



European SeniorWatch Observatory and Inventory -
*A market study about the specific IST needs of older and disabled people
to guide industry, RTD and policy*

www.seniorwatch.de

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The European USHER web site

*How the internet can help patients to cope with severe
sensory impairment.*

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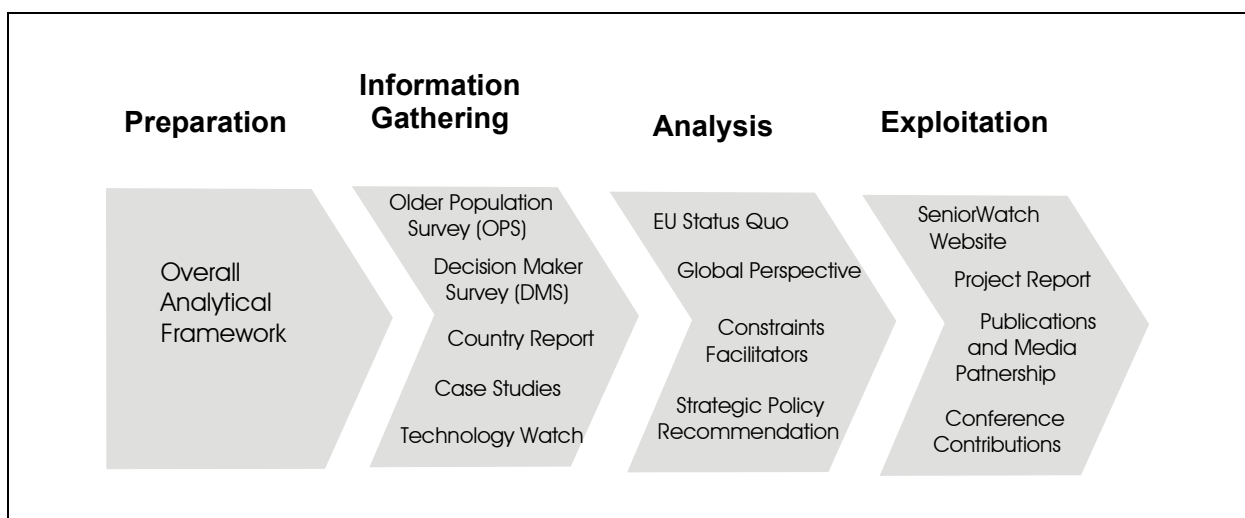
1 Introduction

The SeniorWatch project addresses the need to understand better and to monitor the market dynamics of Information Society Technologies (IST) applications and services targeted at older (and older disabled) citizens. Currently, there is insufficient empirical data about the needs of older citizens which could be met by IST-based applications and services, and a lack of awareness on the part of industry, users and politicians that hampers the rapid exploitation of new market opportunities arising from IST developments. In order to redress this state of affairs SeniorWatch will provide a European single source of empirical information on the market potential of IST-based products and services targeted at older people. The main objectives can be summarised as follows:

- to help and encourage European industry to address the market opportunities, and particularly challenge current competitive advantages of the US industries,
- to enable policy to really influence the current situation and to benchmark achievements between different European regions and countries and to make comparisons with competing world economies (Japan, US) most relevant to the field,
- to inform citizens about what is now possible with the support of IST and, thus, encourage them to demand IST products and services which meet their requirements.

As illustrated by Figure 1-1, these objectives require a comprehensive methodological approach to be applied. On the basis of an overall analytical framework, it integrates a set of complementary research methods such as European-wide surveys of older people and of decision makers in care services, best practice case studies, technology watch work shops and country reports. Synthesising the various types of empirical information gathered with help of these methods will finally enable the project to arrive at an holistic overview, to establish a technology and market observatory, and to derive policy recommendations to accelerate market development. Research results will be exploited by means of different measures.

Figure 1-1: The Project Phases of SeniorWatch



Source: © SeniorWatch, 2001

As part of the project's overall methodological approach the SeniorWatch case studies aim at providing a useful source of information on how the IST-related needs of the target groups in question can adequately be served. They are also intended to help to understand - in a qualitative manner - more deeply specific aspects of the market situation related to IST

products and services relevant for older citizens. To allow a comparative analysis of real-life examples, a common approach for selecting and describing suitable cases was developed. The main selection criteria applied in this context include:

- suitability of the case to provide input to the overall understanding and analysis of the market for IST among older people;
- suitability of the case to serve as an example of a success story (or failure) that can guide and motivate others to take actions that will support the diffusion and take-up of IST by or for older people.

In the following the SeniorWatch case study no.23 is described.

