany) and at Bauhaus University (Weimar, Germany).

**University of Milano-Bicocca, Complex Systems and Artificial Intelligence Research Center,  
Leader of WP7 and WP10.4**

[www.disco.unimib.it](http://www.disco.unimib.it)

The Complex Systems and Artificial Intelligence (CSAI) Research Center belongs to the University of Milano-Bicocca and is hosted by the Department of Informatics, System and Communication (DISCo). CSAI uses the administrative structure of DISCo, which has a long experience in managing multi-partners projects at national and international levels. CSAI was recently founded by professors with the aim to aggregate their competences and research experiences in knowledge representation, support of coordination, innovative interaction and medical knowledge management. This makes CSAI a multidisciplinary scientific institution open to research projects characterised by the application of advanced computer science methods and techniques for the solution of real complex problems, mainly involving the interaction among knowledge workers mediated by ICT technologies.

**Projects**

- **SWIRLS** (Supporting Wards with Interactive Resources and Logic-Based Systems) is a three years project in cooperation with a hospital in Lombardia. It aims at supporting hospital ward practitioners in coordinating their caring activities without disrupting the habitual practices they have established within their work. The main contribution of SWIRLS is a technological and architectural solution that augments the natural interaction with pre-printed paper-based forms and the context-adaptively of situated whiteboards. [www.mac.disco.unimib.it](http://www.mac.disco.unimib.it)
- **MAIS** (multichannel Adaptive Information Systems) project is a three year project funded by Basic Research Funds (FIRB Program) of the Italian Department of Education (MIUR). The MAIS project main research goal was to provide a flexible environment to adapt the interaction and provided information and services according to ever changing requirements, execution contexts, and user needs. [black.elet.polimi.it/mais/index.php](http://black.elet.polimi.it/mais/index.php)
- **WEB-mINDS** (Wide-scale, Broadband, Middleware for Network Distributed Services) is a three year project funded by Basic Research Funds (FIRB Program) of the Italian Department of Education (MIUR). The main goal of the project was developing a platform for ubiquitous remote access, multimedia communications, service customisation. [web-minds.conorzio-cini.it/](http://web-minds.conorzio-cini.it/)

**Key researchers**

**Carla Simone** is Full Professor in Computer Science and director of the Models and Architecture for Coordination Laboratory at DISCo. After completing her Master Degree in mathematics she spent the first part of her career in programming languages design, theory of concurrent processes and business process modelling. Since the '90 she has authored over 50 papers on computer supported cooperative work (CSCW) modelling approaches, knowledge management and the user centred development of CSCW systems. She participated, among others, in the EU funded research projects ESPRIT-BRA (COMIC) Computer based mechanisms of interaction in cooperative work (#6225) (1992-1995); ESPRIT RTD (CAWICOMS) Customer-Adaptive Web Interface for the Configuration of Products and Services with Multiple Suppliers (#10688) (2000-2002). She has been involved in a national "Equal Opportunity" project founded by ITALTEL. She is member of the Advisory Board of the CSCW International Journal.

**Alessandra Agostini** holds a MSc. in Information Science from the University of Milan. She is Associate Professor at the DISCO Department of the University of Milano Bicocca, Italy. Her main research interests are: CSCW, ubiquitous and mobile computing, adaptive Workflow Management Systems, and community ware. She has been project manager, as coordinating partner, of the Esprit LTR Project, # 25572, Campiello, (September 1997 - August 2000). She participated to various EU funded research projects on themes related to her research interests among which: MILK (multimedia Interaction for Learning and Knowing, IST 2001-33165); COMIC (Computer-based Mechanisms of Interaction in Cooperative work, ESPRIT BRA Project, # 6225); Esprit ITHACA Project, # 2705.

**University of Trento, Social Studies of Information Systems Laboratory; Leader of WP2 and WP10.2**

[www4.soc.unitn.it:8080/dsrs/content/e1896/index\\_ita.html](http://www4.soc.unitn.it:8080/dsrs/content/e1896/index_ita.html)

The Social Studies of Information Systems Laboratory (LS3I) is part of the Department of Sociology and Social Research of the University of Trento, with about 20 members of academic and professional staff specialises in the social study of information systems. It has been active for over twenty years in EU, national and industry-financed research and development projects on the following topics: Social Practice Design, Participatory Design, Distribution of Design Responsibilities to Stakeholders, Participatory Design Augmented Business Process Reengineering, End User Tailoring, Information Systems Design leveraging relations, interactions and embodiment, System Design for Change using Frameworks and Reusable Components, Enterprise Innovation Support Systems, Organisation, Deployment and Use of Web Services, Community Systems, Computer-Supported Knowing and Learning, Reflective Training, Participatory eLearning, Problem-Based Learning and Cooperative Learning.

**Projects**

- **“e-Hearth Failure”**, research project of the Autonomous Province of Trento, 2005-2006: A guideline-based shared care through a computer-based cooperative system for the management of heart failure. Despite of tremendous advances in our understanding of the path physiology of heart failure and the development of efficacious therapies, quality of care for patients with HF is suboptimal. Multi-disciplinary and multi-faced interventions may be the only way to deliver effective care in heart failure population. The general aim of the project is to design, develop and evaluate a computer-based cooperative work framework for supporting evidence-based multidisciplinary disease management of patients with heart failure.
- **MAPPER** “Model-based Adaptive Product and Process Engineering”, STREP Project, Contract no:016527, 2005-2008: In the knowledge age dynamic networked organisations will safely enable all stakeholders to be purposefully involved in manufacturing programs. Increased cooperation and collaboration among enterprises during the product lifecycle is a global demand. In line with this demand MAPPER contributes prototypes and other results towards the following vision for European manufacturing: In 2010, agile manufacturing companies can inexpensively form collaborative networks and quickly adapt to market demands.

**Key Researchers**

**Gianni Jacucci** is professor of Information Systems at the School of Sociology of the University of Trento. He coordinates the International PhD Programme in Information Systems and Organisations at the Department of Sociology and Social Research. He is the scientific coordinator of the L3SI. His research regards Participatory Design of IT use, and design for accountability and for user configurability. He leads activities of service and training for innovation in small enterprises and for local communities, including virtual enterprises, telematics for tourism, and IT support in health care and local public administrations.

**Vincenzo D'Andrea** is an associate professor at the University of Trento, where he teaches Information Systems at School of Sociology. His research interests are mainly located on the interface between the technological perspective and the sociological one. Recent topics of interest includes virtual communities, service oriented computing, free and open source licensing, participatory design. He has been involved in several national and international research projects and has published more than sixty papers in international conferences and journals.

**Gian Marco Campagnolo**, has a PhD in Information Systems & Organizations at the University of Trento, Department of Sociology and Social Research (2007), with a thesis on accountability in technology production. He has a Master in Ergonomics from University of Siena, Florence, ISPESL, INAIL, CNR (2003) and a Degree in Communication Science from University of Siena (2002). His main interest is the social approach to ERP, EA and Information Infrastructures and Social Practice Design. He is also responsible for local and European projects at the L3SI (Social Studies of Information Systems Laboratory).

**University of Sussex, Interact Lab, Human Centred Technology Group, Leader of WP10 and WP10.6**

[www.informatics.sussex.ac.uk/interact/index.htm](http://www.informatics.sussex.ac.uk/interact/index.htm)

The Interact Lab is part of the interdisciplinary Human Centred Technology (HCT) Group at the University of Sussex. Research is focused on how people interact with and communicate through technology. HCT currently holds a UK EPSRC Platform Grant in Human Centred Technology, awarded in recognition of its strength and international reputation in this area. Application areas include HCI, interaction design, and ubiquitous computing, with foci on healthcare/telecare, play and learning, technology in the home and support for elderly and disabled people. Research is grounded in theoretical constructs, and has a fundamental commitment to user-centred design and in-context fieldwork to understand needs. A common theme is exploring possibilities enabled by pervasive/ubiquitous sensors, wireless networks, tangible and handheld devices. HCT has significant facilities to support research including a newly refurbished lab and a highly configurable pod vehicle for field work and in-situ studies.

**Projects**

- **Equator** ([www.equator.ac.uk](http://www.equator.ac.uk)): a seven-year Interdisciplinary Research Collaboration (IRC) focussed on the integration of physical and digital interaction through the application of emerging wireless and sensor-based technologies (funded by UK EPSRC 2000-2007).
- **Technologies to support self care** ([www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_4134006](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4134006)): a research project for the UK Dept of Health surveying research evidence for self-care technologies (funded by UK Dept of Health 2006).
- **Motivating Mobility**: Interactive Systems to Promote Physical Activity and Leisure for People with Limited Mobility, focussing on post-stroke rehabilitation; cross disciplinary collaboration with physiotherapists, technologists and user-centred designers (funded by UK EPSRC, to start June 2007-2009)

**Key researchers**

**Geraldine Fitzpatrick** is Director of the Interact Lab and Senior Lecturer in Human Centred Technology. She has a diverse clinical and technical background. She holds a BInfTech and PhD in CompSci & ElecEng from Queensland University. She has worked in industry as a user experience consultant. She has extensive fieldwork and user study experience. And she has extensive clinical experience working as a nurse in community and hospital settings. Her interests are in the design of innovative applications that enhance quality of life and fit in with spatial, social and interactional contexts. She has over 50 publications in CSCW, health informatics, UCD, pervasive computing, etc. Foci include telemedicine evaluations, studies of paper health records and community health care, self care technologies surveys, ubiquitous technologies in the home, and innovative applications for elderly people.

**Eric Harris** (mSc in Robotics) is a research fellow in the Interact Lab. He works on the Equator project where he designs and builds devices and installations, which support new forms of human computer interaction. Eric comes from an industrial background of robotics and machine vision where he filled both technical and operations director positions within a blue chip packaging company. Most recently he has been investigating the use of sensor-based toolkits to enable experience builders to develop innovative applications. He is also interested in the deployment and use of wireless pervasive devices to see how they might enrich user experience within everyday environments.

**Graham McAllister** is a Senior Lecturer in Human Centred Technology at the Interact Lab. He has a BEng in Software Engineering and a PhD in Computer Science, both from the University of Ulster. Previously, he has also been a senior software engineer for Nortel Networks. His research focuses on the use of multimodal technology for people with disabilities, in particular visual impairments. He is also interested in the area of interactive technologies for Serious Games purposes (games for non-entertainment use) and recently completed a three-month industrial placement with a computer games technology company in Denmark. He also has his own company specializing in accessibility and usability consultancy.



**Lancaster University (ULANC), Computing Department, Leader of WP5**  
[www.comp.lancs.ac.uk](http://www.comp.lancs.ac.uk)

Lancaster University Computing Department has a reputation as internationally leading in Mobile and Ubiquitous Computing research, with 6 academic staff and around 25 full-time researchers, and with a long-standing track record of high-impact projects (e.g. GUIDE, a pioneering deployment of a mobile context-aware system, and SMART-ITS, a platform for augmentation of everyday objects with embedded computing). Areas of research activity include location, context and activity sensing in everyday settings; distributed, embedded and tangible user interface technologies ‘beyond the desktop’; and toolkits and platforms for embedded interactive systems. The research approach of the team is experimental and emphasises system prototyping and deployment into realistic use cases, often in cross-disciplinary partnerships, and underpinned by the research team’s skill set spanning hardware, sensors, networking, and distributed computing. In SPHERE, Lancaster will research on sensor devices and networks for activity monitoring, and contribute to development of novel device concepts for engagement of patients and carers.

**Projects**

Lancaster has coordinated a number of EC projects in the Future and Emerging Technologies area (FET) of FP5 and FP6:

- **Smart-Its** (2001-2003) investigated embedded sensing and context-awareness, including the combination of diverse sensor modalities for activity monitoring, and resulted in a novel wireless sensing platform (commercialised as *Particle Computer*).
- **Pin&Play** (2002-2003) developed a novel physical interface technology for rapid re-configurability based on one-wire networking.
- **Relate** (2005-2008) investigates relative location sensing in sensor networks and peer-to-peer networks, with application in emergency response.

In the area of sensing and monitoring, Lancaster was partner in:

- **FP6 CoBIS** project: Studying sensor networks for monitoring of compliant handling of hazardous materials.
- UbiCare project in the UK, investigating body-sensor networking for health monitoring.
- Long-term research initiatives on innovative interactive systems in the UK (**Equator**) and The Netherlands (**Smart Surroundings**).

**Key researchers**

**Hans Gellersen** is Professor of Interactive Systems in the Computing Department at Lancaster University. His research interest is in ubiquitous computing and embedded interactive systems. This spans work on enabling technologies such as position and context sensing, user interfaces and interaction beyond the desktop, and embedding of computing and interaction in everyday artefacts. Hans is one of the Editors of the Personal and Ubiquitous Computing Journal and on the Editorial Board of IEEE Pervasive Computing. He recently served as program co-chair of the Pervasive 2005 and ECSCW 2005 conferences, both world-class in their respective fields. He is involved with a number of research initiatives in ubiquitous computing, including the Equator interdisciplinary research collaboration in the UK, and the Smart Surroundings consortium in The Netherlands, and he has been coordinator of 4 European project in FP5 and FP6.

**James A. Ward** has recently joined Lancaster’s Computing Department as postdoctoral researcher, following completion of a PhD thesis on “Activity monitoring: continuous recognition and performance evaluation” at ETH Zurich.

**University of Limerick (UL), Interaction Design Centre, Leader of WP10.3**

[www.idc.ul.ie](http://www.idc.ul.ie)

The Interaction Design Centre at the University of Limerick is an interdisciplinary research group in the Department of Computer Science and Information Systems focused on the design, use and evaluation of information and communications technologies.

Our focus is on human-centred design, with a strong interest in collaborative settings, exploring the design and use of novel interactive and communicative artefacts to support human activities.

Work in the IDC covers a wide spectrum, from the design and evaluation of new media installations and interfaces to field studies of technology in use in different settings.

