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D.1.1. End user involvement plan and definition of user groups



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5 EXECUTIVE SUMMARY

The value chain is composed of different stakeholders who work together or consecutively in order to provide or satisfy market demands. To give real significance to the project, end-users interests must be taken into consideration in a cross and transversal manner during the whole project. The involvement of active end-users from the beginning to the end of the project will ensure that the project is being carried out in the correct direction to achieve a successful and socially acceptable solution. Consequently, the project results will be used and adopted by disabled users, which is the main goal of the project.

In order to achieve this goal, an end-user involvement plan will be defined and presented in this deliverable. The involvement of the end-users will be broken down in several stages starting with a precise and accurate definition of the target of end-users and a compilation of user requirements. Once these requirements are analysed, the system will be developed. Then, after an evaluation, the system will comply with ethical and privacy issues.

Furthermore, the end-user overall psychophysical state should also be considered when developing the system, since they are specific for each group and will modify the system development. This means, that for each end-user group, several aspects will have to be taken into account. These aspects will be also defined in this deliverable.

Therefore, a specific and useful product will be developed in order to achieve the main objective of the project: to provide disabled people with a product to help them live independently and easily conduct their daily lives. The project won't only have an impact on the quality of life of it users, but will also have an impact on the lives of all individuals who come into regular contact with the enduser, carers and relatives.



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6 OBJECTIVES

Based on the results of the end-user requirements that that will be described in this first phase of the project, a platform which matches the needs and interests of people called young old (people from 55 to 75 years) with visual impairments will be carried out. The platform will in a later stage be tested by end users. This last step will be described in more detail in work package 4.

Taking into consideration the first phase of the project which focus on the user requirements, the specific objectives which will be achieved throughout the development of the work package, have been defined and summarized as follows:

- To involve users in the project development and assign them an active role in the definition of the system.
- To identify user needs in the project development and assign them an active role in the definition of the system.
- Derive high level functional specifications.
- Design testing and perform user evaluation.



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7 PARTICIPANTS

As it has been explained throughout the present document, two different participants in the ALICE project can be easily distinguished in this stage of the project. On the one hand, end-users have a main role in the project. On the other hand, specialized developers and associations will also play an important role. The main characteristics of these different participants will be defined in the next sections.

7.1 END-USERS

To find exact definition for terms like »blindness«, »partial sight«, »visual impairment«, »low vision«, »and vision loss« is not simple. Furthermore, »visual impairment«, »visual disability« and »visual handicap« are used as synonyms, although actually having other meanings. Visual impairment is focusing on the condition of the visual system (in terms of measurements such as visual acuity, visual field and contrast sensitivity), whereas visual disability and visual handicap refers on the condition of the person as a whole (to measure and describe the ability or disability of the person requires broader descriptors such as daily living skills, vocational skills, orientation and mobility skills, reading and writing skills). 1

In some other expert definitions various terms are used for the same or different conditions. For this project's purpose we aim to use the most prevalent criteria of defining blindness, following the categories of the International Classification of Diseases by the World Health Organisation from 2010. Classification is based on vision measuring from a certain distance (Table 1) and presents an International Standard.

¹ Colenbrander A. and Fletcher D.C. (1995). Basic Concepts and Terms for Low Vision Rehabilitation. In: The American Journal of Occupational Therapy, vol. 49, no. 9, 865.



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O ULTURE OF THE PROPERTY OF T	Presenting distance visual acuity	
Category	Worse than:	Equal to or better than:
	6/7.5 - meter	6/18
0:Mild or no visual impairment	8/10 (0.8) - decimal	3/10 (0.3)
·	20/25 – feet	20/70
	6/18	6/60
1:Moderate visual impairment	3/10 (0.3)	1/10 (0.1)
	20/70	20/200
	6/60	3/60
2:Severe visual impairment	1/10 (0.1)	1/20 (0.05)
	20/200	20/400
	3/60	1/60*
3:Blindness	1/20 (0.05)	1/50 (0.02)
	20/400	5/300 (20/1200)
	1/60*	light perception
4:Blindness	1/50 (0.02)	
	5/300 (20/1200)	
5:Blindness	No light _l	perception
6	6 Undetermined or unspecified	
*or counts fingers (CF) at 1 metre.		

Table 1: Definition of visual impairment categories²

When a person's visual acuity is 6/6, the person is able to read the content from 6.1 m away. The same as a person with normal eyesight would see it from 6.1 m. If a person has acuity of 6/12, he sees content from 6.1 m away, the same as a person with normal eyesight would see it from 12 m away.

Vision is normally measured using a Snellen chart (Figue 1), a chart provided with letters of different sizes that are read, one eye at a time, from a distance of 20 ft. People with normal vision are able to read the 20 ft line at 20 ft-20/20 vision—or the 40 ft line at 40 ft, the 100 ft line at 100 ft, and so forth. If at 20 ft the smallest readable letter is larger, vision is designated as the distance from the chart over the size of the smallest letter that can be read.

