Distance Information, Support and Communication for European Carers

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Abstract
We present the Greek pilot of the DISCUS project. The rationale for the project stems from the observation that cost-effective professional health and care services are becoming increasingly important due to changing demographics, and increased demands on limited care resources. There is the opportunity for telematics to directly increase the efficiency and quality of care by making knowledge, skills and experience more accessible to care providers. This is particularly relevant in rural communities where they may have little or no opportunities to share knowledge and experiences with peers, as is the case in the Greek site located in the island of Samos.The primary objective of DISCUS therefore to provide an Internet based information/training, support and communication system especially for carers in more remote areas, which will allow them to exchange ideas and benefit from the knowledge base of other professional carers across Europe. Extensive dissemination opportunities are also foreseen amongst educational/training centres in that the system will provide an easy to use, time-saving and qualified learning resource.DISCUS will follow user centred design principles to develop an Internet based service. The project will test the feasibility of producing a generic service, and will identify the ease with which this can be tailored to meet local conditions.

1.   Objectives

The rationale for the project stems from the observation that cost-effective professional health and care services, using advanced telematics, is becoming even more important with the progressive and proportional increases in the elderly population and people with disability. Apart from the potential for telematics to improve quality of life (QL) and independent living (IL) at the personal level, there is also the opportunity for telematics to directly increase the quality of care by making knowledge, skills and experience more accessible to care providers whether they are located in urban or rural communities where they may have little or no opportunities to share knowledge and experiences with peers, whether they are professional healthcare or social care based, whether they are 'formal' (professionally trained) or 'informal' (caring members of the family or friends) and even whether they are in training as care professionals or already in practice [1].

This can be achieved through telematics based interactive support and communication services which can provide the basis for improved competence and awareness of professionals and trainees, informal carers and others in the caring professions and through this have an impact on the QL and IL of people with disability and elderly people [2]. The specific objectives of DISCUS are therefore to:

- provide an information/training, support and communication system especially for carers in more remote areas, which will allow them to exchange ideas and benefit from the knowledge base of other professional carers across Europe.
- provide information, identified through the definition of users' requirements, and establish communication and file transfer facilities between service providers and experts in caring using the Internet and the World Wide Web as a delivery medium.

The telematics media is an economic, efficient and effective way to meet these objectives because of:

- the increasing use of the Internet and the number of services that can be made available on it,
- the relatively low costs for Internet access that will make it an affordable resource for private and small centres,
- the negligible costs necessary for the demonstrator sites.

The project will develop a generic information resource which will be produced in the English language. This will be evaluated in the UK and in the Netherlands using a sample of potential end users. The first generic site will be operational within the first eighteen months of the project and the lessons learnt incorporated into the development of two national language demonstrator subsequently developed in Greece and Italy and tailored to their requirements. These will also be evaluated with the end user organisations represented in the project, the objective being to produce exploitable products in Greece and Italy by the end of the project. A comprehensive marketing and exploitation plan will be developed

early in the life of the project, which will identify in more detail market requirements and sources of subsequent funding for the services developed.

2.   Strategic approach

The project will provide a range of information resources for care providers, with a particular emphasis on those working in remote or rural areas. This is based on an understanding that in many countries of the EC the point of delivery for social care provision is often in remote areas at a considerable distance from city centres, and relies on the services of personnel with often limited education and access to more traditional forms of educational materials and skills based resources. Information/training, support and communication are required at a <u>distance</u> by professional carers in remote areas for the following reasons:

- rural areas, remote places, hilly and mountainous villages are generally poorly served by the provision of services in general, of health and care in particular, because of environmental barriers.
- a high percentage of elderly people live in these remote places. Their need for care and assistance is difficult to be fulfilled, as environmental barriers restrict the service provider's mobility.
- young and unemployed people living in these remote places might find new work opportunities in the health and care sector, provided that information/training, support and communication opportunities were available.

Internet services are widely available in the European Countries at a relatively low cost and a growing number of users are now experimenting with Internet access (a more detailed overview of the state of the art is given in Section 2.2 below). It is realistic to anticipate that the Internet will continue to develop as an important medium of communication. DISCUS will offer the opportunity to social service providers to exploit some of the possibilities offered by this technology. Initially, access will be made available at centres for social service providers (the pilot sites for the project), with the potential to expand the service further. The project will also work in close collaboration with other initiatives in this area, the most significant being the work of the TAP funded ACTION project.