**Projects**

- **Design Based Medical Training** (Irish project, with Cork University Hospital): The question addressed by this project is the provision of an effective training in procedural skills to health professionals without exposing patients to unnecessary risk. We have built an interactive virtual multimodal learning environment using haptics that can be used by medical trainees to practice spinal anaesthesia.
- **SHAPE Situating Hybrid Assemblies in Public Environments – EU Disappearing Compute**: The project was devoted to developing and evaluating assemblies of hybrid, mixed reality artefacts in public places.
- **Sob** (Sounding Object): EU Disappearing Computerised Sob project developing sound models that are responsive to physical interactions and are easily matched to physical objects.

**Key researchers**

**Liam Bannon** is Director of the IDC and Professor of Computer Science, Dept. of Computer Science & Information Systems. Liam is interested in improving the utility, usability, and desirability of the computational artefacts we design. He has been involved in examining alternative conceptual and methodological frameworks for understanding human activities. This quest for more adequate explanatory frames has led him to examine aspects of activity theory, ethno methodology, and phenomenology. He also wishes to encourage a more participative approach towards the design field. Liam emphasises the cooperative nature of human work and its implications for design, and has played a major role in developing CSCW issues in Europe - being a founding editor of the CSCW Journal. More recently, he has become involved in exploring the field of Interaction Design, as an emerging, and distinct interdisciplinary field that has particular pertinence in this age of ubiquitous technology. Together with the rest of the IDC team, Liam is exploring how to create novel interactive media and infrastructures that will hopefully enhance different aspects of people's lives.

**Mikael Fernström** is a Lecturer, Researcher and Course Director for UL's Masters programme in Interactive Media. He has been the principal investigator on projects like the Sounding Object (SOB), Z-tiles, Self-organising Sensor Networks, Multimedia Browser Project, Sound of Action, Infopolis, LiteFoot. His research interest covers Computer Science, HCI, Electronics, Sound, Music, Multimedia, History, Archaeology and the Performing Arts Lab. Previously working in industry as inventor, electronics engineer, industrial designer, manager, composer and director.

**Dr. Susan Coote** received her BSc(Physio) from TCD in 1994. She then worked clinically in the US and Ireland specializing in the area of neurological rehabilitation. She returned to TCD as a research assistant and was awarded a PhD in 2005. She is currently a lecturer and clinical placement coordinator at the newly established Physiotherapy programme at UL. Her research interests are in the area of rehabilitation following Stroke and Multiple Sclerosis (mS) and include the application of technology in stroke rehabilitation. Her PhD was a clinical evaluation of a robotic therapy device for the hemiplegic upper limb (GENTLE/s project). Current research projects include the evaluation of electrical stimulation in stroke rehabilitation, exercise in people with MS and reflective practice in physiotherapy. She is the coordinator of the first Irish Physiotherapy research hub based at UL and acts as a peer reviewer for two EU funded Framework 6 projects. The acquisition of the new movement analysis laboratory at the Health Sciences building in UL and collaboration with clinical sites across the western seaboard of Ireland offers great potential for furthering her research career.

**IT University of Copenhagen (ITU), Leader of WP9 and WP10.1**

[www.itu.dk/doit](http://www.itu.dk/doit)

Established in 1999, the IT University of Copenhagen (ITU) is devoted to advanced research and graduate and post-graduate studies concerned with information technology (IT) and the opportunities it offers to society. The ITU's research group 'Design of Organisational IT' (DOIT) has a strong reputation as internationally leading in the research areas of Computer Supported Cooperative Work (CSCW) and Participatory Design. Focusing on the challenges posed by complex work domains such as health care, characterised by heterogeneous activities across widely ramified distributed settings, the DOIT team brings to the project substantial experience with the problems of analyzing collaborative work practices, of involving professionals as well as lay people in the design of collaborative information systems design, as well as of developing dynamic coordination technologies for dynamic distributed settings.

**Projects**

The key researchers of the DOIT team have been continually involved in collaborative research projects and program over the last two decades, at the European as well as at the national level. Two current projects illustrate the scope of the team's interests:

- The **HealthcareIT** or HIT program is a joint effort involving three universities and supported by Danish national research councils, and by IT systems vendors and national and regional healthcare providers. The main aim is to develop conceptual frameworks, design principles, prototypes, and methods and tools to support the design, implementation, and use of collaborative health information systems based on evaluation of existing systems and empirical studies of development practices.
- The **CosmoBiz** project, supported by the Danish Research Council for Technology and Production together with Microsoft Development Center Copenhagen, aims at developing formalisations and implementations of 'business process languages' that make it feasible for cooperating mobile workers to construct dynamic 'process models' to handle their coordination needs.

**Key researchers**

**Finn Kensing** is Reader in ITU's DOIT group. His research focuses on the provision of health information systems for continuity of care across professional, sector, and regional boundaries for the support of communication and collaboration in networks of healthcare professionals and patients. He is a member of the international expert panel of the Danish Electronic Patient Record Board, co-founder and manager of The Continuity of Care Initiative under "The Danish Knowledge Network for Healthcare and IT", and is a member of the "Innovation Group" of The Danish Ministry of Science, Technology, and Innovation.

**Kjeld Schmidt** is Associate Professor in DOIT. Coming from a background in sociology, he has since 1985 devoted his research to the area of Computer-Supported Cooperative Work (CSCW). His research interests focus on issues in the development of computational environments to support organisational practices of ordering, as well as the development of the conceptual foundation for 'mutual awareness' support by means of computational technologies. He has since 1992 been Editor-in-Chief of the journal *Computer Supported Cooperative Work*, published by Springer, and has played a key role in developing and organizing the European CSCW research community.

**Peter Carstensen** is Associate Professor in DOIT. His research interests focus on issues of mobility and work context in CSCW.



**Roskilde University (RU), Leader of WP4**

[www.ruc.dk](http://www.ruc.dk)

Research at RU is organised in research groups, one of which is User-Driven IT Innovation. The starting point of user-driven IT innovation is analyses of the needs of users, customers, teams of professionals, organisational units, and businesses. The goals of our research are to achieve more successful IT projects and greater benefits of using IT. We focus on how organisations manage, design, implement, and use IT to support users' needs and business strategies. Research Themes are: 1. Evaluation and effects-driven IT development: How can the effects of IT usage be specified and measured and how can they be assigned a prominent role in the management of IT projects? 2. Computer-mediated communication and coordination in complex organisational contexts: How can IT be used to improve the coordination between professional groups in organisations? 3. Software Process Improvement (SPI): How can organisations improve their software development processes? 4. Diffusion and adoption of IT: How is IT being disseminated throughout our society at large and at organisational and individual levels?

**Projects**

- **Healthcare IT (HIT)**, 2004-2009, [www.healthcareit.dk](http://www.healthcareit.dk). The topic of the HIT project is IT-supported communication and coordination in the healthcare domain. The purpose of the project is to develop conceptual frameworks, design principles, prototypes, and methods to support the design, implementation, and use of collaborative healthcare information systems based on analyses of existing systems and empirical studies of development practices. HIT is co-funded by the Danish Research Council's Program on Information Technology.
- **Effects-Driven IT Development**, 2005-2009, [www.Effects-DrivenIT.dk](http://www.Effects-DrivenIT.dk). The aim of this project is to investigate how the effects of the use of a system could play a prominent role in the development of IT systems and management of IT projects. The idea of effects-driven IT development is generally applicable to all large-scale IT projects but is in this project investigated in the context of Electronic Patient Record (EPR) systems. The project is co-funded by CSC Scandihealth A/S, Ministry of Science, Technology and Innovation, and Region Zealand.

**Key researchers**

**Jesper Simonsen**, [www.jespersimonsen.dk](http://www.jespersimonsen.dk), is Associate Professor in Computer Science. His main research interest is the study of work practices of users and designers for the purpose of offering theories and methods for systems design in an organisational context. This research area includes Participatory Design (PD), Computer Supported Cooperative Work (CSCW), Knowledge Management (KM), Human Computer Interaction (HCI), and Computer Mediated Communication (CMC). Recent application areas include effects-driven IT development, IT in healthcare, method dissemination, groupware, and e-government. Currently, he participates in research projects concerning effects-driven IT development (EDIT) and healthcare IT (HIT). Previously, he worked within the MUST research program, which resulted in the MUST-method - a contemporary Participative Design method. Publication record: 36 international, peer-reviewed articles and 4 books.

**Morten Hertzum**, [www.ruc.dk/~mhz](http://www.ruc.dk/~mhz), is Associate Professor in Computer Science. His research interests concern how artefacts support, and otherwise affect, human activities. These interests are pursued empirically, using a variety of qualitative as well as quantitative methods. His research studies and teaching activities are within human-computer interaction (HCI), computer supported cooperative work (CSCW), information-systems development, and information seeking and retrieval. Currently, he is involved in research projects concerning effects-driven IT development (EDIT), healthcare IT (HIT), and cultural usability (CU). Publication record: 44 international, peer-reviewed articles and 2 books.

**Computers Services and Technologies s.r.l. (CoST), WP6, WP7, WP10**

[www.cost.it](http://www.cost.it)

CoST is a small and lean IT firm, founded in 1989 by three brothers fascinated by Information Technologies and the software development opportunities that were growing up on the PC platform at that time. The CoST mission is conceiving, designing, deploying and disseminating innovative solutions in highly challenging domains, such as bond market, bank transactions, factory control, legacy systems integration and health information systems.

The core business of CoST is Integration and development of customised solutions for data management, real-time data processing and distribution and corporate database management.

Further on data retrieval and integrated processing from heterogeneous industrial devices.

CoST activity is relevant to the following market segments: 1. Industrial: CoST designs control applications for glass container production; control application and tracking of production chains. 2. Finance: CoST designed accessing libraries to the Italian Financial Market (Stock Exchange, MTS, e-mID) and has been involved in several projects related to software components for management of electronic market. 3. Healthcare: CoST designed a data management program finalised to statistic and quality control and monitoring of healthcare services

**Projects**

- PC-DOS NetBIOS based real-time messaging system providing network real-time layer of a distributed Physical Security System (1989)
- PC-DOS integration with a pre-emptive multi tasking environment for textile industry (1990)
- IBM Real-time Interface Coprocessor Development using an embedded multitasking OS (1990, 1995)
- Design and implementation of a protocol for data distribution via Satellite link (1989)
- Design and implementation of a pushing platform working via a subscription protocol Java based and fully WEB browser compliant (Internet explorer 4/5, Netscape 4.X) (2000)
- Design and implementation of industrial software packages fully based on Internet technologies (1999)
- Design and implementation of a Security Supervisor based on WEB technology (2000)
- GIS platform integration and routing algorithm design and implementation (2001)
- WEB integration of real time data via AJAX from OPC (2006)
- OPC Server for data distribution of an arbitrary XML stream (2006)

**Key Personnel**

**Francesco Mattera** is shareholder and cofounder and Project Manager.

**Vito Mattera** is shareholder and cofounder and Project Manager.

**Giovanni Mattera** is shareholder and cofounder and Project Manager.

**Paolo de Rogatis** working area is marketing.

**Engineering Sanità Enti Locali S.p.A. (ESEL), Leader of WP8**

[www.engisanita.it](http://www.engisanita.it)

**ESEL** is the Company of the Engineering Ingegneria Informatica S.p.A. Group that has the domain expertise in the Healthcare market. Engineering Ingegneria Informatica has about 3500 employees and its 2006 revenues of 204 M€ Engineering set up an operational R&D department in 1987, driving the R&D initiatives for the whole Group with 200 highly skilled people, 40 million euros invested in 2003-05, 25 awarded projects and a network of more than 50 international partners. ESEL together with other 13 leading players is one of the founding member of NESSI (Networked European Software and Services Initiative). ESEL has 14 branch offices, 4 software development centres, 636 employees. Actual ESEL skills cover a wide range of areas such as: quality of clinical data management in the areas of female endocrinology, psychology and reproduction; systems for hospital management; telematic services to facilitate information exchanges between general practitioners (GPs), healthcare institutions and healthcare service providers; web-based system enabling patients' clinical data to be shared between GPs, specialists and healthcare institutions that need to work at the patients' home or with occasional patients; Telematic and information technologies for the integrated management of clinical data in oncology; advanced telecommunication protocols exploitation (GSM/GPRS-UMTS) to have continuous information exchange with the Emergency Center.

**Projects**

From 2002 on ESEL participated to HL7 initiatives in Italy and IHE (Integrating the Healthcare Enterprise) in Europe and has participated with success in various editions of the Connect-a-thon obtaining certification on 2004, 2006 and 2007 for many IHE profiles ([ihe.univ-rennes1.fr/con\\_result/](http://ihe.univ-rennes1.fr/con_result/)). Furthermore ESEL has contributed to the constitution of "The Work 11<sup>th</sup> Group of UNI" in 2004, with the purpose to issue standards for the certification of the application of HL7 compliance. Among the research projects in which the company has been involved are:

- EU "Woman" project, as part of the "TELEMATICS" programmes, the objective being to improve the quality of clinical data management in the areas of female endocrinology, psychology and reproduction;
- National Research Programme - M.U.R.S.T- Theme 1 "Integrable and integrated IT Systems for hospital management"; "Telematic Applications" Programme of the European Commission: REMEDES - "European multimedia network for doctors and healthcare institutions";
- EU C-CARE (Continuous CARE) project, as part of the 5th Framework Programme on Technologies for the Information Society, the objective being to develop a web-based system that enables patients' clinical data to be shared between GPs, specialists and healthcare institutions that need to work at the patients' home or with occasional patients;

**Key researchers**

**Dr. Gianluca Milo** - Got his degree in Computer Science Engineering in Engineering Group within the "e-Health Department", 2000 at University of Rome. From January 1999 until May 2001 he worked for the "Italian Authority for the Information Technology in the Public Administration" involved in working groups about document management and digital signature. Till 03/2003 he worked in Etnoteam Group as Business Consultant in "e-Government and e-Health Department". He is now managing the Presales & Marketing Direction of the Engineering Group, "e-Health Department", taking care of all the activities concerning the solution proposal.