²Definition of visual impairment categories. Available online at: http://apps.who.int/classifications/icd10/browse/2010/en#/H53-H54.



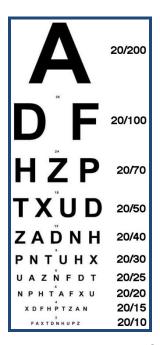


Figure 1: Snellen chart³

There are some other ways which eye care professionals use to measure vision. Clarity (sharpness) of vision indicates how a person's central visual status is. The diopter is the unit of measure for refractive errors such as nearsightedness, farsightedness, and astigmatism and indicates the strength of corrective lenses needed. Furthermore, people do not just see straight ahead; the entire area of vision is called the visual field. Some people have good vision (e.g., see clearly) but have areas of reduced or no vision (blind spots) in parts of their visual field. Others have good vision in the center but poor vision around the edges (peripheral visual field). People with very poor vision may be able only to count fingers at a given distance from their eyes. This distance becomes the measure of their ability to see. The most common chart for Visual Acuity measuring is the Snellen chart, although it is not recommended for low vision patients as the contrast level is generally poor.4 For visual acuity values of less than 0.1 (20/200, 6/60) estimates such as "Count Fingers" and "Hand Motions" are often used. It is recommended that actual measurements at a shorter distance be used instead. Measurement at 1 meter provides the widest measurement range and the simplest Snellen fraction. 5

⁵ Colenbrander A. (2002). Visual Standards: Aspects and Ranges of Vision Loss with Emphasis on Population Surveys. Available online at: http://www.icoph.org/downloads/visualstandardsreport.pdf.



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³ Snellen Chart. Available online at: http://www.mdsupport.org/snellen.htm.

⁴ Appel S.D. and Brilliant R.L. (1999). The Low Vision Examination. In: Brilliant R. L. (Ed). Essentials of Low Vision Practice, 25.

7.1.1 DEFINITION OF USER'S VISUAL CHARACTERISTICS

Low Vision

Low Vision is defined in many ways and has different understandings. Some experts define Low Vision as a significant reduction of visual function that cannot be corrected to the normal range by ordinary glasses, contact lenses, medical treatment and/or surgery and that interferes with the functioning of the individual, thereby creating the disability. On the other hand Colenbrander & Fletcher claim that Low Vision is not a single condition: some suffer visual acuity loss, others suffer visual field loss, some benefit from more light, other need dark glasses. Furthermore, Colenbrander suggests that term Low Vision is used for lesser degrees of vision loss, where individuals can be helped significantly by *vision enhancement* aids and devices.

Visual Impairment

Visual Impairment – to be used when the condition of vision loss is characterized by a loss of visual functions (such as visual acuity, visual field, etc.) at the organ level. Many of these functions can be measured quantitatively.

Vision Loss

Neutral term, used to define any type of degree changes in vision. It could apply to visual acuity as well as to visual field changes. It refers to those who have lost only some vision or who have little vision left. ¹⁰ The term Vision Loss can be used as a general term, including both total loss (Blindness) and partial loss (Low Vision), characterized either on the basis of visual impairment or by a loss of functional vision. ¹¹

Blindness

Total blindness is the inability to tell light from dark, or the total inability to see. This term should be reserved only for those, who can't see anything or have no usable vision. It means totally loss of



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⁶ Faye, 1984 in Southall K. and Wittich W. (2012). Barriers to Low Vision Rehabilitation: A Qualitative Approach. In: Journal of Visual Impairment & Blindness, vol. 106, no. 5, 262.

⁷ Colenbrander & Fletcher 1995, 865.

⁸ Colenbrander 2002, 2.

⁹ Ibid.

¹⁰ Colenbrander & Fletcher 1995, 865.

¹¹ Colenbrander 2002, 2.

vision or inability to distinguish light from dark. Many experts like Colenbrander and Fletcher do not agree with the common usage of the word blindness because the meaning is extended to conditions of partial vision loss.

Legal blindness (which is actually a severe visual impairment) refers to a best-corrected central vision of 20/200 or worse in the better eye or a visual acuity of better than 20/200 but with a visual field no greater than 20° (e.g., as if the person would look through a tunnel). 13

7.1.2 USER'S VISUAL CHARACTERISTICS CAUSES

Despite the fact that much progress has been made in surgery over last couple of decades to prevent certain eye conditions according to data 14, as can be seen in figure 2, refractive errors and cataract remain the leading cause of visual impairment around the world, except for developed countries.

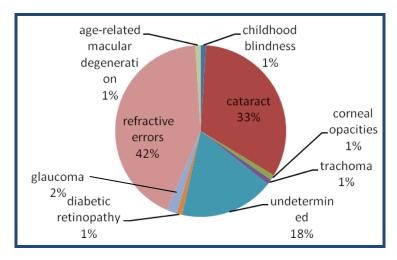


Figure 2: Main causes of Visual Impairment. 15

The main causes of blindness, as it can be seen in figure 3 are: cataract, 51%, glaucoma, 8%, AMD, 5%, childhood blindness and corneal opacities, 4%, uncorrected refractive errors and trachoma, 3%, and diabetic retinopathy 1%. The undetermined causes are still around a 21%.



