



# SUITCEYES

1 Jan 2018 - 31 Dec 2020

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Smart, User-friendly, Interactive, Tactual, Cognition-Enhancer, that Yields Extended Sensosphere  
Appropriating sensor technologies, machine learning, gamification and smart haptic interfaces

[8.14]

## Data Management Plan

Courtesy of LightHouse for the Blind and Visually Impaired, see <http://lighthouse-sf.org>



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Dissemination level		
<b>PU</b>	PUBLIC, fully open, e.g. web	X
<b>CO</b>	CONFIDENTIAL, restricted under conditions set out in Model Grant Agreement	
<b>CI</b>	CLASSIFIED, information as referred to in Commission Decision 2001/844/EC.	

Deliverable Type		
<b>R</b>	Document, report (excluding the periodic and final reports)	X
<b>DEM</b>	Demonstrator, pilot, prototype, plan designs	
<b>DEC</b>	Websites, patents filing, press & media actions, videos, etc.	
<b>OTHER</b>	Software, technical diagram, etc.	

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Glossary	
Abbr./ Acronym	Meaning
<b>D8.14</b>	Deliverable 8.14 – Grant Agreement No. 780814 – SUITCEYES [deliverable number on pages 9, 35-37]
<b>SUITCEYES</b>	Smart, User-friendly, Interactive, Tactual, Cognition-Enhancer that Yields Extended Sensosphere - Appropriating sensor technologies, machine learning, gamification and smart haptic interfaces
<b>WP8</b>	Work Package 8 – Dissemination, Knowledge-sharing & Exploitation
<b>FAIR</b>	Findable, accessible, interoperable and re-usable data
<b>HARPO</b>	Harpo Sp. z o.o., Poland
<b>HB</b>	Hoegskolan i Boras / University of Boras, Sweden
<b>UNIVLEEDS</b>	University of Leeds, United Kingdom
<b>TU/e</b>	Eindhoven University of Technology, Netherlands
<b>HSO</b>	Offenburg University of Applied Sciences, Gemany
<b>LDQR</b>	Les Doigts Qui Rêvent, France
<b>DMP</b>	Data Management Plan
<b>HIPI</b>	Haptic, Intelligent, Personalized Interface
<b>GDPR</b>	General Data Protection Regulation
<b>PMB</b>	Project Management Board
<b>EAB</b>	Ethics Advisory Board
<b>GA</b>	Grant Agreement
<b>RGB-D</b>	Red, Green, Blue plus Depth camera

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# 1. Executive Summary

This Data Management Plan (DMP) defines effective *governance* and *management* of research data generated and or used with the SUITCEYES project. It addresses issues of data generation, ownership, storage, access, exchange, use, openness, protection, preservation and destruction.

This document (and its subsequent updated versions) will act as a guideline and provides an overview of research-data-related procedures within the project. It aims to facilitate collaboration and help avoid unnecessary duplications of work and data creations. It further defines procedures and routines for easy and effective information sharing during the project time and beyond. It is also a useful tool in ensuring continuity and bridging gaps even in the cases of additional new members in the project.

After the introductory parts, Chapter 3 of the document presents an adaptation of five (5) Data Governance Domains of *Data principles*, *Data quality*, *Metadata*, *Data access*, and *Data lifecycle* which aim at defining the decision-making structures that govern data-related issues within the project. Following these, chapter 4 provides further description of routines for data management. The approach of reaching informed consent and other agreements with users taking part in requirements, user studies, video-recordings and other R&D activities has also been included. The document is concluded with a short summary and two appendices.

## 2. Introduction and Rationale

This deliverable – Data Management Plan (D8.14) – incorporates both Data Governance and Data Management and accordingly defines the principals, procedures, and routines that are put in place for the management of research data within the SUITCEYES project.

As such, this document and its subsequent versions, act as a guide to help form an up-to-date overview of the project-related data and related procedures. This DMP is produced with the aim of facilitating information sharing and collaboration, while avoiding unnecessary duplications of work. It also defines the basis for various choices and is meant to help the members to make sound and appropriate decisions when needed. This DMP is also meant to create continuity even in potential cases of membership change.

This document presents the data governance approach adopted, and describes the research data that will be collected, generated and or used. It outlines the related data types and the ways in which the data will be handled both during and after the project. Furthermore, it will describe which data will be made available openly and which data will be kept protected, and the reasons why.

This DMP will remain a living document and will be updated when needed as the project progresses. This deliverable is licensed under the Creative Commons License CC BY-NC-SA (Attribution-NonCommercial-ShareAlike).

### 2.1 SUITCEYES and Open Data

SUITCEYES is a three-year long (2018-2020) Horizon 2020 RIA project with a focus on facilitating communication in cases of deafblindness through a smart haptic interface. The project will address three challenges of (a) improved perception of the physical surroundings, (b) improved exchanges of semantic contents, and (c) enjoyable learning through gamification.

The project involves many areas of research including disability studies, user studies, psychophysics, sensor technologies, face and object recognition, semantics and knowledge management, social media studies, gamification and affective computing, and smart textiles. As such, much data will be accessed used and or generated during the project.

Open data, typically refers to online free distribution of research data and results for access and reuse by third parties towards benefiting both future research and society. With the advances in the “open” movement, a growing demand for open and interoperable research data has emerged.

The view held in SUITCEYES is that all research, and especially those funded by public money, should benefit the whole society, be instrumental for progress, and act as a stepping stone for further research. We will therefore make the research results available through different channels and strive to provide open access to the project data, as far as possible. However, not all data generated and used within SUITCEYES are suitable or appropriate for sharing and reuse, and hence, SUITCEYES has chosen not to participate in the Open Research Data Pilot. The decision to opt out has been based on two factors, the potential for exploitation of results by some partners, but more importantly, the vulnerability of some of the project’s study participants and the sensitivity of the data that will be generated in the project. SUITCEYES involves user-studies (including interviews and observations) of sensitive nature. The participants, due to the small population and specific circumstances of each participant, are potentially easily recognizable. Although we anonymize user-study-generated data soon after collection and before sharing among the project members, this data is still not suitable for making openly available for wider access and use. This decision is supported by the results of multiple studies<sup>123</sup> that have shown the ease of deanonymisation even in areas where stringent efforts have been made in removing identifying data.