**Dr. Vincenzo Croce** is Engineer in Computer Science. He got his University Degree in November 2000 from Palermo University. Since February 2001 is a researcher in Engineering S.p.A. Research and Development laboratory. He was involved with technical responsibilities in the PEPERS project (SECure BANKing application assembly using a component based approach) EU V Framework Program and responsible of P2P ARCHITECT (Ensuring dependability of P2P applications at architectural level) EU V Framework Program. Moreover he has been involved in the Project EMMA (E-Marketplace Multichannel Agent-based architecture), MURST (2000-2003). Currently he is involved in the project PEPERS --6th FP R&D IST Strep - (Mobile Peer-to-Peer Security Infrastructure) as technical director and manages for the PHAROS -6th FP R&D IST Integrated Project. He has authored some scientific publications presented at international conferences.

**Medixine Oy (MX), WP6, WP7, WP10**

[www.medixine.com](http://www.medixine.com)

Medixine is a software company in the mass-market disease management software business. Medixine's platform creates a communication layer between a healthcare provider and its customers, which can be used to facilitate new service delivery models, reduce healthcare costs and improve care. Medixine's goal is to use innovative technology to help the population suffering from a chronic disease, as well as those in a risk group of developing one. The business was founded by a team of doctors in 1995 and it now offers server based solutions in the following areas all using the same core platform:

- Medication management, automatic treatment follow up, health forecasting, RFID patient logging, Chronic disease support networks and virtual clinics, mobile patient terminals for chronic disease monitoring, e-booking, multimodal reminders and questionnaires

**Projects**

- UK Met Office wanted to automate their national health forecasting initiative. Medixine provides a server based system that automatically dials COPD patients to warn them about an adverse weather condition and at the same time asks key questions to make sure they are prepared.
- Further projects deal with the Helsinki Homecare medication management the regional healthcare e-booking systems in Finland.

**Key personnel**

Current Board of Directors:

**Rifat Atun (Imperial College)** is professor of International Health Management and director of the Centre for Health Management at Tanaka Business School, Imperial College London, where he leads a multidisciplinary group of researchers.

**Tapio Jokinen** is the CEO and majority shareholder of Medixine. He is a medical doctor by training and has worked in the field of healthcare IT since 1984. He has also managed a private health care provider and a diagnostic systems supplier. He is the founder and majority partner in Medixine.

**Timo Haikonen** (Director, Finnish National Fund for Research and Development - SITRA) is focused in future healthcare concepts and solutions to improve the health services, in particular with novel digital solutions.

**Jukka Norokorpi** (Chairman of the Board) brings 35 years of experience from the IT industry. During his career he has held executive positions within Nokia, ICL and Teamware group, a subsidiary of Fujitsu.

**Visionradio Ltd. (VR), WP6, WP10**

[www.visionradio.net](http://www.visionradio.net)

Visionradio are business and technical consultants specialising in Business Development and ICT innovation, and are amongst the World leading authorities on development of Internet content for consumer devices. Their principle activity is the creation and enabling of online communities with particular focus on delivery as an interactive internet TV service. Work has included partners and clients such as Panasonic, ntl, Netgem, Microsoft, and NTT DoCoMo. Their future platform development also involves public sector partnerships including DTI, EMDA and the EU ERDF. The main tasks Visionradio will undertake would commence with collaborative consultancy with others in the project consortium to scope and plan a homogeneous, multi-platform service, capable of supporting the heterogeneous practices and other targeted aims of the project. Concerning practical developments our work would include the creation of interactive internet TV applications addressing healthcare information, targeted messages, services and independent living. This work can be extended to developments for other platforms such as PC. In addition, our experience in creation of internet audio, video and animation, plus self-edit internet community tools, can support the delivery of patient information and patient participation.

**Projects**

- In 2005 Visionradio worked in collaboration with De Montfort University on an innovations project, EasyChannel for Content, to explore mechanisms for increasing the East Midlands Creative Industries use of ICT. The project successfully delivered a technology platform demonstrating how creatives could easily maintain their online content without the need for knowledge or access to specific web software, and how the content could be presented from the same source on both internet PCs and Internet TVs. The project was sponsored by East Midlands Development Agency and the European Union ERDF fund.
- In 2003 Visionradio, took a key role on a UK government part-sponsored programme via the DTI known as Services Aggregation under The Application Home Initiative (TAHI) umbrella. This cross-industry and education project had its founding purpose "to prove the technical and commercial viability of aggregated services into the home". Visionradio's role encompassed the management of the project, key design roles and the lead in the design and development of the user interface including the first design principals for the use of a TV to deliver internet content.
- In May 2006, Visionradio launched a trial of interactive internet services accessible via broadband connected televisions. Operating under the easy2™ umbrella, the "Access Andover" service trials focused on local community engagement, offering entertainment, local information, communication and TV commerce and was developed in collaboration with the local community council.

**Key Personnel**

**Malcolm Stewart** set up Visionradio limited in 2000. His business development and consultancy activities include a marketing study for the European arm of NTT DoCoMo, and taking an active lead in the UK Government TAHI sponsored project focused on next generation services to connected users in the home.

**Geoff Ward** has provided consultancy and project management skills into technical and marketing projects including the Services Aggregation project, EasyChannel for Content, and recently with CECED, the European association of white goods manufacturers.

**Sean Patterson's** focus has been on web development including the easy2 and Access Anywhere projects, as well as traditional web customers. Sean has experience in database design and utilisation, and these abilities all combine to extend the Marketing Solutions that are provided by Visionradio.

**Simon Hession** includes web design, database driven dynamic web systems, graphics, video editing and system specification, bench and field testing of 3G mobile networks and wired and wireless IP camera experimental systems.



**Docobo Ltd (Docobo), WP5, WP6, WP10**

[www.docobo.co.uk](http://www.docobo.co.uk)

Established in 2001 from a pan-European consortium of clinicians and technologists, Docobo is a UK-based provider of innovative solutions for the management in their homes of patients with Long Term Conditions.

Currently Docobo provides a range of products and services under the doc@ HOME® brand name. These are based around their HealthHUB™, a medical PDA for collecting physiological, quality-of-life and related life style data. The collected data is transferred to a server using IP connections while messages and graphical feedback information is passed back to the HealthHUB™. Carers access the collected data via a secure web site and 3rd party systems via XML messaging based, B2B interfaces. Docobo systems have been deployed to around 1000 users throughout Europe. It operates an EN13485 compliant medical device quality system and its products are independently certified as Class IIa medical devices in accordance with the Medical Device Directive.

**Projects**

- Development of physiological sensing techniques optimised for home use. FP6 doc@HOME project web site: [www.docobo.co.uk/docathome/index.php](http://www.docobo.co.uk/docathome/index.php)
- Development of methods for interacting with patients, which are acceptable to wide demographic groups including the elderly – FP6 doc@HOME
- Development of methods of presenting multi-dimensional patient data to care providers in a manner that allows efficient & accurate assessment (UK SMART award).
- Provision of automated feedback to patients that is determined by data provided by them, and which promotes self-care (UK SMART award).
- Identification of the health delivery process changes required for the optimal delivery of tele-health services across a range of chronic diseases, in a variety of European regions. The FP6 Reality project Web Site: [www.soi.city.ac.uk/organisation/mim/research/reality/index.html](http://www.soi.city.ac.uk/organisation/mim/research/reality/index.html)
- Docobo lead Health-eLife, a project that formed a business model and multi-national consortium for the provision of tele-health services (Ref. 3) - awarded eTen project of-the-month in Sep 2006. eTen Health-eLife project web site: [www.health-elife.co.uk](http://www.health-elife.co.uk)

**Key Personnel**

**Robert Smith** is the technical director and co-founder. Robert has over 20 experiences of sensors, signal processing and IT systems across a range of sectors. His last 10 years having been spent in healthcare working for international organisations and SMEs. He has developed a number of innovative technological solutions to real-world problems, most recently being the technical lead in 3 major, industry-based, multi-national, collaborative tele-health and infusion therapy R&D projects. His responsibilities include technical development, medical device regulatory approvals, QA, the planning and execution of user trials, the preparation of patients and R&D budget management. He has authored over 20 peer reviewed articles and publications covering subjects ranging from space-based radar systems through to the long-term control of chronic conditions for home-based patients.

**Peter Levene** is the business development director. Peter is a business manager with more than 30 years experience in the international medical device industry. He has managed researchers, designers and engineers internationally, and held positions with responsibility for product research and development, sales and marketing and strategic business development in national and global operations. His business roles have concentrated on the integration of product development and marketing approaches to produce sustainable solutions for the medical device, process control and telematics market segments. He has previously held committee positions on national standards committees with BSI; he has presented papers in Europe, USA, Africa, Middle East and Japan on a diverse range of subjects applied to the medical device industry, clinical practice and healthcare business development.

**Gruppo Per l'Informatica (GPI), WP7, WP10**

[www.gpi.it](http://www.gpi.it)

GPI Spa develops Health Care Information Systems information since 1988, the year of its foundation. GPI promotes the development process of the Health Care sector, with information systems solutions caring of the needs of all actors, and of technological advances. GPI provides hospitals, public and private health service providers with opportune and reliable information tools. The IE (IppocratE) family of GPI software products allows the various operators of the system (general practitioners, hospital specialists, laboratories, health companies, and patients) to communicate and interact. The EU products family meets citizens' needs for increasingly specialized health care services. GPI offers products and a service based on an organic view of health care problems and pursues the European Commission's targets indicated in the "Action Plan for European e-Health Area". It is currently developing a highly advanced and innovative Electronic Patient Record (EPR, implemented particularly in Trentino) based on IT infrastructure and new-generation tools (IE/Repository). GPI has also applied ERP (Enterprise Resource Planning) methodologies to the health sector, giving rise to Health-ERP, an integrated solution to support health organizations and meet the needs of medical, nursing, administrative and management staff (EuSIS/ContaB). GPI has developed special expertise in standards and standardisation in Health Care, as well as in the coordination of the various actors involved in deploying and implementing clinical protocol based disease management interventions.

**Projects**

- Development of a highly advanced and innovative Electronic Patient Record (EPR, implemented particularly in Trentino) based on IT infrastructure and new-generation tools (IppocratE).
- Development of an integrated system to increase the opportunities for disabled and elderly people for an independent life in his own home (AMICO).

**Key Personnel**

**Cristiano Storni** is the responsible for the research area in GPI. He has graduated in Human/computer interaction at the University of Siena and he has got his PhD in Information Systems and Organization in February 2007 at the Department of Sociology and Social research of the Faculty of Sociology of the University of Trento with a Thesis on the social aspects of design practices. He has worked as senior engineer in several IST European Projects on topics such as Knowledge Management, E-Government, Interaction Design and, more recently, e-Health. E-Health is the main research area he is involved with (actually working with technological assistance of elderly people). He is concerned with social, organizational, existential and human factors in technological innovation and he is currently managing the GPI research within these aspects. He has presented several research papers in national and international conferences.

**Diego Calzà** graduated in Informatic Engineering at the University of Trento in 2000 with a thesis on the usage of telematics for distance education. He is expert of participatory design, and has co-authored the development of the Interactive Use Case concept. He has been IT consultant for Know-Change, and has served as CEO of the company, from 2000 to 2006, involved in projects regarding the methodology and technology for technology supported online learning, and for organisational innovation support.

**Medical University of Vienna - Pediatric department (MUW), WP10.5**

[www.meduniwien.ac.at](http://www.meduniwien.ac.at)

Largest University hospital in Austria. Pediatric department with 60 beds (plus intensive care), focus on pediatric pulmonology and allergology, research activities mainly in field of allergology (see below). Relevant to the proposal the department of pediatrics serves the largest CF population of children and adolescents in eastern-Europe. Studies performed in this population are mainly clinical or basic research [21].

**Projects**

A large multicenter EC Project (SPACE, Biomed II Program), investigating the role of house dust mite exposure and its prevention by means of impermeable mattress covers has been performed as a partner. The department of pediatrics is embedded also in a network of universities interested in allergology. The department of Pediatrics participates in the EC-funded projects ALLERGEST (QLK1-2000-01239), REDALL (QLRT 2001 02587) and EURO-PREVAL. As a designated partner institution of GA2LEN, the university of Vienna will be involved in selected studies within the focus area of GA2LEN.

**Key researchers**

**Thomas Frischer** is professor of pulmonology and pediatrics. He has a profound expertise in bronchology, epidemiology of pediatric allergy, pediatric lung transplantation and asthma. Further on in cystic fibrosis, as this is one of his core research interests. Since the beginning of 2007 Thomas Frischer is head and responsible for the the CF unit.

**Zsolt Szepfalusi** is professor of pediatrics, head of allergology and pulmonology research group of the pediatric department of the university Vienna childrens hospital He has an expertise in pediatric allergy and pulmonology. His focuses of interests are diaplacental allergen transfer, food allergy, cystic fibrosis and lung transplantation.