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¹² Colenbrander & Fletcher 1995, 866.

¹³ Colenbrander & Fletcher 1995, 866.

¹⁴ World Health Organisation (2012). Global Data on Visual Impairments 2010. Available online at: http://www.who.int/blindness/en/.

^{15 &}lt;sub>Ibid.</sub>

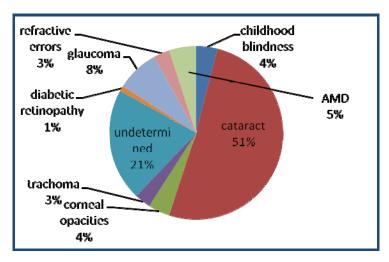


Figure 3: Main causes of Blindness. 16

Cataract

A cataract is a cloudiness or opacity in the normally transparent crystalline lens of the eye. This cloudiness can cause a decrease in vision and may lead to eventual blindness. ¹⁷ Usually, a cataract is age-related condition. It may vary in its severity from a small amount of clouding to dense areas of haziness. In this condition, the passage of light is disturbed, which prevents the eye to focus correctly. The lens is situated behind the iris (the coloured part of the eye). Its purpose is to bend light rays so that they provide a clear image to the retina at the back of the eye.

As a result of age and individual characteristics, the coloration of the lens increases (lack of oxygen), the transparency diminishes and cataract formation begins. The loss of transparency is primary due to the appearance of zones in which the refractive index differs substantially from the one of the surrounds. Visible light is scattered, not transmitted and this has two main consequences: a reduction in image contrast and clarity. 18

The person with a cataract may have blurred vision, suffer from glare and find bright lights uncomfortable. Colours may not appear to be as bright and objects seem dull. The progression of cataracts varies between each individual and often among the two eyes of the same person. In some cases, the person affected sees well in closed environments like their houses, but find that their vision is reduced by glare or at night. Cataracts can cause blindness, but this can be prevented by early diagnosis and treatment.



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¹⁶ Global Data on Visual Impairment, 2010

¹⁷ Chylack L. T., Jr., M.D. (2000). Age-Related Cataract. In: Silverstone B., Lang M. A., Rosenthal B. P. and Faye E. E. (Eds), The Lighthouse Handbook on Vision Impairment and Vision Rehabilitation, vol. 1, 33.

¹⁸ Ibid.

Diabetic retinopathy

The Diabetic retinopathy is the most common diabetic eye disease and one of the leading causes of blindness in most developed countries. It is caused by changes in the blood vessels of the retina. Another common diabetic eye disease is cataract and glaucoma. All these eye diseases can cause severe vision loss or even blindness. 19

The main symptom of the diabetic retinopathy, are some vision changes. But over time, diabetic retinopathy can get worse and cause vision loss. Diabetic retinopathy usually affects both eyes.

Glaucoma

Glaucoma can be considered to be a final common pathway of number of diseases that affect the eye. Glaucoma can be defined as progressive optic neuropathy with a particular pattern of optic nerve damage and visual field loss that results from a variety of diseases affecting the eye, most of which, but not all, cause elevated intraocular pressure (IOP). IOP is not the disease itself, it is caused by the diseases.²⁰ If it is diagnosed early, blindness is nearly always preventable, if untreated can lead to optic nerve damage resulting in progressive, permanent vision loss, starting with unnoticeable blind spots at the edges of the field of vision, progressing to tunnel vision, and then to blindness.

Age-related Macular Degeneration

Age-related Macular Degeneration (MD) is a degenerative disorder of the central area of the retina, the macula, which allows us to see clearly and appreciate colour, and is often associated with severe, central visual impairment.²¹

In the early stages of MD, central vision is blurred and seeing at a distance is difficult. The eye may still have good side vision, but blank spots appear in the centre. Consequently, close to the eye activities such as reading or sewing are difficult. The recognition of people by their faces becomes also a quite complicated task.

Other symptoms for MD include: dimming of colour vision or difficulty in judging heights and distances. Sometimes only one eye is affected by MD while the other eye may stay perfect.MD does not lead to total blindness. This condition occurs most commonly in elderly people.

Figure 4 shows examples of how the vision of a person with the above mentioned diseases is.

²¹ Schwartz S. D. (2000). Age-Related Maculopathy and Age-Related Macular Degeneration. In: Silverstone B., Lang M. A., Rosenthal B. P. and Faye E. E. (Eds), The Lighthouse Handbook on Vision Impairment and Vision Rehabilitation, vol. 1, 83.