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<sup>1</sup> <https://www.esat.kuleuven.be/cosic/publications/article-2576.pdf>

<sup>2</sup> <https://petsymposium.org/2013/papers/sharad-deanonymization.pdf>

<sup>3</sup> <https://pdfs.semanticscholar.org/0057/2338a0fe3a021d93d658be03ed1f1b490205.pdf>

## 2.2 Data Governance and Data Management

In this document we have broadened the scope to also include data governance based on the structural features outlined by Khatri and Brown (2010)<sup>4</sup> where in their state-of-the-art contribution they have defined five data governance domains. Through the use of data governance, there is a distinction made between governance of data and management of data. Management concerns making and implementing decisions. Governance is concerned with the creation of a structure that allows for a decision-making structure. As they exemplify, “governance includes establishing who in the organization holds decision rights for determining standards for data quality. Management involves determining the actual metrics employed for data quality” (Khatri & Brown, 2010: 148). By extending the scope of this document to go beyond data management issues and to also include data governance a more comprehensive approach is adopted.

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<sup>4</sup> Khatri, V., & Brown, C. V. (2010). Designing Data Governance. *Communications of the ACM*, 53(1), 148-152. doi:10.1145/1629175.1629210



## 3. Data Governance

Khatri and Brown (2010) have identified five (5) decision domains for data governance comprising of (i) *Data principles*, (ii) *Data quality*, (iii) *Metadata*, (iv) *Data access* and (v) *Data life cycle*. Khatri and Brown (2010) propose that there is a need for creating a decision-making structure for each of these domains, where the full table with more detail is provided in Appendix 1.

In the following subsections, we outline the plan for SUITCEYES data governance according to these five domains.

### 3.1 Data principles

Data principles concern the overarching ideas about the kind of decisions that are to be made relative to the four other domains. These principles also introduce boundary requirements for the use of data as well as standards for data quality. The role of this domain is to clarify the role of data as an asset. For the current DMP the following data principles have been established as presented in Table 1.

Table 1: Adaptation of Khatri and Brown (2010)'s Domain of Data Principles in SUITCEYES

Domain Decisions	Potential Roles or Locus of Accountability
<ul style="list-style-type: none"> <li>▪ In SUITCEYES data is used for multiple purposes, including forming an understanding of the user needs, preferences and aspirations; forming an informed overview of the related policies; experimentations and conduct of research towards project goals and production of haptic, intelligent, personalized interface (HIPI).</li> <li>▪ The various uses of data are communicated continuously at regular meetings which are held at various levels and in different formats. Furthermore, written documentations and an information sharing tool are further mechanisms for communicating uses of the data.</li> <li>▪ Datasets are seen as assets and are therefore valuable and should be managed accordingly.</li> <li>▪ Ownership implies responsibility and accountability for keeping data assets securely stored.</li> <li>▪ As stipulated in related agreements, some of the data generated in SUITCEYES is of sensitive nature the use of which is regulated by the projects internal operational and ethical guidelines.</li> <li>▪ Such data assets should be handled through principles of privacy by design and data minimization.</li> <li>▪ All practices should be compliant to General Data Protection Regulation (GDPR).</li> <li>▪ The current DMP should be used to guide all handling of data assets. It should also be revised regularly to accommodate the</li> </ul>	<ul style="list-style-type: none"> <li>▪ The Project Management Board (PMB) is the ultimate decision-making body within SUITCEYES, and it is responsible to oversee the existence of appropriate data governance structures within the project.</li> <li>▪ The PMB is responsible for decisions made on data management issues.</li> <li>▪ The PMB should refer difficult issues of data management to the Ethical Advisory Board (EAB) for advice.</li> <li>▪ The project DMP (the text at hand and its subsequent updates) will also be reviewed by the project's EAB.</li> <li>▪ The default structure for ownership is that the partner creating the data also owns it as defined in Grant Agreement (GA) article 26 where some data may be subject to JOINT ownership governed by GA Article 26.2 with the addition of further stipulated in PCA section 8.</li> <li>▪ Data assets and their ownerships are clearly defined in a related tool share with all project members.</li> <li>▪ Securely stored refers both to protection against breach and to instances of force majeure, i.e. fire, data crash etc.</li> </ul>

development of new insights, challenges and problems.	
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### 3.2 Data quality

Data quality is connected to accurate, complete and trustworthy data being available for various research tasks in a timely fashion. Lack of data quality is a fundamental problem for most data intensive work and one of the core issues that can be attended to through the DMP. There are multiple dimensions involved in data quality which will be presented with the help of the following table (Table 2). The role of data quality domain is to establish requirements of intended uses of data.

Table 2: Adaptation of Khatri and Brown (2010)'s Domain of Data Quality in SUITCEYES

Domain Decisions	Potential Roles or Locus of Accountability
<ul style="list-style-type: none"> <li>▪ <b>Accuracy</b> refers to the correlation between recorded value, actual value and the kind of value needed for the research task. A number of crucial questions emerge regarding the user study data. For example: Will the interview transcripts reflect correctly the responses of the participants? Do the local conventions vary at different partner countries? How will the principles of data minimization and privacy by design affect the data sharing and interpretation as cross referenced in different countries of the studies? These accuracy-concerns are addressed by regular meeting and joint analyses among the researchers participating in user studies and collaboration with the User-Data Working Group. For the technical aspects of the project, experimental data, ontologies and so on, there will be other questions asked, and the accuracy of that data will be verified based on domain specific scientific measures and in collaboration with an Analytical-Data Working Group.</li> <li>▪ <b>Timeliness</b> refers to up-to-date values being available at the right time. Timeliness is typically a challenge in complex projects with many dependencies and potential bottle necks. It is crucial for the project members across the board to be aware of the relationships between the different tasks and deadlines to ensure smooth and timely deliverance of results that are needed for the next phase in the project in their own and other work packages in the project.</li> <li>▪ <b>Completeness</b> defines the need for the data to be as detailed, deep and broad as necessary for the research tasks. Related to the user studies, the ambitions for adherence to GDPR legislation and the principles of data minimization and privacy by design will be carefully balanced with the need to capture the data that is necessary for the design of the HIPI and an informed understanding of user needs and preferences. For Analytical data, while collection of broad data may not be bound by the same concerns, a challenge in cases of machine learning may be the lack of enough data. Such a challenge is carefully considered and potential solutions are investigated.</li> <li>▪ <b>Credibility</b> refers to the need that the sources of data assets must be trustworthy. In the user studies utmost care is taken to ensure that most relevant participants are recruited and</li> </ul>	<ul style="list-style-type: none"> <li>▪ The PMB will develop and assign responsibilities to a <i>User-Data Working Group</i> (UDWG) to oversee <b>accuracy, timeliness, completeness</b> and <b>credibility</b> of user data.</li> <li>▪ The PMB will develop and assign responsibilities to an <i>Analytical-Data Working Group</i> (ADWG) to oversee accuracy, timeliness, completeness and credibility of analytical and technical data.</li> <li>▪ There are a number of guidelines and tools devised and routines put in place in the project in order to ensure the <b>timely</b> conduct of all project tasks. The project PCA defines the members' responsibility towards one another, the need for timely deliverance and measures to ensure compliance.</li> <li>▪ The project has established a large network of contacts to allow collection of rich set of user data which will promote data completeness and credibility.</li> <li>▪ Similarly, continued environmental scanning keeps the project members informed of emerging data sources and recent research to promote access to most relevant and appropriate set of data for conduct of research tasks within</li> </ul>