**IRCCS Foundation (PoliMI), WP10.4**

[www.policlinico.mi.it](http://www.policlinico.mi.it)

The IRCCS Foundation “Ospedale Maggiore Policlinico, Mangiagalli e Regina Elena” integrates two of the oldest and most important Italian hospitals, the “Ospedale Maggiore”, mainly dedicated to adults and existing since 1456, and “Mangiagalli, De Marchi and Regina Elena”, traditionally dedicated to woman and child health. The Foundation is a National Institute of Care and Research (IRCCS), recognised by the Italian Ministry of Health, and a training University hospital. The research activity of the Foundation is particularly recognised in cell, organ and tissue repair and transplantation, hosting the Nord-Italian Transplant Network, and in child and adult emergency medicine and rare diseases. Other areas of excellence are high risk pregnancy, neonatal intensive care, adult great obesity and geriatric integrated care. The Child and Adolescent Neuropsychiatry Service of the Foundation Policlinico deals with prevention, diagnosis, care and rehabilitation of neurological, psychiatric and neuropsychological diseases (mental retardation, autism, psychosis, ADHD, mood disorders, dyslexia, language disorders, cerebral palsy, congenital disabilities, epilepsy, muscle diseases etc) in children from 0 to 17 and their families. The Service for Paediatric Multiple Congenital Anomalies is a leading excellence centre for the diagnosis and paediatric follow-up of children affected by MCA/MR (multiple congenital anomalies/mental retardation) syndromes. Patients come from nationwide, and evaluation and follow up are mainly made on an *out-patient* and *day-hospital* basis, to minimise the impact on child and family. Patients with well-defined syndromes perform multi-specialistic evaluations according to the international guidelines for every specific disease.

**Projects**

- **Complex disability project:** Research-intervention project on the existing structure and problems of the network for the care of patients affected by complex disabilities and the participation model. Funding from Regione Lombardia, partnership with associations of families. Years 2005-2006, web site under construction.
- **Governance Project:** internal project of the Foundation Policlinico on the participation model in health care. [www.formazione.eu.com/etica/governance](http://www.formazione.eu.com/etica/governance)
- **Augmentative and Alternative Communication Centre Project:** Research-intervention project towards the development of a participated model of intervention in AAC. Funding from Fondazione CaRiPLO, years 2001-2006.
- **Independence project** for young adults with Cornelia de Lange Syndrome and Williams Syndrome. Partnership between association of families and Service for Pediatric Multiple Congenital Anomalies. [www.corneliadelange.org/informazioni-e-news/visualizza-news-home/browse/2/article/86/progetto-lautonomia-possibile.html](http://www.corneliadelange.org/informazioni-e-news/visualizza-news-home/browse/2/article/86/progetto-lautonomia-possibile.html)

**Key researchers**

**Maria Antonella Costantino**, Medical Doctor, is Contract Professor for Child and Adolescent Neuropsychiatry at the Paediatric Specialisation School of University of Milan and is Director of Child and Adolescents Neuropsychiatry Service and Augmentative Communication Centre at the Foundation Policlinico. She is also member of the National Working Group on Organisation and Management of Child and Adolescents Neuropsychiatry Services, for the Italian Society for Child and Adolescent Neuropsychiatry. Her main areas of interest are Augmentative Communication and Health services organisation and delivery, with specific attention to community-based interventions and users participation.

**Angelo Selicorni**, Medical Doctor, is Contract Professor for Paediatric Multiple Congenital Anomalies at the Paediatric Specialisation School of University of Milan and is chief of the activity of Clinical Genetics of the I Paediatrics Clinic of the State University of Milan, at the Foundation Policlinico. He is also Responsible of the Training Committee of the Italian Society for Paediatric Genetics and Congenital Disabilities (SIMGePeD)

**Azienda Provinciale per i Servizi Sanitari (APSS), WP10.2**

[www.apss.tn.it/](http://www.apss.tn.it/)

The Provincial Agency for the Sanitary Services is a public company of the Autonomous Province of Trento that is committed to the management and coordination of health services and activities for the province of Trento in accordance with the law, the provincial Health Plan and the instruction of the provincial council.

The agency manages and distributes public health services in accordance with the LEA (Assistance Essential Level) as further mentioned here. The hospital organisation is divided into departments that may be structural or functional (both within services and units in different hospitals and within services and units in the same hospital). The central boards have the role to organise, to coordinate and also to design health assistance on the basis of the advices produced by the provincial board and communicated by the general director.

The collective health services in living and working environments consists of all the activities that are required in order to maintain a high quality of everyday life. For instances, here included we may have treatments against infectious and parasitic disease, vaccinations, preventions and quick diagnosis of sickness, protection against risks in everyday environments, pollution compounds and working accidents, pets and animals health, food health etc...

According to the provincial norm, the agency carries out the function of Hygiene and Public Health both centrally and in each single health districts.

Local assistance consists in all the administrative and health services provided by health districts. All the health assistance the patient (also meaning the itinerant) is concerned with is provided by the local district: from the distribution of doctor-surgical facilities to the exemption of the sanitary ticket, from the selection of the general medicine doctor to the management of specialists' visits.

**Projects**

- **AGISCO** (2006) - Global and Integrated approach to Cardiac Decompensation - Internal Medicine Rovereto, [www.agisco.org](http://www.agisco.org)
- **TRIPPS** (1999-2003) - Translation of the result of the research into the practice of health services (under the initiative of the Research Program on Health Financed by the Ministry of Health and coordinated by CeVEAS (Centre for the assessment of the efficacy of Health service))

**Key researchers**

**Mauro Mattarei** has taught and has trained refresher courses for medical (42) and nursing (14) staff. He now trains specialised students in internal medicine and apprentice doctor in General medicine. He is giving courses at the specialisation school in internal medicine (University of Verona). He has been president of the medical-scientific Committee of the Hospital of Rovereto for many years and part of the Committee for the Modernisation of the Company for the Sanitary Services of the Autonomous Province of Trento. Actually, he is part of the CTS of Rovereto. He has presented more than 40 posters at national and international conferences. He is also responsible for the project 'Cardiac Discompensation Management' at the Rovereto district. He attended several refresher courses and he participated also as speaker in scientific conferences with more than 50 scientific publications in scientific journals.

**Brighton & Sussex University Hospitals NHS Trust (BSUH), WP10.6**

[www.bsuh.nhs.uk/AboutTheTrust/RACH.aspx](http://www.bsuh.nhs.uk/AboutTheTrust/RACH.aspx)

The Royal Alexandra Children's Hospital (RACH) is a dedicated children's hospital serving the south-east of England. The Rockinghorse Research Centre has a major focus on childhood respiratory disease, particularly asthma, wheeze in early life, and cystic fibrosis. It has an international reputation in the areas of asthma therapy, infant and preschool lung function. It has also focussed on symptom perception in respiratory illness.

**Projects**

- **Respiratory physiology and lung function in infants and preschool children** (Recently awarded NHS RfPB grant for project: Evaluation of bronchodilator response by interrupter technique as a way of improving the management of wheezy preschool children)
- **Non-invasive respiratory monitoring** (Collaboration with Dr David Wertheim, Kingston University. Recently awarded NHS RfPB grant for project: Non-invasive assessment of respiratory mechanics from pulse oximetry waveform)
- **Exercise and bone health in cystic fibrosis** (Collaboration with Dr Gary Brickley, Sport & Exercise Science, Brighton University, Previously awarded BSMS/BSUH R&D Award)
- **Needle phobia in cystic fibrosis** (Collaboration with Dr Susan Ayers, Dept of Psychology, Sussex University)

**Key researchers**

**Dr Paul Seddon** is head of the Research Centre. His research training was in Alder Hey, Liverpool and Montréal Children's Hospital. He has particular interests in infant and preschool lung function measurement, including non-invasive measurement and integration into clinical practice. He is a member of the Respiratory and Cystic Fibrosis Clinical Studies Group of the UK Medicines for Children Network, of the European Respiratory Society Task Force on Preschool Wheeze and the American Thoracic Society Working Group on Preschool Lung Function Measurement.

***The University Hospital of Copenhagen, Heart Centre at Rigshospitalet (RH), WP10.1***

[www.rigshospitalet.dk](http://www.rigshospitalet.dk)

The Rigshospitalet performs all kinds of modern bypass and heart valve operations, in particular medical and surgical treatment of serious heart diseases, surgical treatment and care for children with congenital heart diseases, treatment of rare heart arrhythmia, heart and lung transplantations and intensive care. As a natural part of its highly specialised treatment and care the Heart Centre has established an extensive research program. Recently, the Heart Centre has started experimenting with a new type of pacemakers/ ICDs, building on the centre's long experience with applications of telemedicine. The latest generation of these devices is able to register, store and communicate data about their own functioning and about the condition and health of the patient. Additionally, their internal program holds the potential of being altered, if necessary, through radio waves and without surgery. This could improve current practices where the patient has to go to the hospital in order for a clinician to access these data and adjust the treatment accordingly. In most cases, however, no adjustments or alterations need to be made. This means that the healthcare provider could save time and money, and the patient could avoid unnecessary stress and anxiety, if distant and periodical monitoring and feedback was possible. Also, distant monitoring could help physicians detect deterioration in the condition of the patient or a malfunction of the pacemaker/ICD. This would allow for timely medical intervention and quick feedback to the patient as well as his or her general practitioner (GP).

The primary contribution of the Heart Centre will be treatment algorithms and social and clinical practice design in relation to the IT-application and services. Further the Heart Centre will contribute to the design and test of dynamic coordination technologies for dynamic distributed settings.

***Projects***

Genetic aspect of cardiac arrhythmia:

- Genetic aspects of atrial fibrillation. Investigation of the incidence of atrial fibrillation in Danish twins (homozygous twins have a doubled risk of atrial fibrillation compared with dizygous twins).
- Impact of genes (coding for various potassium and sodium channels) involved in the shaping of the cardiac action potential in various arrhythmia diseases
- Possible role of inflammation in the pathophysiology of atrial fibrillation.
- Values of cardiac resynchronisation treatment in heart failure (i.e. treatment with pacing to improve cardiac contractility).

***Key researchers***

**Jesper Hastrup Svendsen** is a Clinical Professor of Cardiac Arrhythmia at the University of Copenhagen and at Rigshospitalet.

Further participants:

**Helen H. Petersen** is Deputy Superintendent.

**Nikolaj Christiansen** is bio analyst.

## 2.3 Consortium as a whole

### *Collective quality of the consortium*

University partners have been selected for their academic excellence, their experience in health care, and their record of successful EU projects; industrial partners for their advanced knowledge in technical solutions for telecare and specialised devices.

The key researchers of the ITU, UniMib, UoS, UL, and TUW (mDG) teams have been continually involved in collaborative research projects and programs over the last two decades, at the European as well as at the national level, and together they are internationally leading in the research areas of Computer Supported Cooperative Work (CSCW) and Participatory Design.

With TUG SPHERE has one of the leading European laboratories in computer graphics and medical computer vision, with ULANC in sensor and position technologies for ubiquitous and pervasive systems. UL and UoS have a strong history in interaction design, with UoS holding an EPSRC (Engineering and Physical Sciences Research Council, UK) Platform Grant in Human Centred Technology.

### *Required expertise to achieve the ambition of SPHERE*

Several academic partners are engaged in health care research in the context of national and/or European projects and have established working relationships with local health care providers. UoS, UniMiB, and TUW (mDG) have studied EPRs in different contexts. ITU and RU are involved in a large Danish research programme HealthcareIT. TUW (mDG) has a long-term engagement in studying issues of nursing as well as ethical issues related to IT in health care, and UoS has examined technologies in support of health care.

The proactive approach of SPHERE with its focus on integration and patient empowerment is rooted in the strong background of several partners in Participatory Design (PD) and CSCW. PD stands for a user-collaborative approach, which involves users and researchers as reflective co-designers and evolves from early exploring of practice and visions through field trials with gradually more integrated scenarios and prototypes. CSCW stands for an approach to technology development which is grounded in an in-depth understanding of social and organisational practices and their complexity, and for technology support of coordination mechanisms. ITU and UniMiB bring their joint research on coordination mechanisms to SPHERE.

In addition to the consortium's research excellence in PD and CSCW, ITU brings special competence in IT consulting into the project, RU effects-driven IT development, and UniTN its approach to social practice design (SPD).

TUG, ULANC, UL, TUW (mDG), and UoS will join forces in developing the responsive, expressive SPHERE environment. UL, UoS, and TUW (mDG) will contribute expertise developed in, amongst others, the creative design disciplines (ambient, tangible, etc. computing) to the development of these environments.

SPHERE assembles advanced know-how on Development Environments. It will make use of NESSI, the platform brought in by Engineering SPA, who will benefit from contributions by TUW (DSG), CoST, and GPI in particular for developing a web-based development environment in support of the special requirements of health care services. WP8 will contribute to the Service Oriented Utility Infrastructure working group of NESSI.

### *Complementary roles of industrial partners*

The SME partners included in the consortium cover the spectrum of know-how and services needed in the SPHERE approach. They will provide services and devices for the field trials in the different showcases, participate in these trials from an early stage on with a view on exploitation, and will use the findings from field trials for further developing their products.

Table 2.3.a: Specific contributions of SPHERE industrial partners

<b>Partner</b>	<b>Specific contribution</b>	<b>WP</b>
ESEL	<ul style="list-style-type: none"> <li>As leader of WP8 ESEL focuses on <i>integration and interoperability</i> of health care systems, and on <i>security, confidentiality and privacy</i> of personal data.</li> </ul>	WP8

CoST	<ul style="list-style-type: none"> <li>Implementation of <i>coordination</i> mechanisms and their <i>integration with representation and monitoring</i> technologies</li> <li>Integration of coordination mechanisms in the Development Environment</li> <li>Technical support of the deployment of the implemented coordination mechanisms in the showcases</li> </ul>	WP7 WP8 WP10
GPI	<ul style="list-style-type: none"> <li>Health Care Standards, and <i>standardization</i> related research activities</li> <li>EPR integration, in particular innovative solutions for existing EPRs</li> <li>Technical support of the deployment of <i>coordination</i> mechanisms</li> </ul>	WP2 WP7 WP10
Docobo	<ul style="list-style-type: none"> <li>Management of physiological <i>sensing</i> aspects</li> <li>Provision of PDAs with <i>monitoring</i> interfaces</li> <li>Customise the equipment to meet the particular needs of showcases</li> </ul>	WP5 WP6 WP10
VR	<ul style="list-style-type: none"> <li>Provision of TV-based solutions purposed for <i>expressive display, navigation, interaction and communication</i>.</li> </ul>	WP6 WP10
MX	<ul style="list-style-type: none"> <li>Internet based, traditional and <i>mobile</i> solutions, specialising on <i>multimodal information and communication</i> software for Health Care and wellness</li> </ul>	WP6 WP10
TYNDALL (subcontractor)	<ul style="list-style-type: none"> <li>Introduce/further develop novel systems to support post-stroke rehabilitation, based on Wireless Inertial Measurement Units (WIMU) which allows <i>real-time capture and analysis</i> of movement data that provide the patient with <i>immediate audio-visual feedback</i></li> </ul>	WP5 WP10
Don Gnocchi (subcontractor)	<ul style="list-style-type: none"> <li>Provide a T-shirt (the MagIC system) augmented with <i>wearable sensors</i> to be coordinated, integrated with health services and further developed.</li> </ul>	WP5 WP10

Based on its vast experience with systems development projects in cooperation with industry, UniTN has a special role in monitoring the relations between academic and industrial partners as leader of the dissemination/exploitation WP and in its role as ‘Industry Integrator’.