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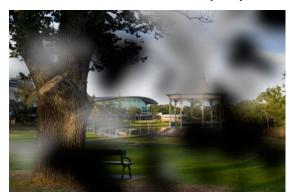
¹⁹ Leonard B. & Charles S. (2000). Diabetic Retinopathy. In: Silverstone B., Lang M. A., Rosenthal B. P. and Faye E. E. (Eds), The Lighthouse Handbook on Vision Impairment and Vision Rehabilitation, vol. 1, 103.

²⁰ Ritch R. (2000). Glaucoma. In: Silverstone B., Lang M. A., Rosenthal B. P. and Faye E. E. (Eds), The Lighthouse Handbook on Vision Impairment and Vision Rehabilitation, vol. 1, 53.

Cataract



Diabetic retinopathy



Glaucoma MD





Figure 4: Vision of an image with different eye desease (Source: http://www.rsb.org.au/)

7.1.3 TARGET OF END-USER GROUP.

In order to carry out a successful analysis of end-users, the first step to follow is to target the users or to classify them according to their distinguishing feature within the project context. In this sense, the target group of this project are principally people in the age group called 'young old' — people from 60 to 75 years of age with visual impairments.

Presently populations are in general ageing. Meaning, life expectancy rises due to several reasons: the main causes being better life-standards over the past few centuries and decades (good health care accessible to majority; more food and more quality foods, etc.). On the other hand birth rates are gradually declining, which mainly occurs in the most developed parts of the world including European countries. Therefore special attention should be given to the following issues such as agerelated problems, health conditions or diseases of elderly people.



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Elderly people are more likely to have some vision problems. In fact, WHO data reveals that globally 65 % of all visually impaired people, 63 % those with low vision and 82 % of blind are older than 50 years; of whom in Europe there are 28.2 million visually impaired 25.5 with low vision and 2 million blind.²² Therefore, changes in vision become more delicate with ageing, but until recently, this issue has been neglected.

The end-users testers will be provided by two organisations: UBPS from Slovenia (SLO) and COMBD from U.K (these two organisations will be described in section 7.2). Four groups will be assembled in Slovenia and the United Kingdom representing a statistically sound sample of elderly vision impaired people. The main features of end-users that will participate in the project are shown in table 2.

Target groups of end-users		
Number of groups	4 groups	
	(2 in UK, 2 in SLO).	
Characteristics of subgroups	In each country 2 groups (1 blind and 1 partially sighted)	
Age of participants	55-75	
Number of participants	20 (in each country) 23	

Table 2: Testers groups characteristics.

In order to have a wide range of testers and to obtain as much diversity of opinions as possible, testers with different visual disease will be selected. The profile of the testers which will be provided by each entity is shown in table 3.

UBPS	COMBD
Glaucoma	Macular Degeneration
Cataract	Diabetes
Diabetes	

Table 3: Visual diseases of testers.

²³ For project purposes 15 participants is the minimum. In order to avoid some problems, which might occur later on because of possible participant's withdrawal, we suggest 18-20 people (9-10 for each group).



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²² Source: http://www.who.int/blindness/en/

7.1.4 PSYCHOPHYSICAL STATE OF END-USERS

As mentioned in previous sections, the term "visual impairment" includes several eye-conditions, which could not be defined from only one scientific point of view. Consequently, special attention should be paid on diversities of individuals involved into the project taking into account psychological and social aspects.

Psychological aspects

The type of vision loss an individual has experienced and the life stage at the onset of the visual impairment reveals significant information about the person, which is very important for the further analysis as the diagnosis can affect the adjustment process.24

From a psychological point of view, self-esteem is also a very important part of each individual's personality. The factors that contribute to self-esteem of a visually impaired person are the same ones that contribute to anyone's self-esteem. The way people feel about themselves influences the way they are able to perform, and performance, in turn, affects the way they feel about themselves and the way they are perceived by others.²⁵ Self-esteem is the key factor for successful life.

The psychological implications to be considered when dealing with end-users include the learning of concepts, mental abilities and school/professional achievement, personality traits and the process with the adjustment to blindness. Vision plays a very dominant role in the conceptualization process of learning properties and attributes of people, objects and events. The more severe the vision loss is the less a person can be dependent on visual sensory data and the must rely on other senses, primarily hearing and touch. Furthermore, opportunities for learning from experiences are more limited for blind people and require more careful planning, as conceptualization without vision could have many difficulties: some objects and events are too large, too far away, too dangerous or too quick to permit the observations, and verbal descriptions often do not provide an adequate basis for concept formulation. Nevertheless, blindness does not impair one's innate ability to process or manage sensory information intellectually.

However, it should be take into account, that blindness itself tends to aggravate latent or pre-existing personality traits e.g.: the more dependent people are, the more likely they will use blindness to rationalize even greater dependency (a non-conformist may use blindness as an excuse for eccentric

²⁵ Tuttle D. W. and Tuttle N. R. (2004). Self-esteem and Adjusting with Blindness: The Process of Responding to Life's Demands, 3rd ed., Thomas Books, 5.