<p>best user-study practices are put in place to ensure high levels of trustworthiness in the results. Regarding the technical and analytical data, in general Best Available Technology (BAT) and evaluation methods will be utilized.</p> <ul style="list-style-type: none"> <li>▪ A set of measures defined in task and work package meetings in collaboration with UDWG and ADWG will be used for <b>evaluation</b> of data quality and associated data collection procedures.</li> </ul>	<p>SUITCEYES.</p> <ul style="list-style-type: none"> <li>▪ Measures for data quality will be discussed, set, and documented in regular task and work package related meetings. These measures will be promoted and followed up by the two data working groups UDWG and ADWG.</li> </ul>
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### 3.3 Metadata

Metadata includes descriptions of data assets. Proper use of metadata facilitates findability and, in the long run, quality of research. The role of the metadata domain is given as Establishing the semantics or “content” of data so that it is interpretable by the users. Khatri and Brown (2010) make a distinction between three types of metadata. These will be reviewed below according to the way that they are seen as relevant for the project.

Table 3: Adaptation of Khatri and Brown (2010)’s Domain of Metadata in SUITCEYES

Domain Decisions	Potential Roles or Locus of Accountability
<ul style="list-style-type: none"> <li>▪ For describing and documenting different datasets a tool in the form of a project-wide spreadsheet has been devised with multiple columns that each describe an attribute of the dataset at hand. This tool generally includes the following sub-categories of information.</li> <li>▪ <b>Content metadata</b> describes the contents of different datasets, including whether data has been generated through user studies, policy studies, or technical experimental research streams. The list of related attributes includes (but is not limited to) dataset identifier, data description, source and mode of creation. It also describes whether the data can be shared openly or is of sensitive nature and special care is required.</li> <li>▪ <b>Storage metadata</b> involves information about means of data storage. This involves the choice of local and cloud-based as well as level of cryptology necessary for different kinds of data. For each dataset and based on the level of sensitivity (whether it can be openly shared or not), ownership and data type, the appropriate means of storage is defined.</li> <li>▪ <b>User metadata</b> relates to various annotations that different project members may associate with various data assets. This can involve notations on usage, findability, preferences and user history.</li> <li>▪ <b>General metadata</b> refers to all the other attributes and information recorded about each dataset, these include area of use, ownership, date of creation, history of change, the standards used, general technical format of data, compatibility level with different analysis tools, the procedure for metadata and data update, and more.</li> </ul>	<ul style="list-style-type: none"> <li>▪ The UDWG and the ADWG in collaboration with different instances in the project will develop a plan for the types of data used and create and provide guidelines related to appropriate storage procedure for each set of data.</li> <li>▪ UDWG and ADWG oversee that the metadata tool is kept updated (as potentially new types and sets of data may emerge) and includes sufficient details to provide appropriate information towards effective further data generation, use, and potential reuse, storage and long-term preservation.</li> <li>▪ The members collaborate closely with the two data work groups to facilitate their task of overseeing the upkeep of metadata information.</li> </ul>

### 3.4 Data access

Building upon compliance with GDPR as well as principles of data minimization and privacy by design, there needs to be a clear plan for data access in place. The role of this domain is to specify access requirement of data. The UDWG and the ADWG will be tasked with development of a plan for data rights to various data assets. The PMB will monitor development of this plan. The plan will also be evaluated by the EAB as elaborated in the following table.

Table 4: Adaptation of Khatri and Brown (2010)'s Domain of Data access in SUITCEYES

Domain Decisions	Potential Roles or Locus of Accountability
<ul style="list-style-type: none"> <li>▪ <b>Risk assessment</b> related to data value and sensitivity will be conducted on regular basis.</li> <li>▪ <b>Data access</b> related to sensitive material within the project is based on a clearly defined need for purposes of research as monitored and decided upon by the PMB.</li> <li>▪ Mechanisms for sharing such data should be through cryptology technology.</li> <li>▪ Other data assets can be shared publicly (<b>Open Data</b>) but decisions on such initiatives will be taken at a later stage of the project when all of the research needs of the project are clearly understood.</li> <li>▪ Appropriate <b>naming conventions</b> as well as use of <b>standards</b> for data sets should be adopted to ensure interoperability within the project.</li> </ul>	<ul style="list-style-type: none"> <li>▪ Sharing of sensitive data will be monitored and decided upon by the PMB.</li> <li>▪ UDWG and ADWG will be tasked to oversee the procedures for information security and alert of deviations and potential risks.</li> <li>▪ Continued dialogue with partner organisation IT support centres will take place to ensure being kept updated on security and preservation issues.</li> </ul>

### 3.5 Data lifecycle

All data moves through various lifecycle stages and this DMP is designed with an awareness of this. The role of this domain is to determine the definition, production, retention and retirement of data. Informed decisions related to each stage of data lifecycle has gained increased importance in the light of compliance with the GDPR principles of data minimization and privacy by design. Some of the measures and related decisions are outlined in Table 5.