2 The European USHER web site. How the internet can help patients to cope with severe sensory impairment.

2.1 Description

Usher patients can profit from a web-based information system.

It is generally believed, that blind or severely visually impaired persons are isolated and excluded from information and communication services based on visual input - even more so if in addition to the visual sense also the hearing sense is impaired. The overall aim of this case study is to show, that Usher patients suffering from a combined visual and hearing impairment, as well as their relatives and support groups can profit from a web-based information system. The concrete objective of the European Usher website was to establish a multilingual and accessible website providing information on all relevant medical and rehabilitation aspects for Usher patients and other interested target groups.

The European Usher website was constructed in the framework of the EU project TENCARE aiming at the initiation and evaluation of telecommunication-based home care services for European citizens. After an initial examination of existing websites related to the needs of Usher patients, it became clear that a large amount of English language information was available already, but that a well structured, comprehensive and accessible website would certainly fill a gap. Also, most existing sites were private copies of a few original sites like the website produced by Sense, a public UK institute for the rehabilitation of deaf-blind and hard-of-hearing persons. At that time (1999) Sense did not apply any accessibility criteria to the design of its website.

Hence it was decided to produce a website with the following **key features**:

- Presentation of identically structured information in three languages: English, French, German
- Presentation of basic medical information with a focus on comprehensibility, comprehensiveness and accessibility for Usher patients, with particular emphasis on rehabilitation measures and help services that are available for individual patients and their support groups.

Direct website information covered the following contents:

- Medical information; impact on personal life; help with regard to assistive technology, legal, vocational and psychological aspects; research on Usher syndrome.

Indirect website information covered:

Addresses of patient organisations and rehabilitation institutes; conferences and seminars; discussion lists and link collection; literature etc.

The following **accessibility criteria** were implemented in accordance with the Web Accessibility Initiative (WAI) of the world wide web (W3) consortium:

- universal design (e.g. no isolated text-only pages)
- easy usability (e.g. instructions for use of braille or speech oriented browsers)
- identical layout and navigation principles for all three websites and web pages
- all graphics or pictures with alternative text
- Cascading Style sheets for formatting purposes and for flexible browser adjustment

The prevalence of Usher patients is about 1:30.000, i.e. about 3.000 patients in Germany and about 25.000 in Europe. Statistics of visitors of the website are produced since middle of 2001 and since then (until end of 2001) more than 1.000 hits were registered. Reactions of individual users to the Usher website were generally positive, e.g. "The contents is interesting and most important to cope with the disease and its consequences" , or "The overview on the homepage and the following pages are well structured, so that I had no difficulties with both browsers (Lynx, Internet, Explorer 5.0)". Answers from a few selected users showed, that except for the websites research area all contents was considered as either "most important" or "important" (on a scale from 1 = most important to 5 = unimportant). The Usher Europe website received "2 star rating" by "Bobby", an automatic validation programme for website accessibility for partially sighted and blind people.

Marketing of the website was and still is the main problem. The organisation responsible for the development of the website is commercially oriented and had to stop further updating and design activities for the website once the EU funded project was completed. Although one international patient umbrella organisation (Retina International) offered to include the Usher website among its own webpages, the transfer was not carried out for the following reasons:

- The Usher site would have been "lost" within the general "Retina" (not: Usher) oriented information services
- The contents of Retina International site is oriented towards national patient organisations rather than towards the needs of individual patients
- Retina International could not guarantee a continuous updating of the Usher website due to lack of voluntary personnel and finances

National retina organisations, on the other hand, although occasionally visiting the European Usher website, were reluctant to integrate it into their own website as it was "too international". Splitting the Usher Europe website into three national sub-websites, did not seem reasonable either.

Given the overall small number of Usher patients and support professionals, the "critical mass" of visitors of the Usher Europe website will be crucial for its long term survival. Once this critical mass exists, pressure on the patient umbrella organisations may arise from the bottom to take over and continuously update the Usher website. In particular the European Usher Study Network, already using the website for publishing its own events, may be ready to overtake and redesign the Usher Europe website for its own purposes.

The main advantages of the Usher Europe website are:

- Presentation of comprehensive and basic medical information on the Usher syndrome in an accessible format for patients with visual impairments.
- Identically and well structured overview of basic Usher related information in three languages

The main disadvantages of the website are:

- An "external" commercial organisation is as owner of the website offering information for patients and voluntary patient organisations
- The website can not offer national information deep enough to compete with monolingual national Usher websites

An alternative strategy would be the transfer of the three single websites to interested national patient organisations or the replacement of the Usher Europe website by a new European usher patient umbrella organisation's website.