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²⁴ Graboyes M. (1999). Psychosocial Implications of Visual Impairment. In: Brilliant R. L. (Ed). Essentials of Low Vision Practice, 12.

behaviour etc.).²⁶ Any kind of vision change means a trauma in a person's life. Therefore everyone who deals with this change goes through the adjusting process, which could be a unit of the following sequential phases: physical or social trauma; shock and denial, mourning and withdrawal; succumbing and depression; reassessment and reaffirmation; coping and mobilization, and the last self-acceptance and self-esteem.

Social aspects

The possibility of blindness is a terrifying thing in all people. In the younger person, there are huge issues relating to socialising, studying, and getting a job. In the older person, independent living may be jeopardised. In all patients, there may be existential questions about self-definition, fear of isolation and the possibility of depression. This needs to be acknowledged yet sensitively balanced with the reality of the condition, e.g. it is fairly unusual for conditions to lead to total blindness and the patient can often learn to use their residual vision. 27

People who are visually impaired have a tendency to be more frequently socially isolated or have feelings of loneliness. They are not always able to find companions for conversation, often waiting to be spoken to first. In a group of individuals with sight loss often find it difficult to know when comments are directed to them. They are less able to observe the non-verbal undertones of social interaction. Frequently, isolation is a consequence of how sighted people approach to the visually impaired, especially when they are uncertain about the way of doing it and they rather step back instead. Due to difficulties mentioned above, also blind people many times give up and prefer not to socialise with others, which could result in the creation of an active fantasy life and pessimism.²⁸

7.2 SPECIALIZED ASSOCIATIONS

As it has been mentioned above, two specialized associations will carry out the ALICE project. On the One hand COMBD, from UK and on the other hand UBPS from SLOVENIA.

7.2.1 COMBD

COMBD is a charity with a mission to enable blind, predominantly older people, to embrace new technology that provides a window on the world. From 2006 COMBD has been distributing free from www.screenreader.net software, 'Thunder' that makes a computer talk. Up to now, screen reader technology has been available but at a high cost to each individual. Most blind people remain poor and there is no other way of including all of them in the digital 21st century. Over 300,000 blind



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²⁶ Wright 1983 in Ibid, 54.

²⁷ http://www.patient.co.uk/doctor/Gradual-Loss-of-Vision.htm

²⁸ Tuttle & Tuttle 2004, 40.

people have downloaded COMBD software in the last 5 years. COMBD see the mobile smartphone that can 'talk' as a tool for safe and sound travel enabling blind and other disabled people to confidently venture outside their homes. COMBD has developed a suite of smartphone applications that link the nervous blind traveller with remote emergency help and publically available travel information. Importantly the phone is also able to provide, via a speech function, personalised points of interest so that the traveller knows exactly where they are within their journey, i.e. "You are now outside the Day Centre", "Get off the bus now". The 'Georgie' technology is unique and nothing similar is available to blind people. Georgie will also be of help to those with early Alzheimer's and other older people who have difficulties with using public transport.

For the purpose of the ALICE project COMBD can recruit from a large database of existing end-users to test, trial and gain the user perspective for the project's developed technologies. And COMBD key staff has over 20 years involvement with those with little or no sight in training them to embrace new technology. COMBD feels that its skills set and considerable experience will make an excellent fit with other partners in the current project. COMBD has a proud record of mass-distributing effective affordable technology to a blind and visually impaired client group.

7.2.2. UBPS

The Union of the Blind and Partially Sighted of Slovenia is an independent, non-government and non-profit disability organization and it is the umbrella organisation for nine regional associations of the Blind in Slovenia with more than 4000 members. It has been working since 1920 and it is the oldest Slovenian organisation for the people with disability. The main aims of the Union are to promote the rights and interests of People with Sight Loss and to provide information, support, different services and activities on the national level in order to meet the special needs in their daily lives and work.

In accordance with our vision and with co-operation with our regional associations we provide a wide range of programmes and activities for our members, their relatives and volunteers such as: knitting, embroidery and crochet; excursions; lectures, house-keeping and daily living activities; sporting activities (showdown, chess, nine pin bowling, swimming etc.); computer courses; mobility courses; Braille courses; self-help groups; seminars; training with relatives of a blind or partially sighted person; organising social events; training other senses; Informing members – publishing newspapers in different formats (Braille, audio, large print, e-news); and maintaining the network of volunteers.

Furthermore, we provide, lobbying, library for the blind, and provision of technical aids. We strive to improve educational and employment opportunities, social and health care and to encourage Blind and Partially Sighted to take an active role in the decision making process and enable them to live a full and independent life.