Table 5: Adaptation of Khatri and Brown (2010)'s Domain of data lifecycle in SUITCEYES

Domain Decisions	Potential Roles or Locus of Accountability
<ul style="list-style-type: none"> <li>▪ <b>Data inventory</b> will be conducted on multiple occasions during the project.</li> <li>▪ <b>Data lifecycle plan</b> will be defined as part of the metadata tool, mentioned above. That is, at the time of data creation, not only the data will be defined, but plans will be put in place for data lifecycle, including long-term retention and even future destruction if appropriate.</li> <li>▪ Towards <b>compliance with legislations</b> and other regulations, some data and records are required to be kept for given periods of times. An overview of such regulation is formed through access to related guidelines and in collaboration with partner organisations' archival departments.</li> <li>▪ At the time of project conclusion, the sensitive data will be securely archived based on the timelines specified in the metadata tool or made publicly available through different channels.</li> </ul>	<ul style="list-style-type: none"> <li>▪ During the project, the UDWG and the ADWG will be tasked with recommendations for data life cycle management.</li> <li>▪ The UDWG and the ADWG will also supply recommendations on data that might at some stage be made available as open data.</li> <li>▪ The UDWG and the ADWG might also make recommendations of changing physical storage and alternating practices of metadata during various stages of data lifecycles.</li> <li>▪ Formal decisions related to the recommendations made by the UDWG and the ADWG will be made by the PMB.</li> </ul>

## 4. Data Management

Based on the data governance structures described above, the following sections describe the project-related datasets and actual measures and steps employed to ensure effective production, access, use, reuse, storage and preservation of data within SUITCEYES making it FAIR – findable, accessible, interoperable and re-usable.

### 4.1 Data collected/generated within SUITCEYES

There are a number of different data types and datasets either collected or generated within SUITCEYES. Some of this data is defined as sensitive and not suitable for sharing or openly making available to third parties. Others will be deemed as intellectual assets of partners and intended for future exploitation or are subject to other copyright issues and will not be shared openly or not at least before adequate measures have been taken. A third group of data will be made available under the open data principals for use and reuse by third parties.

The main datasets in SUITCEYES contain data resulting from user-studies, policy studies, bibliographic searches, collections of semantic vocabularies, algorithms, technical experiments in the project. For administrative purposes we have grouped these data under two broad categories of User Data and Analytical Data.

All sensitive data that will include personal information or result from interviews and observations are placed in the first group. All the other data-sets (although some not related to experiments) fall in the same category. Table 6 provides a summary of these data and its main categories. The separate group of Social Data is also provided in the table as a data about the potential interest of different groups, social media data and disseminated information about the project.

Table 6: Main categories of data and the methods of its collection/generation

Category	Type of Study	Methods of collection/ generation	Data
User-Data	User studies	Interviews, observations, reaction tracking, audio visual recording, qualitative data analysis tools	Transcripts, psychophysical data and informed consent forms
User-Data	Policy studies	Interviews with decision makers	Transcripts
Analytical-Data	Policy studies	Policy documents collection	Policy documents
Analytical-Data	Literature studies	Searches in bibliographic databases (e.g. Web of Science).	Bibliographic metadata, collections of articles and other publications
Analytical-Data	Semantics	Searches for and collection of a set of sign language vocabularies	Sets of sign language vocabularies
Analytical-Data	Semantics	Searches for collections of social haptic signals	Sets of social haptic signals
Analytical-Data	Deploying visual understanding algorithms	Wearable RGB-D (Red, Green, Blue and Depth) cameras or RGB and depth sensors	Benchmark datasets from wearable cameras for activity recognition, object detection, face and hands detections,

			navigation
Analytical-Data	User studies	Scientific instruments (temperature loggers, am-meters, thermography, optical microscopy, video, tensiometers, martindale etc.)	Technical measurement data (temperature, time, vibration amplitudes, frequencies)
Social-Data	Social interactions	Appropriate accounts on the social media	Data about potential interest of groups, disseminated information about the project

## 4.2 Standards for collection, creation, and reuse

There are a set of standards and guidelines related to each type of data collected or generated within the project. For example, there is a detailed interview protocol that defines clearly the aim of the interviews; the procedure for the interview, analysis, collaboration between the researchers who conduct the user-studies; instruction about how the interviews are to be conducted, the instructions for ensuring informed consent by the participants; the interview questions and more. In other cases, for example for bibliographic studies, the information scientist within the project will apply best practice for data collection, pre-processing, analysis and visualizations. Similarly, each of the researchers in the project will apply their field expertise to ensure compliance with standards and data quality.

Furthermore, information is recorded about each sets of data, in a descriptive accompanying document. The type of information included may vary from one descriptive overview document to the next, but in general the types of information that are included may comprise of information about the contents, the source, means of data collection or generation, privacy level, storage details, retention instructions, member(s) involved in data creation, notes, dates of creation, use, versions, tools involved, methods used, and so on.

Additionally, a select set of such information is uniformly captured in a Metadata Tool (Appendix 2), which for each dataset within the project defines the dataset's unique id and name, data type, description, ownership, purpose, area of use, size, level of data sensitivity, depository, duration of preservation, reuse instructions, accompanying metadata, required tools and methods, data quality assurance process, and pertinent ethical considerations.

The information provided in the Metadata Tools therefore provides guidelines as to whether each specific set of data can be shared for reuse or will be of sensitive nature and would need to be protected and not shared.

## 4.3 Ownership and responsibilities

In SUITCEYES, some data will be generated and other data may be captured for further analysis and use within the project. The ownership of the collected data will remain with the original owner. For the rest, the default structure for data ownership in SUITCEYES is that the partner creating the data also owns it as defined in GA article 26. Where some data is subject to JOINT ownership, this is governed by Grant Agreement Article 26.2. Further stipulated are listed in the project's consortium agreement, section 8.

For the sake of clarity and future reference, the name(s) of data generator(s) and owner(s) is (are) clearly stated in the Metadata Tool. The data owners are responsible to provide the required information that informs the project of the level of data sensitivity and means of storage and retention.

The PMB is the ultimate decision-making body within SUITCEYES and as such it is also responsible for decisions made on data management issues. The PMB is also responsible to oversee the existence of appropriate data governance structures within the project. Towards this, the PMB will develop and assign responsibilities to two Data Working Groups one for User-Data and one for Analytical-Data. These working groups will collaborate with project members and will oversee accuracy, timeliness, completeness and credibility of data.