3.   User needs to be addressed

In the case of a home help in more remote areas, the carer may be virtually untrained, with a poor education and possibly poor literacy. DISCUS will provide an information/training, support and communication system which will pay special attention to the needs of such carers and provide practical support to them. A detailed user requirement will be established early in the project, the emphasis of which will be on providing practical support for the functional aspects of care provision. For example practical advice on care will be provided on such topics as moving patients in bed, assisting in personal hygiene etc. Where appropriate multimedia information sources will be developed to include, text, photographs, graphics and video footage. In addition to these resources the service will include:

- an information structure which includes data (addresses, contact points, etc.),
- support on problems concerning technology, geriatrics, psychology, physiology, sociology, hygiene, legislation, ethics, etc.
- communication with other carers on key issues, on a local, national and international basis.

These services will be constructed to specifications arising from the user requirements against which they will also be evaluated.

4.   Innovation

The project will not be developing innovative technology, and will rely instead on existing PC and Internet technology to support service provision. The project will however **develop an innovative support service for care providers**, and develop the information resources and infrastructures needed to support these activities. There is evidence of computer-aided learning (CAL) packages being used, or considered, for professional social work managers (e.g. ProCare [3], which develops courseware to support teaching and learning in social work and nursing courses). However, these packages do not meet the communication and on-going support needs of carers, particularly those in more remote areas, who would benefit from discussing issues with other carers and learning about new technologies which could better meet the needs of elderly people. DISCUS is more than a CAL package - it is a telematic information, support and communication system that will bring carers across Europe closer together.

5.   Methodology

The project will collate available best practice and experience in the care of elderly and disabled people, and in the first instance draw on the extensive literature on this topic already available. This

will be supplemented by data capture activities with service providers, drawing on practical experiences of providing care support. The project will follow a user centred design philosophy, and will adopt the USERfit [4] design methodology developed by the TAP USER project. Emphasis will be placed on capturing requirements from representative end users, building a generic system prototype and then evaluating the system with a suitable sample of end users. This information will be used to refine the specification for the generic system as well as contributing to the development of two demonstrators tailored to local needs in Italy and Greece [5].

The user requirements phase of the project will identify the high priority information needs and ensure that the needs of the care service providers are included, but in the broader sense that the overall needs of the indirect users, the primary beneficiaries i.e. elderly people and people with disabilities themselves, are kept foremost in mind and captured directly during the data collection process. A generic database of common shared experiences, information and support will first be designed. Cultural issues and attitudinal differences in care provision across Europe will be considered, as well as procedures for dealing with differences in language, word connotations, and formats to make the generic system easily transferable to other countries. Some carers in more remote areas may be virtually untrained and poorly paid, with a poor education and possibly poor literacy. The user requirements capture will also consider these issues and may, as a consequence, specify particular interface design guidelines to better meet users' needs - or it may suggest that access to the system should be done via a local centre and "gatekeeper", who will have good literacy and communication skills, as well as the essential access to the Internet [6],[7]. The generic system (tested at two sites - UK and the Netherlands) will then be moulded to meet the needs of the two pilot sites in Italy and Greece. These two countries have a welfare system characterised by social services mainly provided on a human, rather than a technological basis, and indicate a clear need to provide service in remote areas. The two pilot sites will test the extent to which the generic materials can be tailored to particular countries without major changes. From this pilot assessment, we shall be able to assess potential harmonisation across Europe with respect to language, content and accessibility of the DISCUS tools.

The information content will be identified during the user requirements phase, but, as well as advanced telematics, is likely to include elements on psychology, anatomy, physiology, geriatrics, sociology, hygiene, alimentary sciences, domestic economy, legislation, and pan-European and local contacts for more information, support and discussions. Support will include specific advice and practical information on physical and emotional issues identified in user requirements capture. It is likely to include, for example, advice on best practice in lifting an elderly person or a person with disability, and available strategies to cope with the problem of wandering for an elderly person with dementia. Sources of help and relevant legislation will also be provided, and tailored to the individual countries at the pilot sites [8]. Where legislation is not available, guidelines and codes of practice from other countries will be welcomed in many sectors. For example, the British Medical Association and the Royal College of Nursing (1995) provide guidelines on the use of tagging devices for people with dementia and the need for consent of the person involved. How other carers cope and how they feel about this ethical dilemma needs to be discussed more widely across Europe [2], and the DISCUS system can provide such an open forum for discussion.