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8. USER INVOLVEMENT METHODOLOGY

8.1 USER CENTERED DESIGN

User Centered Design (UCD) means a development approach which focuses on the end-users who will use the product or service created (Courage & Baxter, 2005). The aim of UCD is that the product/service developed should suit the user, rather than making the user suit the product/service. This is accomplished by employing techniques, processes, and methods throughout the life cycle of the product/service, that maintain the focus on the user from the very beginning until the end. There are three key principles of UCD (regarding Courage & Baxter, 2005) which we apply throughout the project:

- An Early focus on Users and Tasks: The first principle focuses on the systematic and structured collection of users' requirements. By letting the user be involved from the beginning, the usability of a product and the usefulness of a service are maximized. The earlier the end-user is involved in the project the earlier inappropriate project work will be avoided. Thus the first step to be carried out in ALICE is to gather user requirements to get an understanding of what the user really wants and needs.
- Empirical Measurement of Product/Service Usage: This principle focus on the usability and testing of prototypes/models. A usability test is provided to users who are furthermore asked to complete a session of tasks with a prototype or the final product. Different metrics such as errors and task completion rates are analyzed in order to improve the product/service before the final version is developed.
- Interactive Design: The final principle recommends that collected requirements are used to
 design, modify, and test repeatedly the product/service. The development cycle is not
 something to go through; it is continuously iterated and fine-tuned with each cycle until the
 best product/service is obtained.

A schema of the UCD can be found in figure 5.



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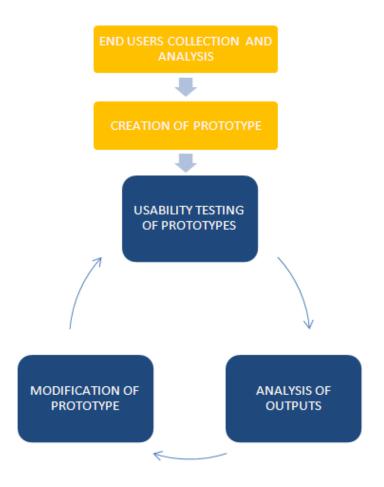


Figure 5: Schema of the UCD.

8.2 PROCEDURE

The requirements, needs and wishes of end-users will be the backbone of the ALICE project. As it has been mentioned in several sections, they will be collected, compiled and analyzed from the very beginning of the project in order to have a bottom-up approach.

Furthermore, the end-user will be asked to participate at each iteration of the product to provide their feedback. Furthermore, once the requirements have been collected, the product will be modified repeatedly and the opinion of the end-users will also been asked in a second round. Participants will be told that, although no detail has yet been agreed, that they will be asked to test and review at least 3 iterations of ALICE, including the final product, over the coming 27 months. With each iteration, users understand that they are to provide suggestions and guide the change of requirements according to their empirical knowledge of using ALICE. By user involvement in the design phase the system will improve and new requirements can be included with every iteration until all the "nice to have" features are in place.



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The phases that will be part of the procedure and development methodology of the ALICE project are as follows:

- Phase 1: Requirements collection.
- Phase 2: Initial trial and iterations.
- Phase 3: Final trial.

The first step for the user requirement data collection is to develop a questionnaire, together with the two other partners involved in this task, UBPS and COMBD. The overall results from the user requirement data collection will be to guide the developers to design and adapt the ALICE platform taking into account each target group. Based on the questionnaires and interview results, the same participants will attend smaller groups where, using participatory design methods, will give their inputs for specific issues of the system such as appearance, understanding... etc.

In the second and third phases of the project, trials will be conducted. The final evaluations of the ALICE platform during the third phase will mainly observe how the users interact with the final prototype and how the technology accepted.

During the second and the third phase, working or focus groups will be organized. The working group is thought to complement the data collected in the interview to gain a deeper and holistic view of the users' interests and needs. A group of individuals will be brought together to discuss their experiences or opinions around the topics introduced by a moderator. These encounters will be practical sessions where the moderator will show the participants some examples of the platform so as to generate an active participation and response of the participants about the new system. This method is good for quickly understanding user perceptions about a particular topic or concept. One of the key benefits is that the group dynamic brings up topics you may never have thought to ask about and it can stimulate new ideas (Courage & Baxter, 2005). Also problems, challenges, frustrations, like, and dislikes among users can be discovered in a working group. They are a good help for the researcher to understand the users' opinions, attitudes, preferences and initial reactions

The detailed procedure and plans for both evaluations will be specifically prepared for each phase based on the results obtained in the previous phase. A scheme for the global procedure can be found in figure 6.