#### 4.4 Dataset labelling convention

Each dataset will be assigned a unique identifying number (each dataset receiving the next consecutive available number as indicated on the Metadata Tool).

To facilitate labelling of datasets, much of the identifying information about each dataset will be provided in the Meta-Data Tool and potential accompanying data descriptive file. Therefore, the actual labelling of the dataset will be as follows:

**SC-DS\_ID\_Name**

Where SC-DS is indicative of SuitCeyes-DataSet. ID refers to the dataset's unique identifying number. Finally, Name is to be formed in a way to provide immediate meaningful information about the content of the dataset.

Example: **SC-DS\_1\_WoS-809 items-deafblindness-2018-02-02**

#### 4.5 Storage and sharing (during and after the project)

Currently, the main depository for SUITCEYES data is BOX, which is a data storage and sharing solution, procured nationally within Sweden for use by Swedish universities and their collaborators. This storage facility has been approved as meeting the standards set by the GDPR requirements. Some data may be stored locally at partner organisations in accordance to secure GDPR-compliant guidelines. The consortium identifies the level of security; sensitiveness; storage requirements; retention instructions; sharing routines; and the specifics of archiving, preservation, and or destruction for each set of data as they emerge and as the project progresses. These parameters will define how the data within the project are to be handled.

#### 4.6 Data quality and evaluation

The consortium has defined guidelines, procedures, and routines to ensure a general level of quality of data and research work by the means of the structures that are put in place. In addition to this, each member of the project is competent in their his or her specific area of research and well familiar with related guidelines and best practices to ensure quality of work and to apply appropriate evaluations measures. Furthermore, the internal review structures and collaborative feedback by colleagues is a further means for ensuring quality of work, data and research.

#### 4.7 Ethical and legal compliance

As mentioned earlier, SUITCEYES involves user studies. The partners involved in these studies either hold or will seek and obtain ethics approval from their national ethics review boards. Based on the procedures described above, the sensitive data generated or used within the project will be subject to guidelines and related best practices. After assigning codes for future cross-referencing purposes, personal identification information will be removed from the interview and observation data, soon after data collection and before sharing (only if needed) with other project members.

The consortium partners are also aware of the GDPR (EU) 2016/679<sup>5</sup> which is a regulation in EU law on data protection and privacy for all individuals within the European Union. It also addresses the

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<sup>5</sup> REGULATION (EU) 2016/679 OF THE EUROPEAN PARLIAMENT AND OF THE COUNCIL of 27 April 2016 on the protection of natural persons with regard to the processing of personal data and on the free movement of such data, and repealing Directive 95/46/EC (General Data Protection Regulation): <http://eur-lex.europa.eu/legal-content/EN/TXT/PDF/?uri=CELEX:32016R0679&from=EN>



export of personal data outside the EU. The GDPR aims primarily to give control over personal data and to simplify the regulatory environment for international business by unifying the regulation within the EU. It also involves decisions regarding which datatypes can be characterized as containing sensitive information and how such information is stored and shared. Each partner is aware to examine the possibility of protecting its results and must adequately protect them within the project, and after its finishing. It is especially important if the results can reasonably be expected to be commercially or industrially exploited and protecting them is possible, reasonable, and justified. The consortium considers its own legitimate interests and the legitimate interests (especially commercial) of the other partners. Already on the stage of submitting the project application the consortium decided to opt out of the Pilot on Open Research Data in Horizon 2020. It is connected with:

- allowing the protection of results (e.g. patenting)
- incompatibility with privacy/data protection

Where possible within the SUITCEYES project, the partners are using healthy adults, so that one can minimise the burden on the target user group. In other words, people with deafblindness are only being called upon where their “expert user” perspective is required. For healthy users, ethical risks are low – there is no sensitive data being recorded, so the only concerns are around data protection and health and safety. The partners will only work with those people with deafblindness who have the capacity to consent, and who have the communication skills to carry out an interview. Interviews will be conducted via a caregiver, so that the participant is with someone familiar and with someone skilled in acting as an intermediary. Interviews will be conducted in a location of the participants' choice – in this way they will be in a familiar environment. Naturally, informed consent forms will always be applied.

#### **4.8 The approach and format of reaching informed consent**

The approach to be used to reach informed consent, or any other agreement with end users taking part in requirements and other user studies, has been proposed and performed from the beginning of the project. This approach and the format of reaching informed consent for this target group is of usage also for other R&D activities and are made available / published as an important output (the templated used by the consortium from the beginning of the project are shown in Appendix 3). Moreover non-sensitive data are stored in a Google drive folder (according to D1.1 Quality Assurance Plan). The YouTube videos and other dissemination materials involving the presence of users and outside participants require reaching informed consent for the target group presented on the video, materials etc. In case the consortium will decide to video-record the interviews, iteration of the agile process for WP7 or other activities and applications involving persons outside the consortium, the DMP requires to use the consent form that includes reference on how to treat these materials (please check the forms in Appendix 3).

At the start, the consortium informs that giving consent to process any personal data collected in the context of SUITCEYES is entirely voluntary and that the consortium commits to protect personal data, and process it only according to applicable laws and regulations such as the GDPR. The consent might be withdrawn at any time, however withdrawing it might not effect immediate stopping of using the material and that it does usually not affect material that has already been made public.

One is informed that the material collected will be used in internal training of project members and/or published in which media channels, e.g. billboards, newspapers, website, TV programs, Twitter, YouTube, LinkedIn etc. It is important to note that the consortium informs that published material probably reaches large audience and that the consortium is not able to control other use of the material. It is also mentioned that publishing the material on social media means that the material is transferred to companies based in the United States. These companies are members of the "Privacy Shield"- agreement and are thus considered to ensure an adequate level of protection of personal data.

SUITCEYES ensures transparency with processing personal data. There is a possibility of receiving information about the way of processing and copying personal data. It will be received in a structured, commonly used and machine-readable format. The consortium can rectify or supplement personal data that is inaccurate or incomplete.

It is possible to erase personal data under certain circumstances, however personal data that has been already made public, e.g. published on social media is usually not affected by a withdrawn consent. Because of legal provisions we may also be prevented from immediately erasing personal data. Lodging a complaint to the supervisory authority is also possible. Therefore, the privacy is an important issue for SUITCEYES consortium and we do the best to protect personal data of internal and external members of the project.