#### **Complementarity of expertise within SPHERE**

The consortium’s collective expertise makes sure that all objectives of ICT-2007.5.1 can be covered and its complementarity mirrors the complexity of the issues that need to be addressed:

- Competence in PD and CSCW will help ground technology development (monitoring, interactive representations, coordination mechanisms) in user needs and anchor the technologies in patients’ home environments on the one hand, patients’ and carers’ practices on the other hand.
- Access to the field is guaranteed by the participation of health care institutions as partners in SPHERE. They will provide access to current projects and involved patients and carers; will participate in the development of the quality framework (WP3) and the evaluation framework, representing the clinical point of view; will help design the field trials; and will, together with the SPHERE partners, contribute to evaluating the SPHERE approach. They will also provide connections with the health care community and help build the user group of SPHERE.

Table 2.3.b: Matching expertise against objectives of ICT-2007.5.1

<b>Call objectives</b>	<b>Involved expertise</b>	<b>Main partners</b>
Improved productivity of healthcare systems by facilitating patient care at the point of need, health information processing and quicker transfer of knowledge to clinical practice	CSCW, coordination mechanisms Innovative EPR solutions Development Environment	UniMiB, ITU, TUW, CoST, GPI, Docobo, ESEL
Continuous and more personalised care solutions, addressing the informed and responsible participation of patients and their informal carers (family/friends) in care processes, and responding to the needs of elderly people	Interactive representations Sensor technologies Interaction design PD CSCW	TUG, ULANC, UL, UniMiB, TUW, UoS, ITU, RUC, UniTN, MX, VR; Docobo, Tyndall, Don Gnocchi
Savings in lives and resources by focusing on prevention and prediction rather than on costly medical interventions after symptoms and diseases have developed	Interactive representations Sensor technologies Coordination mechanisms Effect-driven IT development	TUG, ULANC, UniMiB, RUC, CoST, GPI, Docobo, Tyndall, Don Gnocchi
Higher patient safety by optimising medical	Interactive representations	TUG, ULANC, UniMiB,

interventions and preventing errors	Sensor technologies Coordination mechanisms	CoST, GPI, MX, VR, Docobo, Tyndall, Don Gnocchi
Leadership of the eHealth and medical imaging/devices industry that is well rooted in Europe, and attracting back to Europe research activities of the pharmaceutical industry	Sensor technologies Interactive representations on different output devices Development Environment	ESEL, CoST, Docobo, Tyndall, Don Gnocchi. MX, VR
User needs, personal data security, confidentiality, privacy	PD, ethics Development Environment	TUW, ESEL
Reimbursement scheme and legal framework for using new systems	Social/clinical practice design	ITU, TUW, UniTN
Integration in healthcare processes and the interoperability of eHealth systems	Coordination mechanisms Development Environment	UniMiB, TUW, ESEL, CoST, GPI
Address the needs of many citizens (notably the elderly) for better health, well-being and mobility		All

**i) Sub-contracting:**

The SPHERE platform with its six showcases needs to be equipped with unobtrusive, minimally invasive devices for monitoring activity, environmental, and physiological parameters. SPHERE will work with solutions that are commercially not yet available. Given that the project resources do not allow to further extend the consortium, subcontracting to two companies that are leading in this field is the least costly and most efficient solution to this problem. Moreover, one of these companies, Don Gnocchi, is not available as a partner to SPHERE as they participate already in another proposal under the same challenge 5.1.

The Interaction Design Centre at UL has already cooperated with Tyndall, GPI has a long tradition of collaboration with Don Gnocchi. Both companies are interested in taking up experiences within SPHERE for further development of their products. Letters of intent of both companies are attached to the proposal.

**Don Gnocchi** is a non-profit organisation, inspired by principles of Christian charity and of full promotion of the human being. They pursue aims of social solidarity in the fields of health care, social and social-health, giving priorities to those who are most in need. They promote and conduct scientific research and carry out educational and training initiatives. In the past few years, health activities have continued to expand significantly. These include hospital care, residential and outpatient hospital facilities, and home care. Most services are for rehabilitation, as well hospitalisation for the acutely ill in both, medical and surgical areas. Within SPHERE, Don Gnocchi will focus on care solutions by addressing the direct involvement and participation of patients and their network of informal carers (from family to friends). The aim is grounded in the logic of prevention of error and prediction of problems against costly medical interventions. According to this, the foundation will provide the SPHERE project with a T-shirt (the MagIC wearable system) augmented with sensors to be coordinated, integrated with different health services and solutions. Don Gnocchi will provide a service of personalisation of the just mentioned T-Shirt to the SPHERE context and this is why a sub-contracting approach has been selected for this organisation and its contribution to the project.

The **Tyndall National Institute (Tyndall)** was created in 2004 at the initiative of the Department of Enterprise Trade and Employment in Ireland and University College Cork (UCC) to bring together complementary activities in photonics, electronics and networking research at the National Microelectronics Research Centre (NMRC), several UCC academic departments and Cork Institute of Technology (CIT). Tyndall will fabricate and supply the SPHERE project with customised versions of their Wireless Measurement Units (motes) and specialised sensor solutions. While Tyndall is a National Research Institute in Ireland with research activities ranging from advanced materials and nanotechnology to microelectronics to photonics, they are also providing advanced fabrication facilities. One of the factors that differentiates Tyndall from other research institutes and university departments is the range of state-of-the-art fabrication facilities which it can make available to both its

internal and external research communities. The Central Fabrication Facilities (CFF) has processing capabilities in the areas of silicon, micro-electromechanical systems (mEMS), compound semiconductors and polymers.

SPHERE will also subcontract the task of **Ethical Advisor**, described in 2.1.1. Here the reason is that the ethical conduct in all aspects of SPHERE needs to be assessed by an independent observer from outside and not by the involved researchers themselves. TUW will advertise this position. Candidates should have previous experience with ethical reviews of research projects in the health care area and a background in professional ethics or an equivalent field.

**ii) Other countries:**

SPHERE has invited **Ellen Balka, Professor, School of Communication, and Senior Research Scientist, Centre for Clinical Epidemiology and Evaluation at Vancouver Coastal Health Authority**, a regional health provider agency in western Canada, to join the project with her own funding.

Professor Balka is the principle investigator of the ACTION for Health project, a 4 year \$3 million research program funded by Canada's Social Sciences and Humanities Research Council of Canada that engages in applied field research about the role of technology in the production, consumption and use of health information. Dr. Balka is also a member of the British Columbia Alliance on Telehealth Policy and Research (BCTPR) to Enhance Home and Community Care & Chronic Disease Management, a research consortium whose research agenda has much in common with SPHERE. Dr. Balka's research moves from a focus on work practices (undertaken through ethnographic studies in field settings) to public policy research which addresses policy issues and concerns that are introduced—and must be overcome—to support the successful implementation of new technology. Throughout the duration of the ACTION for Health research programme, Dr. Balka has worked closely with Professor Ina Wagner and her staff at TUW, who has served as a co-investigator on the ACTION for Health Tam. In addition, Dr. Balka has worked with numerous other SPHERE team members over the last 12 or so years, in less formal settings such as workshops.

Dr. Balka will bring considerable expertise about field data collection in health care settings, and the relationship between policy (organisational and public policy) and practice related to technology uptake in complex healthcare settings. Dr. Balka will seek research funding from the Social Sciences and Humanities Research Council of Canada to support her participation at SPHERE events. In addition, Dr. Balka will seek to develop a field site in Canada that will be of interest to both British Columbia Alliance on Telehealth Policy and Research team members and SPHERE team members. Although the exact nature of such a project will depend upon negotiation with team members and Canadian research partners once funding is in place, it is anticipated that a Canadian field site could afford opportunities to conduct ethnographic field studies about technology use in context, amongst an elderly population interested in aging in place. Such field work might address the use of existing technologies piloted in new and novel settings in a Canadian setting, or might offer the possibility of field testing SPHERE prototypes in a North American environment. Pending funding, Dr. Balka will also engage in discussion and analysis of SPHERE data, and will participate in SPHERE showcases.



## 2.4 Resources to be committed

### *Financing*

The SPHERE IP is a "cost-sharing" project, with costs being shared between the Consortium and the EC. Thus each partner involved will sustain "costs" in order to participate. These costs are primarily the cost of labour - that is of personnel working on the project and not on other business. Most of the industrial participants have already been involved in other EU projects and so understand the need for financial stability, and the necessity to have, for example, a positive Net Work and the capacity to be able to finance their involvement from company resources. For public bodies involved, such as universities and government departments, this question is clearly not an issue.

For each partner, direct personnel costs have been calculated and overheads have been assigned individually to partners based on their known rates. Typically these are between 40% and 60% of personnel costs for partners using Full Costs. A small number of partners have elected to use the "Real Indirect Costs"; most of the SPHERE partners are using "Special Transition Flat Rate". The effort and costs of the project can, by the very nature of an IP, only be estimated. This is because the work will be determined to a great extent by the results of the showcases.

### *Durable Equipment*

The cost of equipment for the project has been included in the estimated costs shown in the A3 forms. In order to develop and realize the embedded, responsive multi-parametric monitoring systems (WP5) the lead development partners ULANC, ITU and TUG will acquire significant durable equipment.

This includes different types of health monitoring hardware (unobtrusive and minimally invasive, multi-parametric monitoring devices and components), tracking and measuring hardware (pedometers, GPS receivers, laser or camera-based systems, etc.), interactive devices that allow to bring monitoring back into the control of patients, mobile network access (UMTS, WiFi), light-weight portable devices (smart phones, PDAs), and laptops.

Some measuring equipment will be supplied (or acquired based on previous experience) and further developed by partners like:

- Docobo: PDAs with monitoring interfaces and display capabilities
- Medixine: Bluetooth enabled monitoring equipment
- Tyndall (subcontractor): Wireless inertial measurement units (WIMU)
- Don Gnocchi (subcontractor): the MagIC system- a wearable sensors t-shirt

For WP6 Interactive representations the leading development partners TUG, TUW and UL will acquire durable equipment in order to develop and implement the innovative interaction and representation system. This will include the equipment for the instrumentation of home-like environments for patients, as well as the caretakers and doctors in professional environments.

Equipment will comprise desktop and workstation computers, projector equipment, audio equipment, sensing equipment and in particular mobile devices such as PDAs and smart phones.

Some equipment for interactive representations will be supplied (or acquired based on previous experience) and further developed by partners like:

- Docobo: PDAs with monitoring interfaces and display capabilities
- Medixine: Experience with smart phones
- Visionradio: Basic TV-based solutions for display, navigation, interaction, communication
- CoST: Basic coordination mechanisms to be integrated with representation and monitoring

For WP7 Inter-network coordination purposes the leading development partners UniMiB, GPI and CoST will acquire durable equipment like laptops, desktop and workstation computers that together with interactive surfaces, large screens and projectors enable coordination between different stakeholders. Additionally mobile, wireless equipment like smart phones, handhelds and ultra mobile PCs will be acquired to develop functionalities supporting distributed coordination.

All partners will acquire durable equipment like laptops for Research Assistants to facilitate data collection in the field. The majority of the budget will be used to acquire devices for participant patients and families to use in their homes and clinicians to use in their offices or on the move: off the shelf devices, for initial explorations and feedback: specific devices to support rollout and use of

showcase prototypes e.g., smart phones and personal digital assistants for data transmission and feedback, large screen displays, off-the-shelf monitoring devices, and so on. Data storage devices will also be acquired to support the secure storage of participant data including audio and video data, which imposes significant space implications.

#### ***Travel and other costs***

With such a large consortium, it is inevitable that there will be a need for face-to-face meetings, in addition to e-mails, telephones and videoconferences. Apart from the kick-off meeting there will be up to 3 project assemblies per year of 3-4 days (as described in 2.1), which be planned as working meetings. They will be combined with Management Board, Executive Board, and Scientific Board meetings. In addition there will be workpackage and task-related meetings, including meetings connected with the preparation and evaluation of field trials at the different experimental sites, and travels to conferences and other dissemination events. Specific additional travel costs have been added for the coordinator and also for the training activities.

Face-to-face meetings are essential for project integration and collaboration, in particular in the first project year and in connection with major field experiments and dissemination activities.

#### ***Resources complementing the EC contribution - Baseline Technologies***

A project such as SPHERE, where application showcases will be based on new and innovative technologies will heavily rely on the availability of existing baseline technologies, which can be provided to other project partners as a start-up. They are essential to make the overall work plan feasible. The following technologies will be made available to other project partners within the project consortium:

- TUG is developing a collaborative Java-based information visualisation framework for clinical data, which will provide a foundation for the work in WP6.
- The Interact lab at UoS has dedicated space facilities to facilitate the local adaptation and in-lab prototyping of devices, as well video equipment to support the analysis of fieldwork data. The lab also has a wirelessly-enabled mobile lab vehicle to facilitate studies in the field.
- ULANC: The Common Sense Toolkit (CSTK): this is a collection of tools, written mostly in C++, that assist in the communication, abstraction, visualisation, and processing of sensor data.
- UL and Tyndall are bringing a fully working and complete wireless sensor platform (hardware and software) to the project. Their previous work has been financed by Science Foundation Ireland in a number of projects. As they have total control of the platform, it can be easily adapted to other types of sensors, form-factors, etc
- UniMiB has developed Djess (Distributed Jess), a distributed rule-based programming environment rooted on Jess (Java Expert System Shell) that has been used as middleware for cooperative and context-aware applications.