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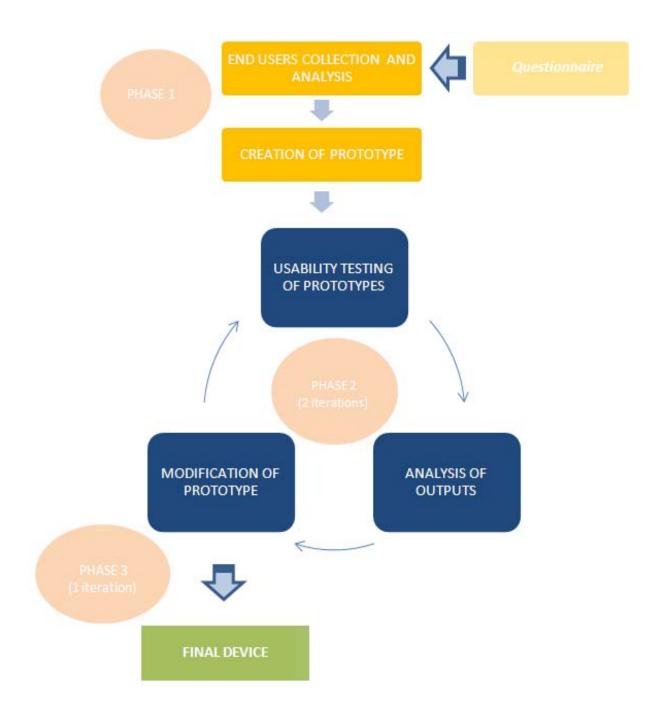


Figure 6: Schema of the procedure.



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8.3 ESTABLISHING CONTACT WITH THE PARTICIPANTS

8.3.1 COMBD PROCEEDING

All the testers are very willing volunteers but we agreed to pay them a small engagement fee plus any appropriate travel expenses. Participants will be paid €67 for their participation plus appropriate user travel costs by public transport or taxi if necessary. Most live within 1 hour travel time from Peterborough UK to facilitate management of the work

All testers are emotionally at ease with their disabilities and are within the normal intelligence range.

The UK user group will communicate via standard PC email and telephone. According to privacy issues, users will be identified by a number and initials e.g. 2.TT = First totally blind group Sally Smith or 3. CC = Bill Bloggs. Each will sign a participation consent form, a non-disclosure form and receipts for payment forms.

Participants understand they are to test a specialist smartphone which will give them a range of useful mobility information in a way which will not bombard their senses. They will expect to be handling headphones and a camera. Furthermore, participants understand that it will not be possible within the project budget to provide a free ALICE at the conclusion.

8.3.2 UBPS PROCEEDING

Most of the work with the end-users will be in Ljubljana. In this part of the country the biggest regional association is located with the largest number of members (more then 1000). All participants live within half an hour's travel time and will be therefore be available for testing any time. This will make it more convenient for them as well as for the researchers. Participants will be paid €67 for their participation plus appropriate user travel costs by public transport or taxi if necessary.

All testers are emotionally at ease with their disabilities and are within the normal intelligence range.

Communication with the end-users will be held by telephone, email and mail. According to privacy issues, users will be identified with the code explained in the previous section. They will be provided of questionnaires and samples of consent letter and other documents, if necessary. When the consortium agrees on these documents, end-users will be finally invited for interview. According to Slovenian labour legislation, a special contract with everyone is required in order to reimburse the cost. These special contracts will specify the terms of work, commitments of the researchers and end-user, amount of the payment, rights of the end-user, approximate timetable and other obligations. There is also certain feedback expected from the end-users at each stage of the testing. They will provide essential information and suggestion for the further development of the ALICE device.



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D.1.1. End user involvement plan and definition of user groups

UBPS will contribute with sample of questionnaire, sample of consent letter and other documents, if necessary. When the consortium agrees to these documents, end-users will be finally invited to be interviewed.

To protect anonymity and identity of the end-users, the UBPS will devote special attention to several aspects. First of all, the researchers and developers of the ALICE project will not put participants at risk at any point in the project and will respect fundamental ethical principles in their dealings with participants. The typed interviews or any other document will NOT contain any mention of the end-users name, and any identifying information will be removed. A unique numbered code will be used rather than names or other personal details. All the research material will be stored in a secured location within UBPS.



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9 MATERIAL

As mentioned in section 8, testers will be provided with questionnaires at interviews and samples of consent letter and other documents, if necessary.

Interviews are one of the most frequently used user requirements gathering techniques and have been successfully used in previous projects. An interview is a guided conversation in which one person seeks information from another and has some advantages over other methods. There is a variety of different types of interviews that can be conducted, depending on constraints and needs. For the ALICE project the structured interview with already closed questions is considered the most appropriate one in the first phase in gathering user requirements. Structured interviews have some positive features like: quick to analyze, questions asked are consistent across participants, and also generally more questions can be asked than in an unstructured interview.

As it has been explained in section 7.1.4, in addition to questions related to the ALICE device itself, the psychophysical state should also be considered when developing the system, since they are specific for each group and will modify the system development. Consequently, the information needed from the tester, which will be obtained from the questionnaire, will cover several areas as it is shown in figure 7.

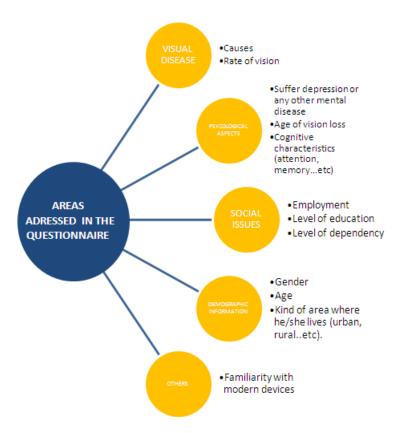


Figure 7: Scheme of the areas addressed in the questionnaire.