Various formats of reaching informed consent have been used in SUITCEYES from the beginning of the project, e.g.:

- The consent forms for the interviews with the users within WP2 in Greek, German, Swedish, Dutch and English
- Non-Disclosure Agreements that were signed with the advisors, symposia participants, and e.g. persons who helped in transcribing some parts of the interviews
- The informed consent forms used for experiments in the Netherlands (in Dutch)
- The informed consent form (in English) used by HB for taking photos, filming and publishing (for various university applications, also used in the project)
- A letter of consent regarding video/audio recording or photos in German
- Universal consent form created in the second year of project in accordance with the project identity.

The templates of these informed consent forms can be found in Appendix 3.

## 5. Summary

This DMP incorporates both Data Governance and Data Management and accordingly defines the principals, procedures, and routines that are put in place for the management of research data within the SUITCEYES project. The SUITCEYES partners will make the research results available through different channels and strive to provide open access to the project data, as far as possible. However, not all data generated and used within the project are suitable or appropriate for sharing and reuse, and hence, SUITCEYES has chosen not to participate in the Open Research Data Pilot. The main datasets in SUITCEYES contain data resulting from user-studies, policy studies, bibliographic searches, collections of semantic vocabularies, algorithms, technical experiments in the project. For administrative purposes these data has been grouped under two broad categories of User Data and Analytical Data. For the sake of clarity and future reference, the name(s) of data generator(s) and owner(s) is (are) clearly stated in the Metadata Tool. The data owners are responsible to provide the required information that informs the project of the level of data sensitivity and means of storage and retention (relevant informed consent forms are also used). The PMB as the ultimate decision-making body within SUITCEYES is also responsible for decisions made on data management issues. Each dataset is assigned a unique identifying number (each dataset receiving the next consecutive available number as indicated on the Metadata Tool) and the main depository for SUITCEYES data is BOX, which is a data storage and sharing solution. This storage facility has been approved as meeting the standards set by the GDPR requirements. Some data may be stored locally at partner organisations in accordance to secure GDPR-compliant guidelines.

The DMP will be updated over the course of the project whenever significant changes arise, such as (but not limited to):

- new data
- changes in consortium policies (e.g. new innovation potential, decision to file for a patent)
- changes in consortium composition and external factors (e.g. new consortium members joining or old members leaving).

# 6. Appendices

## Appendix 1

Framework for data decision domains (Khatri & Brown, 2010: 149)

<b>Data Governance Domains</b>	<b>Domain Decisions</b>	<b>Potential Roles or Locus of Accountability</b>
<b>Data Principles</b> <ul style="list-style-type: none"> <li>• Clarifying the role of data as an asset</li> </ul>	<ul style="list-style-type: none"> <li>• What are the uses of data for the business?</li> <li>• What are the mechanisms for communicating business uses of data on an ongoing basis?</li> <li>• What are the desirable behaviors for employing data as assets?</li> <li>• How are opportunities for sharing and reuse of data identified?</li> <li>• How does the regulatory environment influence the business uses of data?</li> </ul>	<ul style="list-style-type: none"> <li>• Data owner/trustee</li> <li>• Data custodian</li> <li>• Data steward</li> <li>• Data producer/supplier</li> <li>• Data consumer</li> <li>• Enterprise Data Committee/Council</li> </ul>
<b>Data Quality</b> <ul style="list-style-type: none"> <li>• Establishing the requirements of intended use of data</li> </ul>	<ul style="list-style-type: none"> <li>• What are the standards for data quality with respect to accuracy, timeliness, completeness and credibility?</li> <li>• What is the program for establishing and communicating data quality?</li> <li>• How will data quality as well as the associated program be evaluated?</li> </ul>	<ul style="list-style-type: none"> <li>• Data owner</li> <li>• Subject matter expert</li> <li>• Data quality manager</li> <li>• Data quality analyst</li> </ul>
<b>Metadata</b> <ul style="list-style-type: none"> <li>• Establishing the semantics or "content" of data so that it is interpretable by the users</li> </ul>	<ul style="list-style-type: none"> <li>• What is the program for documenting the semantics of data?</li> <li>• How will data be consistently defined and modeled so that it is interpretable?</li> <li>• What is the plan to keep different types of metadata up-to-date?</li> </ul>	<ul style="list-style-type: none"> <li>• Enterprise data architect</li> <li>• Enterprise data modeler</li> <li>• Data modeling engineer</li> <li>• Data architect</li> <li>• Enterprise Architecture Committee</li> </ul>
<b>Data Access</b> <ul style="list-style-type: none"> <li>• Specifying access requirements of data</li> </ul>	<ul style="list-style-type: none"> <li>• What is the business value of data?</li> <li>• How will risk assessment be conducted on an ongoing basis?</li> <li>• How will assessment results be integrated with the overall compliance monitoring efforts?</li> <li>• What are data access standards and procedures?</li> <li>• What is the program for periodic monitoring and audit for compliance?</li> <li>• How is security awareness and education disseminated?</li> <li>• What is the program for backup and recovery?</li> </ul>	<ul style="list-style-type: none"> <li>• Data owner</li> <li>• Data beneficiary</li> <li>• Chief information security officer</li> <li>• Data security officer</li> <li>• Technical security analyst</li> <li>• Enterprise Architecture Development Committee</li> </ul>
<b>Data Lifecycle</b> <ul style="list-style-type: none"> <li>• Determining the definition, production, retention and retirement of data</li> </ul>	<ul style="list-style-type: none"> <li>• How is data inventoried?</li> <li>• What is the program for data definition, production, retention, and retirement for different types of data?</li> <li>• How do the compliance issues related to legislation affect data retention and archiving?</li> </ul>	<ul style="list-style-type: none"> <li>• Enterprise data architect</li> <li>• Information chain manager</li> </ul>

# Appendix 2

## SUITCEYES Metadata Tool

The following information is recorded for each set of data collected or generated within the project. (One dataset item is included here to exemplify.)