#### ***Partner contributions***

Matching funds required from the partners will be provided from each partner's own resources. This includes costs for staff, equipment, providing office space and a working environment for the research. Some partners will provide previously developed devices for the field trails, where some of these devices are prototypes not sold at the moment, and therefore provide the consortium with unique possibilities. Additionally the partners plan to invest internal resources which are not shown in the tables of the planned work, and will thereby provide significant effort to SPHERE.

#### ***Adequacy of the overall financial plan***

As can be seen from the distribution of effort across workpackages, the SPHERE workplan ensures efficient use of resources (personnel, durable equipment) across workpackages. Technologies will not be developed 'per se' but bundled and integrated to be deployed and evaluated in real clinical and home settings.

### 3 Section 3: Impact

#### 3.1 Expected impacts listed in the work programme

The European health care sector is facing major challenges due to the increasing proportion of elderly people, the increase of chronic diseases, and new generations of people that increasingly demand specialised, integrated, personalised, high-quality treatment. Without the support of new advanced technologies this trend might entail an unprecedented pressure on the expenditures for health care. SPHERE aims at meeting this challenge by developing integrated care solutions that enable patients to take more active control of their own care and treatment in ways that will provide integrated, specialised, personalised, high-quality treatment and at the same time reduce the need for expensive hospitalisation.

SPHERE builds on the notion of integrated care, with the objective to

- Integrate monitoring technologies in patients' homes
- Provide patients as well as informal carers and clinicians with responsive and configurable environments in support of data collection, representation, and expression
- And hereby enable patients to effectively manage their treatment while being at home and strengthen patient participation and inter-network coordination.

The SPHERE approach will contribute in multiple ways to the expected impacts listed in the work programme. The SPHERE results will be measured and evaluated, including quantitative indicators documenting the impact of the proposed technologies, comprising, among others, utility value and effects with regard to

- Improved productivity of healthcare systems by e.g. reducing hospitalisation and costly medical interventions;
- Continuous and more personalised care solutions;
- Integration of non-invasive, multi-parametric monitoring of health, activity and environmental parameters within patients' home environments and other suites of applications;
- Output systems supporting different views and multimedia representations;
- More active participation of citizens in illness prevention and care processes;
- Support of coordination in distributed and heterogeneous care environments;
- Extending functionalities of existing EPR solutions with technologies developed for use in patients' home environments;
- Savings in lives and resources, including higher patient safety.

Examples of measurable data include: costs; admissions to hospitals, outpatient clinics and GPs; frequency and severity of acute episodes; compliance with medication and treatment regimes; patient and carer satisfaction levels; staff workload tasks; and so on. Appropriate data will be collected from baseline and/or non-intervention groups and compared with data collected during the use of the SPHERE solutions.

##### 3.1.1 Care-related impacts

###### *Stabilizing of cost*

***A valuable contribution to the stabilisation of the cost of the health delivery systems without compromising the quality and efficiency of healthcare.***

SPHERE will improve the ways in which chronically ill patients are taken care of in their homes, making them more independent of hospital services. This will enhance the possibilities of identifying health problems and risks at an early stage, hence reduce the days a patient has to spend in hospital. Improved monitoring of the patient in the home will reduce the need for regular examinations at hospitals and outpatient clinics. Integration of the technologies in the patient's home with EPR systems at the hospital – and advanced communication means between hospital clinics and the patient while at home – will further reduce the need for expensive hospitalisation.

### ***Increased productivity and higher quality of care***

***Improving the productivity of healthcare systems by facilitating of patient care at the point of need and through better health information processing. Higher quality care at the patient location, and resource savings by reducing hospitalisation and costly medical interventions.***

Higher quality of care will be attained in SPHERE by introducing configurable coordination mechanisms that improve communication and cooperation of formal and informal carers on the one hand, by enlarging the possibilities for patients and carers to identify interpret and express health problems and needs on the other hand.

### ***Support of people at risk***

***Better support and increased reassurance for people at risk.***

Integrating monitoring in patients' homes, providing them with awareness and control mechanisms that are easy to understand, as well as enlarging their possibilities of expressing their concerns and needs will enhance the interactive nature of healthcare work, reassuring patients and enabling them to take more control over their own health.

Configurable coordination mechanisms, in combination with adequate feedback and information, will enable clinicians to reassure patients and leave space for self-management to them and their families.

### ***Patient empowerment***

***Facilitation of more active participation of citizens in illness prevention and care processes.***

Patient empowerment is a healthcare philosophy that posits that optimal outcomes of healthcare interventions are achieved when patients become active participants in the healthcare process [13]. According to this philosophy, cost-effective healthcare requires communication, consultation, and collaboration among healthcare professionals, as well as with patients, their families, and community resources. Patient empowerment aims at transforming the healthcare professional/patient relationship and educating people to prevent disease (e.g. by changing their lifestyle) [3].

By its emphasis on the need for social and clinical practice design, SPHERE will help patients and their families to appropriate the monitoring, representation, and coordination technologies in ways that enhance their own role in illness prevention and the care process. SPHERE allows patients to actively participate in decisions surrounding their own care.

### ***Steps to bring about those impacts***

Several steps are needed to bring about those impacts to

- Understand patients' conditions at home, their interaction with family members, informal and formal carers;
- Propose to technology developers ideas in support of self-management, coordination, and communication;
- Evaluate these technologies in real settings and to support the development of appropriate social practices around them;
- Evaluate if clinicians can improve their ability to assess a patients' needs and to devise appropriate action using the technologies.

## **3.1.2 Interoperability of standards and seamless communication**

***Accelerating the establishment of interoperability standards and secure and seamless communication of health data between all involved partners, including patients.***

Where possible, SPHERE will attempt to influence the development of standards in emerging areas in which some of its basic research will take place. It will define a methodology addressing standard and interoperability issues in using SPHERE services and systems, including in particular the monitoring of standards that are relevant to the development of SPHERE, and the contribution to standardization organisations/bodies where appropriate.

Seamlessness will be attained by implementing flexible coordination modalities that are configurable by the users according to their local needs.

## **3.1.3 Reinforced leadership**

***Reinforced leadership of the EU Personal Health Systems industry, including consumer ICT products for initial assessment, monitoring and management of the health status.***

SPHERE will develop consumer ICT products, whose utility value for patients as well as informal and formal carers will be documented and validated on the basis of an effect-driven evaluation framework. Moreover, the products will be tested and validated in different disease areas in different countries, with their different legal and organisational frameworks.

### 3.1.4 The need for an European approach

SPHERE aims at European solutions and products and not just national ones. The reasons for this are diverse: e.g. the increase in transnational flows of patient data for a diversity of purposes (including research); the mobility of patients; the geographical distribution of expertise, combined with the increasing availability of remote consulting by specialists; and, finally, the need to reinforce EU Personal Health Systems and the associated industry. This aim is reflected not only in the composition of the project consortium but also in the size and geographical distribution of the SPHERE Experimental *Stage*. We plan to ground technology development and evaluate solutions in a diversity of (national) cultures, local practices, and organisational, as well as legal frameworks. A critical mass of showcases is needed for developing an approach to “Personal Health Systems of Monitoring” that is widely applicable.

### 3.1.5 Other national or international research activities

Consortium members are involved or in contact with a series of national and international research activities:

- Partecipasalute Project ([www.demade.it/cms/](http://www.demade.it/cms/)) : Joint project between Istituto di Ricerche Farmacologiche “Mario Negri”, Italian Cochrane Collaboration, patient associations and other partners to support patients and families to participate and decide about their health care.
- National Centre for Rare Diseases, Italian Istituto Superiore di Sanità ([www.iss.it/cnmr/](http://www.iss.it/cnmr/)) Network of Italian Public Health Institutions on Rare Diseases: Research project on best quality organisation of Centres for Pediatric Complex Disabilities of the Italian Society for Paediatric Genetics and Congenital Disabilities (SIMGePeD)
- PoliMI has research contacts with the Centre for Childhood Disability Research, McMaster University, Canada ([www.canchild.ca](http://www.canchild.ca)).
- The Health Information Systems programme (Jens Kaasbøll, Professor) [www.hisp.info/confluence/display/HISP/Home](http://www.hisp.info/confluence/display/HISP/Home)
- Regional communication within and across health organisations (Eric Monteiro, Professor) [www.idi.ntnu.no/~ericm/regional.htm](http://www.idi.ntnu.no/~ericm/regional.htm)
- *Changing Networks of Care: Professionals, professions and the Rise of ICT in Health Care* (Roland Bal, Professor) [www.bmg.eur.nl/personal/r.bal/projects.html](http://www.bmg.eur.nl/personal/r.bal/projects.html)
- The Danish Knowledge Network for Healthcare and IT ([www.sundhedsit.net/index.php?id=399](http://www.sundhedsit.net/index.php?id=399))
- IBM Almaden Research Center (Jeanette Blomberg, Manager): Research on Services: Perspectives on practice-oriented service design
- BioSensorNet (Professor Morris Sloman) [www.doc.ic.ac.uk/~mss/Biosensornet.htm](http://www.doc.ic.ac.uk/~mss/Biosensornet.htm)
- UoS is a member of the Telecare Knowledge Network (TKN) ([www.tis.bl.uk/tnk](http://www.tis.bl.uk/tnk)). TKN is a forum for care providers, suppliers and academics (through workshops, meetings and online) to share results and insights and to explore research opportunities through identified funding.
- TUW is a participant and co-lead of the Canadian ActionforHealth Project funded by the Social Science and Humanities Research Council of Canada ([www.sfu.ca/act4hlth/](http://www.sfu.ca/act4hlth/))

### 3.1.6 Assumptions and external factors

Among the factors that will influence the expected impact of SPHERE are:

- The diversity of hospital systems and EPR solutions which will be taken into account by interoperability standards and interfaces and the success of initiatives such as CONTINUA in developing interoperability standards in a timely way;
- The increased interconnectivity, the deployment of high performance networks, and the development of mobile technology as facilitating our approach;
- The expectations of professional communities and their investment in the development of skills needed in a telecare environment;
- The increasing expectations of citizens who want best care available for all;

- The problems of elderly patients to understand and relate to new technologies/devices which will be met through interface and interaction design
- The growing up of a new generation of children and parents (see showcases on CDL and CF) who are eager to appropriate novel technical solutions.

## 3.2 Plan for disseminating and exploiting knowledge

### 3.2.1 Approach

SPHERE dissemination and exploitation will be conducted within a clearly defined framework of resources and activities which will be defined in the project's dissemination and exploitation plan. This plan will be evaluated and updated before M5 (the second release of the SPHERE approach). All partners will collaborate in the dissemination of the results among the IST community, the clinical, carers and research communities, and the general audience.

#### *Dissemination and exploitation team*

Responsible of the dissemination activities is University of Trento (UniTN), that plays also the role of Industry Coordinator (see 2.1.1), supported by all partners. UniTN will coordinate a dissemination and exploitation team composed by a representative from each of the different six countries involved in the SPHERE project. This team will be able to coordinate targeted and planned dissemination actions, taking the different national specificities and opportunities in account.

Four-monthly check-point meetings will be organised (as part of project assemblies) in order to

- Verify the accomplishment of goals and expected results
- Modify strategies and tools according to the feedback from the SPHERE Community and the public web-site
- Find new opportunities to enhance the project results.

Dissemination and exploitation activities are performed to ensure that the project reaches its goals: that the world at large is informed of its progress, that suitable training is organised in using the project results, and that these be accessible to the general public, and be fully exploited by industrial partners, by academic partners, and by clinical partners.

#### *Dissemination Plan and Activities*

The project will launch both, internal and external dissemination activities. The main purpose of

- **Internal dissemination activities** is to facilitate the efficient functioning of the project by ensuring that all relevant information necessary for progress and good results in the project will be available when needed;
- **External dissemination activities** is to bring the scientific results of the project available to the corresponding research communities and to ensure that they will have maximal impact.

Besides the main purposes, additional goals for both internal and external dissemination activities are also envisaged to contribute to the strengthening of the European research community and to engage with actors beyond the research community and with the public as a whole, to help spread awareness and knowledge and to explore the wider societal implications of the project.

One central question is how SPHERE helps the health care actors to adapt and integrate the methods into their repertoire for action, to take on new roles, and to become more creative in fulfilling these roles. As the introduction of new methods often fails, direct consulting for guiding and mentoring caretakers will be essential. This is accomplished whenever feasible through organisation of a combination of lectures, making room for reflections on current and emerging practices, establishing apprenticeship relations, and supervision of technical as well as personal skills.

The main purpose of the dissemination activities is to guarantee a world-wide visibility to SPHERE, which will be ensured by measures specified in the workpackage description.

### 3.2.2 Communication

#### *The SPHERE Community*

An Open Community will be organised since the beginning of the project to give to SPHERE a valuable consistency in terms of consensus building and critical mass aggregation. The SPHERE

members will be invited to follow and assist the project during specification, evaluation, and dissemination phases. SPHERE will also use the Open Community members as multipliers, encouraging participants to inform their own networks of the project. The Community will be open to all the users potentially interested in the SPHERE project:

- **The Telecare community**, including research centres interested in knowing features and solutions of the development of the new applications; companies interested in designing and building new scenarios in different contexts of the health and home care areas; software developers interested in developing for similar applications in health care projects.
- **End-user organisations**, including e.g.
  - *Professional users* - health care professionals (clinicians, nurses, physiotherapists) who may want to use the experiences in SPHERE to develop new applications and their professional organisations;
  - Health care institutions, who may be interested in understanding the benefits of the SPHERE approach for raising awareness, augmenting existing knowledge, and upgrading related projects and initiatives;
  - *Patients, informal caregivers* as well as *patient advocacy groups* and *charity organisations* promoters of the SPHERE approach in their local communities and networks;
  - *Local administrations*, and *self care organisations*, etc., which are looking for approaches and applications to enhance the quality of patient's life.