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10 ETHICAL ISSUES

General international ethical guidelines for scientific investigation will be followed during the development of the project. The idea is that the research is conducted in a correct way and that the experience will be as pleasant as possible for the users involved.

As within WP 1 of the ALICE project, Deliverable 1.4 is totally dedicated to ethical and data protection and only some relevant points for the current deliverable are highlighted here.

Data protection

To guarantee the user's anonymity, all the individuals will be assigned an alphanumeric code at the beginning of their participation. In this way personal information will be disassociated from project related data in a different database that will not be used for further analysis.

Time limit

The design of the user requirement data collection has been done with the end users in mind. The questionnaire is designed to collect both the data the researchers are interested in but also to minimize the time users have to spend in the test laboratory.

<u>Information</u>

Users will receive thorough information about the project at initial contact with the project. They receive the consent form and also a separate information sheet with more details specified to take home.



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10 CONCLUSIONS

The involvement of active end-users is one of the main features of the ALICE project, because the participation of end-users during the whole project life ensures that the project results achieve all their requirements and consequently ensures that the project outcome will be used and adopted by them.

In order to achieve this, ALICE has developed an end-user involvement plan and procedure. The involvement plan will consist of a definition of testers which will be provided by UBPS and COMBD. They will establish a communication process with them where they will gather their requirements. All this information will be collected throughout specific questionnaires which will be carefully developed for this action and for this project. Furthermore, they will be analysed and the data will be compiled and delivered to technicians in order to take it into consideration when developing the ALICE platform.

An iteractive design will be followed because users will be contacted in a second phase to test some of the technological developments in order to ensure that they match with their requirements. Depending on the results, necessary amendments will be carried out. Some final evaluations of the ALICE platform will be carried out mainly to observe how the users interact with the final prototype and how the technology is accepted.

With a focus on continuous feedback from the end-user, a relevant and useful product will be achieved: a product that provides disabled people with technology that helps them to live independently and more easily live their daily lives.



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11. REFERENCES

- Appel S.D. and Brilliant R.L. (1999). The Low Vision Examination. In: Brilliant R. L. (Ed). Essentials of Low Vision Practice, pp 19-47.
- Chylack L. T., Jr., M.D. (2000). Age-Related Cataract. In: Silverstone B., Lang M. A., Rosenthal B. P. and Faye E. E. (Eds), The Lighthouse Handbook on Vision Impairment and Vision Rehabilitation, vol. 1, pp 33-52.
- Colenbrander A. (2002). Visual Standards: Aspects and Ranges of Vision Loss with Emphasis on Population Surveys. Available online at: http://www.icoph.org/downloads/visualstandardsreport.pdf.
- Colenbrander A. and Fletcher D.C. (1995). Basic Concepts and Terms for Low Vision Rehabilitation. In: The American Journal of Occupational Therapy, vol. 49, no. 9, pp 865-869.
- Definition of visual impairment categories. Available online at: http://apps.who.int/classifications/icd10/browse/2010/en#/H53-H54.
- Graboyes M. (1999). Psychosocial Implications of Visual Impairment. In: Brilliant R. L. (Ed). Essentials of Low Vision Practice, pp 11-19.
- Leonard B. & Charles S. (2000). Diabetic Retinopathy. In: Silverstone B., Lang M. A., Rosenthal B. P. and Faye E. E. (Eds), The Lighthouse Handbook on Vision Impairment and Vision Rehabilitation, vol. 1, pp 103-127.
- Ritch R. (2000). Glaucoma. In: Silverstone B., Lang M. A., Rosenthal B. P. and Faye E. E. (Eds), The Lighthouse Handbook on Vision Impairment and Vision Rehabilitation, vol. 1, pp 53-81.
- Schwartz S. D. (2000). Age-Related Maculopathy and Age-Related Macular Degeneration. In: Silverstone B., Lang M. A., Rosenthal B. P. and Faye E. E. (Eds), The Lighthouse Handbook on Vision Impairment and Vision Rehabilitation, vol. 1, pp 83-101.
- Southall K. and Wittich W. (2012). Barriers to Low Vision Rehabilitation: A Qualitative Approach. In: Journal of Visual Impairment & Blindness, vol. 106, no. 5, pp 261-274.
- Snellen Chart. Avaliable online at: http://www.mdsupport.org/snellen.html
- Tuttle D. W. and Tuttle N. R. (2004). Self-esteem and Adjusting with Blindness: The Process of Responding to Life's Demands, 3rd ed., Thomas Books.
- World Health Organisation (2012). Global Data on Visual Impairments 2010. Available online at: http://www.who.int/blindness/en/.



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