The generic and then the two tailored systems, will be evaluated with professional carers, from the perspectives of functionality, usability, utility, acceptability, accessibility and impact with respect to the information content and user interface. Field tests of the system will be made at four sites. The two pilot sites (Italy and Greece) will then test the extent to which the generic materials can be passed to particular countries without major changes. Monitoring activities will be conducted to assess the interaction between the users and DISCUS tools. This will enable the project team to classify and quantify the navigation of users through the different information resources and services available. This data is vital order to evaluate the way in which users exploit the available information and services, thus contributing to the iterative design process.

6.   Expected Results

The project will develop a support and training network for professional carers, and by the end of the project this will have been demonstrated operating in Greece and Italy. The extent to which a generic solution can be developed will also have been assessed by that time, along with the effort required to tailor such a generic system to local needs. This information will prove invaluable in the development of a marketing and exploitation plan for the project.

A provisional marketing and exploitation plan will be drafted early in the project, but this will be more clearly specified after evaluation has taken . Only when the generic tool has been tailored to individual countries, will it be possible to assess the ease and acceptability with which the generic tool can be harmonised with other languages, contents and methods/places for access.

The Internet and World Wide Web provides a suitable infrastructure for the exploitation of the project, as the infrastructure is in place for potential users to easily gain access to the service, and the mechanisms for establishing subscription only services on the Internet are already well established. The Internet also makes it easy to provide information update and enhancement, allowing the service to be easily developed and extended in the future. A key aspect of the marketing plan will be to identify the most suitable delivery mechanisms. This may be through personal subscription to the service, or conversely by obtaining corporate funding from key organisations for the future maintenance and development of the service. In either case a suitable pricing policy for the service to be maintained will be established.

Whilst the main users of the system will be professional carers, working or training in private companies (co-operatives, associations, foundations, profit and non-profit enterprises, etc.) and public institutions (schools, training centres, job centres, employment counselling centres, etc.). However, DISCUS envisages that with more widespread use of the Internet and World Wide Web technology, private individuals and family members will also be able to benefit from the information/training, support and communication with other carers of the elderly.

Once the DISCUS system is implemented, a variety of relevant products will emanate, e.g. CD ROM's and further tailored systems to meet the information and support needs of various countries, especially where contacts may have been limited in the past, e.g. in eastern Europe. Thus, the most important product of all will be the DISCUS network itself. More precisely, the Consortium discerns the following goals:

Short-term goal: Within 1 year after the end of the project, a CD ROM version of the generic information and support packages, as well as the tailored packages for Greece and Italy.

Mid-term goal: Within 2-4 years the DISCUS network should have been extended to further EU countries, covering a wider variety of languages and content, and linked to further WWW sites across Europe. The number of successful tailored tools will be dependent on the results of the evaluation and harmonisation with respect to language, content and accessibility.

Long-term goal: In 5-8 years, the DISCUS network should be extended not only to further countries, but also to include new multimedia and interactive services, transferring also voice and image, following relevant technical developments in RACE and ESPRIT.

7. The Greek Pilot

The Greek demonstration site will be located in the island of Samos (Aegean Sea), and consists of the following organisations:
∑ Municipal Home for the aged of Samos
∑ Association for the Assistance of the Municipal Home for the Aged of Samos
∑ Aegean Health Institute

The server for the Greek tailored system will be located at the main office of BIOTRAST, located in the Thessaloniki area. BIOTRAST is the coordinator of the Greek site and responsible with NetSmart for any technical and telecommunication development. The demonstration site has the following characteristics:

∑ The Municipal home for the aged of Samos together with the rest of the organisations in Samos area houses hundreds of elderly people. Their families, careworkers, volunteers, partners from other co-operatives will have daily contacts with the DISCUS Web server and knowing that such a system is available would encourage carers to access it;

∑ All of the participating institutions have a fast access to the Internet and are regular users of email and file transfer facilities. The environment is therefore equipped, both technically and psychologically, to deal with the system implementation and exploitation;

∑ costs related to implementation, evaluation and monitoring will be reduced by taking advantage of the existing infrastructure and network of users.

8. References

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