*The SPHERE Community can further contribute to enhance the visibility of the project through the multiplier effect: all the members will use their web site in order to disseminate the SPHERE web site, they will present SPHERE in all the events they will attend, they contribute to disseminate the promotional material, they will try to attract new adopters.*

### **SPHERE media plan**

Public awareness will be created specifically through the SPHERE media plan and the SPHERE brand activities. The media plan will be based on the definition of:

**Objectives:** The aim is to disseminate and valorise the project results and steps, increasing the awareness of the telecare community as well as end-user organisations, defining the market sectors for Personal Health Monitoring Systems.

**Strategy:** An appropriate strategy will be elaborated, in order to reach different target audiences. These specific audiences will be identified through surveys and on the one hand, using the networks of showcase participants on the other hand. The most appropriate media vehicles will be identified, in order to reach these targets.

**Tools:** Realisation of tools supporting the media plan: an info-package explaining the SPHERE project objectives and expected results and other tools targeted to wide audience and experts.

**SPHERE Web Site:** This web-site will receive deep attention because it will play a major role in the dissemination of the outcomes of the project. It will be attractive and will provide much functionality (documents uploading and downloading, demonstration videos and trial version downloading, SPHERE conference registration, news, online forums, etc.). It will be possible for visitors to this site to record their views and comments for the project to consider.

**SPHERE Branding:** A project identity will be developed early in the project, including logo, colour scheme, style sheets, etc. to ensure consistent and homogenous presentation of all materials.

*The branding will foster the SPHERE visibility and identity.*

**E-Advertising:** the Internet will be intensively used together with its related means of electronic communication to disseminate the outcomes of the project. Bulletin boards, newsgroups, websites, electronic letters, and European Commission dissemination services are some of the electronic media that will be used.

**Communication Material:** a set of documents will be prepared both, in traditional (paper, poster, brochures, DVDs) and in innovative digital form available on the web site or on e-brochures and e-flyers. Persuasive and attractive documents in a selection of languages will be produced to address the various market segments. A promotional video will be produced including demonstrations of the showcases.

**Global scientific dissemination**

**Contribution to industry exhibitions and conferences:** SPHERE outcomes will be regularly presented to potential end-users through trade-shows, workshops and the SPHERE Community meetings. The project will develop and disseminate through presentations at key events and publications in international conferences and journals or to international authorities or user groups.

*SPHERE will be presented at a large number of international events and initiatives. This activity will guarantee a worldwide visibility and will elevate awareness on the SPHERE project.*

**SPHERE Workshops:** At least two international workshops will be organised, led by the partners with strong experience of workshops' organisation and hosting. SPHERE will also participate to the major international events in the field.

**SPHERE award:** A SPHERE Selfcare Award will give a prize for the best thesis on Selfcare, and for the best technological solution in the sector proposed by SMEs. The procedure will be identified during the project activities. The award will be addressed to research student and to SMEs.

*This activity will foster the visibility of SPHERE into the Academic and SMEs world.*

**Concertation activities:** SPHERE will maintain close links, and actively encourage synergies with related research projects.

**3.2.3 Training**

*Training contributes to dissemination purposes, as it helps guarantee early adoption of SPHERE solutions and increase interest and visibility to the project.*

*Training has a multiplier effect - each SPHERE Community member can be trained and in turn can become trainer and replicate training modules of interest into their own organisation or into other organisations linked to their own.*

The SPHERE project will provide training for members of the SPHERE Consortium, for end-users involved in showcase activities, and for the SPHERE Community.

The main goal of training activities within the SPHERE Consortium is to spread knowledge on technologies and methodologies used within the project. End-users (patients, informal carers and formal carers) will need training in e.g. how to work with technology devices/representations in-situ; researchers in how to engage users in social/clinical practice design or how to deal with ethical issues. Technology developers will need training in special technical issues across workpackages and in how to work with quality criteria and design principles. It is expected that the training modules themselves contribute to the development work within the project.

The objective of training offered to the SPHERE Community of researchers, industry and SMEs, health institutions and organisations, formal and informal caregivers, patient organisations, etc. are an important part of SPHERE dissemination activities. Two levels of training are planned: one focusing on the available technologies and the other on their use in integrated care environments. We in particular are planning:

- A seminar for government health department policy/strategy people and clinicians about components of the SPHERE approach, focussing on themes, such as e.g. how to get coordination systems to work in complex teams; how to use expressive interfaces for patients and families and integrate these into healthcare; issues to be considered around monitoring devices for different types of situations.
- Academic partners will offer tutorials for young researchers and PhD students at relevant conferences or at their home institution.

The training modules and activities described in Table 3.a will be adapted to the different audiences of end-users, SPHERE Consortium members, PhD students, policy makers, SMEs, and so forth. All training activities are free of charge, also for participants from outside the consortium.

Table 3.a: Training modules and activities by workpackage

Workpackage	Training modules and activities
<b>WP3 Quality Framework</b> - including ethics (1PM): Project partners involved: <b>All</b>	<ul style="list-style-type: none"> <li>• Creation of tutorial material for working with quality framework and design principles</li> <li>• Training to work with quality framework and design principles</li> <li>• Training to work with ethics vignettes</li> </ul>



<p><b>WP4 Ongoing evaluation</b> (2PM): Project partners involved: WP4 and showcase partners (WP10)</p>	<ul style="list-style-type: none"> <li>• Creation of tutorial material for working with the evaluation framework including principles with regard to effects-driven IT development.</li> <li>• Training to work with the evaluation framework and effects-driven IT development</li> </ul>
<p><b>WP5 Embedded, responsive, multi-parametric monitoring</b> (1PM) Project partners involved: ULANC +All participants in WP5</p>	<ul style="list-style-type: none"> <li>• Development of a tutorial on sensing and monitoring technologies targeted to promote an understanding of available technology and emerging developments</li> <li>• Hands-on training workshop on rapid prototyping of sensor-based applications for technology developers.</li> </ul>
<p><b>WP6 Interactive representations and interaction design</b> (1 PM): Project partners involved: TUG + All participants in WP6</p>	<ul style="list-style-type: none"> <li>• Creation of tutorial material on principles of information visualisation</li> <li>• Training in using information visualisation applications</li> </ul>
<p><b>WP7 Inter-network coordination</b> (1PM): Project partners involved: UniMiB + All participants in WP7</p>	<ul style="list-style-type: none"> <li>• Creation of tutorial material about the approach for modeling and integration of coordination mechanisms</li> <li>• Training to work with the selected approach and the related methods and tools</li> </ul>
<p><b>WP8 Development Environment</b> (1PM): Project partners involved:</p>	<ul style="list-style-type: none"> <li>• Creation of tutorial material about the applications and supporting tools as well as the core services in the development environment</li> <li>• Training to use applications and supporting tools and to maintain core services of the development environments</li> <li>• Training to develop new applications/services on top the development environment.</li> </ul>
<p><b>WP9 Social and clinical practice design</b> (2PM): Project partners involved: ITU + All participants in WP9</p>	<ul style="list-style-type: none"> <li>• Creation of tutorial material about methods for social and clinical practice design</li> <li>• Training in using these methods</li> </ul>
<p><b>WP10 Experimental Stage</b> (3PM) Project partners involved: UoS + All participants in WP10</p>	<ul style="list-style-type: none"> <li>• Training of patients, families/informal carers and formal carers to use devices/representations in-situ</li> <li>• Training of showcase participants in overall showcase approach (in collaboration with WP 4 on evaluation training)</li> </ul>

### 3.2.4 Exploitation

Exploitation of project results, to ensure their wider use within the Enlarged European Community and on the global market will be a key activity for all health care partners, with the industrial partners playing the central role. These will prepare a business plan addressing joint exploitation by the consortium partners.

#### *Exploitation plan*

Exploitation will follow several steps:

- Perform a market analysis, identifying trends and potential competitors;
- Define the products and services that could be made available through SPHERE, addressing market entry and technical deployment strategies, organisational structure of operations, and exploitation strategies;
- Assess the main operational costs;
- Analyse the various existing business models that are currently in use, and examine their suitability for the SPHERE Showcases; possible collaboration models for post-project joint exploitation by the partners will be analysed, including a spin-off company or an extended cooperation agreement.

#### *Groups of Interest*

SPHERE will leverage four concepts and establish four corresponding *Groups of Interest* within the SPHERE Community for the development, provision, distribution, integration, deployment,

implementation, and validation, of the advanced health care services conceived, mocked-up, prototyped, tested, and validated, in its show cases. Four different groups of interest will be created:

- *A **Care Giver User Group (CGU)**, to be established and developed from the germ of users from the show cases*
- *An **Industrial Providers and Distributors Group (IPD)**, to be established and developed from the germ of industrial partners in the consortium*
- *A **Technology Integrators and Deploy-ers Group (TID)**, to be established and developed from the germ of spin-off technology integrators and deploy-ers companies*
- *A **Social Practice Design, Counselling, and Training Group (SPD)**, to be established and developed from the germ of the collection of partners interested and skill-ed in participatory design and social practice design approaches*

#### **The SPHERE Concept for Exploitation**

The early focus on exploitation will allow feasible approaches realised early in the showcases to drive development of the SPHERE methodology, tools and services. All industrial partners, providers of health care services and tools, plan to market the resulting innovative health care services for a wide range of purposes in different environments, e.g. regional health care agencies, as well as users, as hospitals, and other care provider institutions. SPHERE will enable its industrial partners to extend their portfolios of solutions implementing an innovative disease management methodology featuring participative collaboration; expressive, visual scenes based monitoring; and patient emotions awareness. The project will also extend the range of effect-based application services, built on top of the platform of SPHERE, especially in the areas of collaboration, facilitating user participation, and secure interaction. In addition to chronic care, such services are also important enablers of future solutions in areas of key strategic importance to the companies, such as visual monitoring of health care process execution, and web services in health care and e-health.

The SPHERE exploitation strategy will be significantly strengthened through establishment of the four entities above, namely the SPHERE Groups of Interest CGU, IPD, TID, and SPD (T2.4.6), and of the network of SPHERE-related spin-offs.

### **3.2.5 Management of intellectual property**

In general, the Consortium Agreement will ensure that all project partners have access to all *background knowledge* of other project partners as far as required to carry out the project. All partners will define their contribution of background knowledge before the start of the project to become part of the Consortium Agreement.

Concerning *foreground knowledge*, detailed regulations will be provided in the Consortium Agreement. It is intended to make all project reports, unless designated for internal use only, publicly available, or otherwise an excerpt of their results will be made available. Their distribution will primarily be done via the SPHERE public web page. The Consortium Agreement will regulate access rights for using *foreground knowledge* in subsequent research activities.

In general it is anticipated to make software development (as far as not restricted by background knowledge) publicly available. However, access to software and especially hardware developments, which have an immediate commercial value for one or several partners, or are subject to patents, will not be made public unless sufficiently protected.

Enterprise or knowledge models will be the property of the user communities described in the models, but any general model templates and fragments herein will belong to the project.

### **3.2.6 Management of issues concerning standards and interoperability**

WP2 will also be responsible for, in cooperation with WP5, WP6, WP7, and WP8, dealing with relevant standards for the development of SPHERE. The aim is, where possible, to attempt to influence the development and establishment of standards in emerging areas related to the SPHERE research domain. This will be accomplished by the definition of a methodology addressing standard and interoperability issues in using SPHERE service and systems, including in particular the monitoring of standards that are relevant to the development of SPHERE.

Included in our activity is the tracking of standards that are relevant to the development of SPHERE. Where possible, SPHERE will attempt to influence the development of standards in emerging areas in which some of its basic research will take place. We shall define a methodology addressing standard and interoperability issues in using SPHERE services and systems, including in particular the monitoring of standards that are relevant to the development of SPHERE, and the contribution to standards organisations where appropriate (see 1.2.1 and Annex II). This will involve:

- Defining a methodology addressing interoperability, and standards
- Monitoring standards
- Input to standards bodies

## **4 Section 4: Ethical Issues**

### **4.1 The 'situated ethics' approach**

SPHERE approaches ethics as a research issue as part of WP3 Quality framework. Based on previous research, our aim is to study 'situated ethics' – the everyday conflicts connected to introducing the SPHERE approach and their moral dimension. This is based on the assumption, that ethical issues reveal themselves in the complex dynamics which unfold in everyday situations between actors, such as doctor, patient, family members, nurse, and technical support/vendor. Their situated character lends itself to the narrative form – story-telling. The situated, everyday conflicts are connected to larger ethical issues – they are instantiations of such larger issues. They are often also connected to legal issues. We argue that understanding the context and the mundane details of situations in which ethical issues arise, and grounding them in people's everyday experiences may make it easier to address, and deal with ethical issues.

For identifying ethical issues we use a framework which draws on several sources. Biomedical ethics [7] introduces a four-principles approach – autonomy, justice, beneficence, and non-maleficence. Related to virtue ethics, the ethics of care originally emerged as a feminist critique to traditional theorizing (see the pioneering work of Carol Gilligan [23]). It focuses especially on personal relationships and character traits that are valued in them. It has been reformulated as an ethics of responsibility, which with respect to science and modern technology stresses issues of accountability and liability. Furthermore, given the many opportunities information and communication technologies offer, it is vital to take account of the need for privacy, respecting people's right to maintain boundaries, but also to preserve privacy, autonomy, confidentiality, and solitude. Other ethical issues connected to ICT are transparency – awareness of and the ability to understand IT systems and their implications – and literacy. This widening catalogue of principles or issues reflects the plurality of perspectives and the complexity and specificity of areas such as modern technology and health [53]. We expect a series of ethical issues to arise. All of these issues will need

- responsible treatment by technology developers
- in-depth exploration and ethical case deliberation with stakeholders.