Dataset ID	Name	Data type	Description	Creator/ Generator and Owner	Purpose of data collection/generation	Area of use of data	Format	Size	Level of data sensitiveness (whether it will be made openly available or not)	If sensitive, means of secure storage and transfer of data	Depository	Duration of preservation	Preservation notes (if relevant)	Reuse instructions	Accompanying metadata, and related standards for interoperability	Tools and methods needed to generate, use or access data (if any)	Related data quality assurance processes	Pertinent ethical considerations
1	WoS-809 items-deafblindness-2018-02-02	Bibliographic data	809 items Search conducted on February 2, 2018 Database: WoS Search terms: deafblind* OR deaf-blind* OR "deaf blind*" Output format: full record including citation information	Captured by Nasrine, Owner WoS	Bibliometric studies of the field	Bibliographic data	txt	809 items, 599 KB	Non-sensitive (restricted due to copyright policies at the host databases, that is while HB has licences to retrieve such data for research purposes, we are not allow to make the data available to others)	Non-sensitive, by not making the data publicly available we will meet the required safeguards.	Project's internal depository.	For the duration of the project	No need for long term preservation as the data will remain available at the source databases, furthermore newer publications will be added to the collection and our collected data will be outdated for longer term use.	see previous column	This data by itself is metadata on scholarly publications. Other metadata on date of search and retrieval, search terms used, database information, stop words and so on is included in the accompanying data overview document.	WoS provides the required functionality for data search and download. Other tools (e.g. VOSviewer, Gephi, Raw and so on) are used for data analysis.	The process for data search and retrieval (including database, access date, numbers, pre-processing procedures, etc) are all recorded for audit and duplication. Pre-processing of data is conducted using OpenRefine to optimise data consistency	When it comes to the use of meta-data we have sought and have permission for use. When it comes to analysis of abstracts, there is a grey area where the principle of fair use is adhered to. Data mining of full text is problematic and subject to copyright holders for each of the items used needs to be contacted for permission. We therefore avoid datamining of the full text.

# Appendix 3

## Informed consent forms used in SUITCEYES

The consent form used for the interviews with the users within WP2 (in Greek)

H2020-EU.2.1.1. Project ID: 780814 

### Άδεια για χρήση προσωπικών δεδομένων για έρευνα

#### Ο σκοπός του συγκεκριμένου εγγράφου:

Σας ζητάμε να υπογράψετε την άδεια αυτή προκειμένου να είναι δυνατή η χρήση προσωπικών σας δεδομένων για ερευνητικούς σκοπούς. Η συμμετοχή στην έρευνα είναι εθελοντική και, στην περίπτωση που επιλέξετε να συμμετάσχετε, πρέπει να υπογράψετε τη συγκεκριμένη άδεια, ώστε τα ελεγχόμενα δεδομένα να είναι δυνατά να χρησιμοποιηθούν για τους ερευνητικούς σκοπούς του έργου.

#### Το αντικείμενο της μελέτης:

Οι στόχοι της μελέτης είναι οι εξής:

1. Ποιες είναι οι προσδοκίες των ατόμων με τυφλοκώφωση σε σχέση με την αυτόνομη διαβίωση;
2. Ποιες είναι οι εμπειρίες και οι απόψεις των ανθρώπων με τυφλοκώφωση σχετικά με την πρόσβαση σε σχετικές και χρήσιμες τεχνολογίες;
3. Ποιες είναι οι εμπειρίες και οι απόψεις των ανθρώπων με τυφλοκώφωση σχετικά με τη χρήση συσκευών και ειδικότερα απτικής τεχνολογίας;

#### Περιγραφή της συμμετοχής σας:

Στα πλαίσια της συγκεκριμένης έρευνας, χρήσιμες θεωρούνται οι πληροφορίες που αφορούν τον τρόπο εκτέλεσης καθημερινών δραστηριοτήτων. Οι συνεντεύξεις θα έχουν τη μορφή ελεύθερης συζήτησης, προκειμένου να υπάρχει μεγαλύτερη ευελιξία έκφρασης για τους συμμετέχοντες. Εάν δεν επιθυμείτε να απαντήσετε σε μια ερώτηση, μπορείτε να το κάνετε. Αντιστοίχως, οι ερευνητές θα είναι πρόθυμοι να απαντήσουν σε ερωτήσεις για τον εαυτό τους, εάν τους το ζητήσετε.

#### Ο λόγος που οι ερευνητές θέλουν τα προσωπικά σας δεδομένα:

Τα δεδομένα όλων των συμμετεχόντων στην έρευνα είναι απαραίτητα για τη διερεύνηση ποικίλων αναλύσεων που θα οδηγήσουν σε ερευνητικά αποτελέσματα με

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σημαντική κοινωνική απήχηση και αξιοποίηση. Τα δεδομένα σας αξιοποιούνται μόνο στα πλαίσια του της έρευνας που περιγράφεται παραπάνω.

#### Χορήγηση και χρήση των προσωπικών σας δεδομένων:

Τα δεδομένα σας θα χρησιμοποιηθούν από τους εταίρους του έργου καθώς επίσης και από ερευνητικές ομάδες εκτός αυτού αποκλειστικά για ερευνητική χρήση. Οι ερευνητικές ομάδες αυτές είναι εγκεκριμένες από το έργο και ακολουθούν τους ίδιους κανόνες εχεμύθειας και ασφάλειας με αυτό.

#### Προστασία των προσωπικών σας δεδομένων:

Όλα τα προσωπικά δεδομένα θα παραμείνουν απόρρητα, όπως ορίζει η αντίστοιχη Ευρωπαϊκή νομοθεσία και ο κανονισμός λειτουργίας της Επιτροπής Ερευνών.

#### Χρονική διάρκεια της άδειας:

Η άδεια αυτή δίνεται για πέντε (5) έτη και αφορά μόνο τα δεδομένα που συλλέχθηκαν στη συγκεκριμένη έρευνα.

#### Απόσυρση της συγκατάθεσής σας:

Μπορείτε να αποσύρετε την άδεια σας μέχρι τις 31-Οκτ-2018 ειδοποιώντας την ερευνητική ομάδα του ΙΠΤΗΛ (ΕΚΕΤΑ). Από τη στιγμή που αποσύρετε την άδεια για χρήση των δεδομένων σας, ο ερευνητής από εκείνη τη στιγμή θα σταματήσει τη συλλογή και χρησιμοποίηση οποιωνδήποτε δεδομένων προκύπτουν. Ωστόσο, η ερευνητική ομάδα θα μπορεί να χρησιμοποιήσει δεδομένα που έχουν στοιχειοθετηθεί πριν από την ακύρωση της άδειας.