Context

Main financial support for the development of the website came from the European Commission by funding the TENCARE project. The company responsible for project leadership is now providing funds for sustaining the Usher Europe website on a small scale even though the original project is completed. Also, a major speech browser manufacturer is sponsoring the website.

Contents and layout of the website have generally received recognition by Usher patients because of its contents and accessibility features. This was also due to the early involvement of user groups in the contents, structuring and design process. In particular "educated" Usher patients organised in a subgroup of Pro Retina as well as dedicated German ophthalmologists from eye clinics contributed suggestions to the design of the Usher Europe website.

Results

The Usher website (www.usher-europe.org) has reached its main objective and is being used by visually and hearing impaired usher patients and their relatives as well as by Usher organisations all over Europe. The website is linked to other patient and professional websites, in particular to the website of Sense, the main rehabilitation institute for Usher patients in the United Kingdom and Europe. The Usher website is registered with major search engines (e.g. Yahoo) and is still available on the empirica server. Although a new business owner has not been found after completion of the original project, the Usher website is still accepted by the main target groups.

2.2 Analysis

Impact

There are clear indicators that the Usher Europe website did have a positive impact on the targeted groups:

- links were placed on other relevant websites (e.g. Sense website)
- Although Usher syndrome is a very rare disease the number of visitors of the Usher Europe website is respectably high
- In reaction to and partly based on the Usher Europe website some national patient organisations (e.g. Pro Retina) have started to design their own Usher webpages as part of their overall websites
- On request of the European Usher Study Group (EUSG) representing the European Usher patients, the Usher website is now publishing regularly events and activities of the EUSG (conferences, projects, seminars)

In spite of this success, however, the company owning the Usher website until now (end 2001) has failed to transfer it to European expert owners. The number of visitors would certainly be higher, if the website would not be hosted by a commercial organisation, but by a public or voluntary organisation involved in the rehabilitation of Usher patients.

As doctors are rarely well informed about the disease and as Usher patients find it difficult to access print information, accessibility to the Usher website may have contributed to a significant increase in their quality of life.

Furthermore, two invisible effects may have resulted from the website:

- Usher patients in smaller European countries may have become motivated to form their own Usher groups
- For existing Usher groups the effective use of the website information may have saved costs in the dissemination of information and in the acquisition of new members.

Lessons to learn

The main lessons to be learned from this case study are for European policy makers:

- individual educated patients, even if suffering from severe impairments, need to be included from the beginning in R&D projects aiming at the establishment of services for disabled people; this will help taking their interests and needs into account at an early point of time.
- Also the managing board of patient organisations should formally be integrated in the R&D decision making process in order to ascertain market oriented direction, sustainability and smooth transfer of project results;
- The establishment of websites for disabled people must take special accessibility criteria of the web accessibility initiative (WAI) into account if it is to be successful; the use of assistive tools (e.g. speech browsers) should be made available on the accessible website itself
- Mirror websites, like the Usher website must take care to avoid legal conflicts by explicitly including "no-liability-clauses" and information about the original websites on each page.
- Disability and patient support groups should be informed regularly and systematically about EU R&D results (e.g. websites) and be helped to make the information available to interested users.
- NGOs willing to take up and implement EU project results (e.g. websites) should receive 100% "transfer activity funding" by a special "social application transfer programme". The main focus of such a programme would be the training of NGO volunteers in the assessment of the relevance and the implementation of R&D results for their organisations and members.
- Industry should monitor R&D programmes of the EU for relevant websites in order to support their viability and prevent obsolescence of contents by commercials or by other low cost support measures.

Perspectives

The average number of 10 to 20 hits per day and 250 to 350 hits per month on the Usher Europe website justify the continuous support and updating of the website by its owner even after completion of the EU TENCARE project. However, in the long run, a national or European Usher patient organisation needs to take over the website or it will loose connection to the real world and die. The visitors of the website today are visually and hearing impaired individuals (Usher/RP), patient support organisations (Hoerhilfe, EUSN, retino, Pro Retina), rehabilitation institutes (Rehadat, Tiresias, Sense) as well as research institutes (e.g. libraries, NIH).

As the Usher website is only irregularly updated and other national Usher websites emerge, it must be expected, that interest in the Usher Europe website will fade. In the next years new EU sponsored Usher related projects will establish their own websites (e.g. Gendeaf, Cause, Charge) and thereby further contribute to the obsolescence of the Usher Europe website if no cooperation or establishment of a Europe-wide Usher portal comes about.

2.3 Acknowledgements and links

Person to contact

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Literature

- Final report of EU TENCARE project, Bonn 2000.

WWW links

www.usher-europe.org