#### ***Issues of literacy:***

Configurability and the introduction of novel interactive representations, together with the possibilities for expressiveness they offer, require attention to the ability of patients (elderly people, children) and family members to understand and manipulate these possibilities.

#### ***Issues of transparency***

Configurability presupposes that users understand the choices offered to them and that easy ways of interacting are provided. Are users provided with a valid and simple model of what the system does; are they made aware when their activity has an effect on the system? Furthermore, with a whole set of novel networked devices to be installed in the home, there is a need to make users aware of their presence

#### ***Issues of surveillance***

Remote diagnostics technology changes surveillance and it is necessary to study which surveillance dilemmas users and suppliers identify in remote diagnostics technology and the rationale behind their perspectives. In implementing awareness and control mechanisms, technology developers have to offer choices with respect to the visibility and non-visibility of monitoring devices.

#### ***Issues of standardisation***

What can be standardised and dealt with in the same way? How can standardisation be achieved and at the same time variation still be possible? Does this affect the quality of care?

#### ***Issue dealing with equitable allocation of resources***

Although aiming at stabilizing the costs of care for the chronically ill, the SPHERE approach also has to examine the extent to which equipping the homes of some selected patient groups affects notions of equality and the fair allocation of resources.

### ***Issues of privacy and confidentiality of patient data***

This is the best researched area of ethical and legal concerns in health care and there is legislation on the European and national level addressing these issues (see 1.3.5). However, we will have to examine if existing legislation is sufficient, needs to be harmonised or new legislation has to be drafted to account for novel technological possibilities.

## **4.2 The benefit and burden of the experiments**

The question of the benefit and burden of the experiments and the effects it may have on the research subject will be addressed in several ways:

- Close cooperation with clinicians and other carers will help identify benefits and risks prior to the field trials;
- Patients and their families will be involved from the very beginning of the project in the research – the initial fieldwork, the planning of the experiments, and the discussion of research findings. In this way they will have the opportunity to understand potential benefits and burdens and also influence the design of technologies and experimental set-ups;
- Informed consent forms will be used from the beginning of the project, in agreement with local and national consent procedures and the exigencies of the particular experiments;
- The effect-driven evaluation developed as part of WP4, will help identify and later evaluate particular benefits.

## **4.3 Involvement of regulatory bodies**

In the involved countries – A, DK, IRE, IT, and UK – we will cooperate with the local ethics committees in place in the cooperating hospitals. The national ethics committees or data protection commissions will be approached in case new, unaccounted ethical issues arise.

## 4.4 Ethical issues table

	YES	PAGE
<b>Informed Consent</b>	X	
• Does the proposal involve children?	X	
• Does the proposal involve patients or persons not able to give consent?		
• Does the proposal involve adult healthy volunteers?	X	
• Does the proposal involve Human Genetic Material?		
• Does the proposal involve Human biological samples?		
• Does the proposal involve Human data collection?	X	
<b>Research on Human embryo/foetus</b>		
• Does the proposal involve Human Embryos?		
• Does the proposal involve Human Foetal Tissue / Cells?		
• Does the proposal involve Human Embryonic Stem Cells?		
<b>Privacy</b>		
• Does the proposal involve processing of genetic information or personal data (eg. health, sexual lifestyle, ethnicity, political opinion, religious or philosophical conviction)	X	
• Does the proposal involve tracking the location or observation of people?	X	
<b>Research on Animals</b>		
• Does the proposal involve research on animals?		
• Are those animals transgenic small laboratory animals?		
• Are those animals transgenic farm animals?		
• Are those animals cloned farm animals?		
• Are those animals non-human primates?		
<b>Research Involving Developing Countries</b>		
• Use of local resources (genetic, animal, plant etc)		
• Benefit to local community (capacity building i.e. access to healthcare, education etc)		
<b>Dual Use</b>		
• Research having direct military application		
• Research having the potential for terrorist abuse		
<b>ICT Implants</b>		
• Does the proposal involve clinical trials of ICT implants?		
<b>I CONFIRM THAT NONE OF THE ABOVE ISSUES APPLY TO MY PROPOSAL</b>		

## **5 Section 5: Consideration of gender aspects**

In keeping with the European policy of equal opportunities and attention between women and men, and in accordance with the Commission's strategy<sup>5</sup> and the articles 2 and 3 and 141 of the Treaty of Amsterdam, the SPHERE Management Board will take great care to guarantee the gender balance in all aspects of the project.

SPHERE has a female coordinator and several female workpackage leaders.

SPHERE will specifically address women's interests and needs as patients or family members:

- It will develop gender sensitive strategies for setting up the showcases
- It will make use of women's creative approaches to care-taking.

Moreover, SPHERE will support women as researchers:

- The Management Committee will ensure that all partners will advertise research positions for the project so as to inform and attract women researchers (e.g. through appropriate mailing lists and other channels).
- All partners will ensure that women researchers in the project get involved in tasks and activities that help them develop their skills and profile as researchers. (In the current plan the project coordinator is a woman and at least three out of nine research workpackages (WP3, WP7, WP10) are lead by women).
- All partners will also ensure that women researchers in the project have adequate time to participate in WP2 Dissemination activities (publications, participation in academic conferences, etc.)

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- C2) Cocoon <http://www.cocoon-health.com>
- C3) Dicoems <http://www.dicoems.com>
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## 7 Annex II: Overview of standards in health care

Table 7.a: Dependability-related standards as they apply to Telecare Monitoring Systems

Physical systems	Safety	Reliability and availability	Maintainability	Confidentiality and integrity	Usability and learnability	Fitness For Purpose
<b>Component devices</b> (e.g., sensors, personal devices, displays)	ISO 13485 ISO 13488 ISO 14971 <i>IEC 61508?</i>			IEC 61508 Data Protection Act	ISO 9241 ISO 13407	Not applicable to single device
<b>Communicating components</b>	<i>IEC 61508?</i>			IEC 61508 Data Protection Act	ISO 9241 ISO 13407	Not applicable to single device
<b>Home system + call centre</b> (incl. Operators and Procedures)	BSI EN 50134 <i>IEC 61508?</i> ASAP COP Part 1	BSI EN 50134? ASAP COP Part 1	ASAP COP Part 1	IEC 61508 Data Protection Act ASAP COP Part 1	ISO 9241 ISO 13407	
<b>Home system + call centre + care support network</b>	BSI EN 50134 ASAP COP Part 1 BS 5979	BSI EN50134 ASAP COP Part 1		IEC 61508 Data Protection Act ASAP COP Part 1	ISO 9241 <b>ISO 13407</b>	

Table 7.b: List of main interantional standards and a short description

Domain	Main International Standards	Short Description
<i>Terminologies, Classifications and Vocabularies</i>	<b>ICD</b> International Classification of Diseases (WHO) ICD-9, ICD-9-CM ICD-10	The ICD has become the international standard diagnostic classification for all general epidemiological and many health management purposes. It is used to classify diseases and other health problems recorded on many types of health and vital records including death certificates and hospital records.
	<b>ICF</b> International Classification of Functioning, Disability and Health (WHO)	ICF describes how people live with their health condition. ICF is a classification of health and health related domains that describe body functions and structures, activities and participation. The domains are classified from body, individual and societal perspectives.
	<b>ICHI</b> International classification of Health Interventions (WHO)	The purpose ICHI is to provide States, health care service providers and organisers, and researchers with a common tool for reporting and analysing the distribution and evolution of health interventions for statistical purposes.
	<b>SNOMED CT</b> Systematised Nomenclature of Medicine - Clinical Terms	Coding system, controlled vocabulary, classification system and thesaurus aimed to provide comprehensive clinical terminology. Designed to "capture information about a patient's history, illnesses, treatment and outcomes".
	<b>UMLS</b> Unified Medical Language System	A controlled vocabulary; "Metathesaurus and semantic

		network with lexical applications". UMLS is a compendium of a large number of national and international vocabularies and classifications (over 100) and provides a mapping structure between them.
<i>Knowledge retention, rerepresentation, sharing and exploitation</i>	<b>Arden Syntax</b> (ANSI)	Syntax for representing and sharing clinical knowledge in Medical Logic Modules.
	<b>GELLO</b> (HL7, ANSI)	Object-oriented query and logical expression language to provide an interface between clinical information and data and electronic clinical decision support functionality. GELLO is based on the Object Constraint Language of the Object Management Group.
	<b>GEM</b> Guideline Elements Model	Standard for the representation of clinical practice guidelines in XML format.
<i>Documentation Architectures, Conceptual Models, Data structures</i>	<b>CDA v2</b> Clinical Document Architecture (HL7)	XML-based markup standard for the representation and transfer of clinical documents.
	<b>RIM v3</b> Reference Information Model (HL7)	RIM expresses the data content needed in a specific clinical or administrative context and provides an explicit representation of the semantic and lexical connections that exist between the information carried in the fields of HL7 messages.
	<b>CCR</b> Continuity of Care Record (ASTM)	XML-based patient care record summary standard designed to provide a standard format to support core data sharing between care providers and systems.
	<b>CEN 13606</b> European electronic healthcare record interoperability standard	The European electronic healthcare record interoperability standard (2004). Includes: EHR reference model, archetype interchange specification, reference archetypes and term lists, security functions, exchange models to support communication.
	<b>ISO 18308</b> Clinical and technical requirements for an Electronic Health Record Reference Architecture	Clinical and technical requirements for an Electronic Health Record Reference Architecture "that supports using, sharing, and exchanging electronic health records across different health sectors, different countries, and different models of healthcare delivery".
<i>Data transfer, Messaging</i>	<b>HL7</b>	Standard to support clinical and administrative electronic data exchange in healthcare.
	<b>DICOM</b>	Industry standard for transferring and retrieving diagnostic medical images (X-rays, MRI, CT, nuclear medicine, ultrasound) and information between electronic devices.

Main institutions and bodies involved in the definition of standards in the area of health care:

- ISO - International Organisation for Standardisation ([www.iso.org](http://www.iso.org))
  - ISO TC 215 Technical Committee on Health Informatics
- HL7 - Health Level 7 ([www.hl7.org](http://www.hl7.org))
- CEN - European Committee for Standardisation ([www.cenorm.be](http://www.cenorm.be))
  - CEN TC 251 Technical Committee on Healthcare Informatics
- WHO - World Health Organisation ([www.who.int](http://www.who.int))
- ASTM - American Society for Testing and Materials International ([www.astm.org](http://www.astm.org))
- CONTINUA – member organisations are a part of an alliance for interoperable tele-health solutions: <http://www.continuaalliance.org/home>
- Mobilearn gives a list of some tech standards:
  - <http://www.mobilearn.org/standards/standards.htm>
- CEN TC251 - Standardisation in the field of Health Information and Communications Technology (ICT) to achieve compatibility and interoperability between independent systems and to enable modularity (<http://www.centc251.org/>)
- ISO TC215 - Standardisation in the field of information for health, and Health Information and Communications Technology (ICT) to achieve compatibility and interoperability between independent systems.
- Standards in the fields of disease coding classifications include ICD9/10 and SNOMED CT (<http://www.nhsia.nhs.uk/snomed>).
- ENV13940 – Clinical pathways: the standard, currently under finalisation
- <http://eprints.ucl.ac.uk/archive/00002292/> provides pointers to health record standards.

## 8 Annex III: Main subcontractors

Centri  
Milano: "Istituto Palazzolo", "Carlo Girola",  
Monza (MI), Pessano (MI), Lodi, Inverigo (CO),  
Malmate (VA), Brescia, Rovato (BS),  
Salice Terme (PV), Torino, Parma, Sarzana (SP),  
Marina di Massa (MS), IRCCS Pozzoliatico (FI),  
Colle Val d'Elsa (SI), Falconara Marittima (AN),  
Roma, Salerno, Acerenza (PZ)

 **Fondazione  
Don Carlo Gnocchi  
Onlus**

**IRCCS "S. Maria Nascente"**  
20148 Milano - Via A. Capecelatro, 66  
tel. 02 40.308.1 - fax 02 40.09.22.97  
email: direzione.mi@dongnocchi.it  
Internet: www.dongnocchi.it

To: GPI Trento

cc: SPHERE Consortium  
Prof. Jacucci, University of Trento

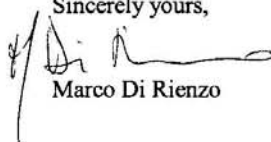
**Ref: EC proposal SPHERE**

Milano, 3 May 2007

Dear Sirs,

With this letter Fondazione Don Carlo Gnocchi would like to support the European Commission proposal called SPHERE and, if successfully funded, accept your invitation to stipulate a subcontract agreement with GPI for the use of an adequate number of wearable sensors T-Shirts and the support for adaptation to activities in the SPHERE project show cases during the four year of the project.

Sincerely yours,

  
Marco Di Rienzo

*our ref. 22/07*



Lee Maltings, Cork, Ireland  
Tel: +353 21 4904177  
Fax: +353 21 4270271  
Email: info@tyndall.ie

Prof. Dr. Ina Wagner  
Institute for Technology Assessment & Design  
Vienna University of Technology Email:  
Argentinerstrasse 8  
Vienna  
Austria

The undersigned hereby confirms, on behalf of Tyndall National Institute - UCC that our organization wishes to participate in the Health proposal **Supporting Participation in Healthcare with Expressive, Responsive Environments** within the call FP7-ICT-2007-1, proposed by Prof Dr Ina Wagner.

A handwritten signature in purple ink that reads "Conor Delaney".

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**Mr Conor Delaney**  
**Finance Manager.**  
**03/05/2007**

[www.tyndall.ie](http://www.tyndall.ie)