#### Πρόσβαση στα προσωπικά σας δεδομένα:

Έχετε το δικαίωμα να ζητήσετε και να δείτε τα προσωπικά σας δεδομένα. Για λόγους επιστημονικής ακεραιότητας, το σύνθετο είναι να επιτρέπεται η εξέταση από τους

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συμμετέχοντες των δεδομένων τους μετά τη λήξη των εργασιών του ερευνητικού πρωτοκόλλου.

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#### Δήλωση συγκατάθεσης

Δηλώνω ότι έχω διαβάσει και κατανοώ την περίληψη για την παραπάνω μελέτη και είχα την ευκαιρία να υποβάλω ερωτήσεις

Κατανοώ ότι η συμμετοχή μου είναι εθελοντική και ότι είμαι ελεύθερος/ελεύθερη να αποχωρήσω οποιαδήποτε στιγμή το αποφασίσω, χωρίς να χρειάζεται να εξηγήσω τον λόγο και χωρίς η ιατρική μου περίθαλψη και τα νόμιμα δικαιώματά μου θιγούν.

Κατανοώ ότι μέρη του ιατρικού μου ιστορικού μπορεί να γίνουν γνωστά σε συγκεκριμένα υπεύθυνα άτομα και τις υπεύθυνες αρχές, όπου αυτό σχετίζεται με τη συμμετοχή μου στην έρευνα. Δίνω την άδεια σε αυτά τα άτομα να έχουν πρόσβαση στο ιατρικό μου ιστορικό.

#### Συμφωνώ να συμμετάσχω στην παραπάνω έρευνα

Υπογραφή συμμετέχοντος: \_\_\_\_\_

Ημερομηνία: \_\_\_\_\_

Όνοματεπώνυμο συμμετέχοντος: \_\_\_\_\_

Υπογραφή εκπροσώπου συμμετέχοντος: \_\_\_\_\_

Ημερομηνία: \_\_\_\_\_

Όνοματεπώνυμο εκπροσώπου: \_\_\_\_\_

Σχέση με το συμμετέχοντα: \_\_\_\_\_

Υπογραφή ερευνητή: \_\_\_\_\_

Ημερομηνία: \_\_\_\_\_

Όνοματεπώνυμο ερευνητή: \_\_\_\_\_

The consent form used for the interviews with the users within WP2 (in German)



Projekt	SUITCEYES
Anlass	Interview zur Evaluation von Nutzerwünschen und -bedürfnissen

## Einverständniserklärung

**BESCHREIBUNG:** Interview zur Evaluation von Nutzerwünschen und -bedürfnissen, um die Anforderungen an einen ersten Prototyp eines intelligenten Kleidungsstücks für Menschen mit Taubblindheit im Rahmen des EU-geförderten Projektes „SUITCEYES“ abzuleiten.

**LEITUNG:** Prof. Dr. Oliver Kom, Lea Buchwetz

**ZIEL:** In der Studie wird ermittelt, welche Anwendungsszenarien durch das intelligente Kleidungsstück unterstützt werden könnten. Hierfür werden den Teilnehmern mit Taubblindheit bzw. eingeschränktem Seh- und Hörvermögen Fragen aus einem leitfadengestützten Interview zu derzeitigen Gewohnheiten, Beschäftigungen und dem Umgang mit neuen Technologien gestellt.

**ABLAUF:** Die Probanden erhalten eine kurze Einführung in das Projekt. Das Interview erfolgt sequenziell in Einzelgesprächen mit der Unterstützung der Betreuer.

**DAUER:** Die Dauer der Studie liegt pro Teilnehmer bei 30 bis 90 Minuten.

**ERHOBENE DATEN:** Dokumentiert werden die Antworten aus dem Interview. Bei Einverständnis (gesonderte Einverständniserklärung für Bild-, Video- und Tonaufnahmen durch das Affective and Cognitive Institute der Hochschule Offenburg), werden die Interviews aufgezeichnet und für die Transkription und spätere, projektrelevante Zwecke verwendet.

**VERÖFFENTLICHUNG:** Die Ergebnisse sowie Teile der Dokumentation dieser wissenschaftlichen Studie werden in Fachartikeln publiziert und auf Fachkongressen vorgestellt. Die Ergebnisse werden aggregiert dargestellt und sind nicht auf einzelne Probanden rückführbar (Anonymität).

**RISIKEN:** Während der Studie entstehen keine Risiken. Die erhobenen Daten werden sicher gespeichert und die Anonymität der Teilnehmer und Begleiter ist gewährleistet.

**RECHTE DES TEILNEHMERS:** Wenn Sie dieses Dokument gelesen haben und sich für die Teilnahme an der Studie entscheiden, gelten die folgenden Rechte: Ihre Teilnahme ist freiwillig und Sie können diese jederzeit ohne Angabe von Gründen abbrechen. Durch einen Abbruch wird Ihnen kein Nachteil entstehen. Sie haben ferner das Recht, die Beantwortung bestimmter Fragen zu verweigern.

Durch die Unterzeichnung dieses Dokuments erkläre ich mein Einverständnis mit der Teilnahme an der Studie zu den oben beschriebenen Bedingungen.

Datum: \_\_\_\_\_

Name: \_\_\_\_\_

Unterschrift: \_\_\_\_\_





The consent form used for the interviews with the users within WP2 (in Dutch)



#### Instemming onderzoeksdeelname

Studie: Interviews met mensen met doofblindheid.

#### Doel en Procedure

Het doel van dit onderzoek is om middels een interview inzicht te krijgen in de behoeften van mensen die doofblindheid hebben en op welke manier technologie zou kunnen bijdragen aan het vergemakkelijken van dagelijkse activiteiten. Het gesprek duurt ongeveer 60 minuten. Het interview wordt gevoerd door dr. Myrthe Plaisier en/of prof. dr. Astrid Kappers van de Technische Universiteit Eindhoven.

#### Vrijwilligheid

Uw deelname is geheel vrijwillig. U kunt zonder opgave van redenen het gesprek afbreken. Mocht u een vraag niet willen beantwoorden dan mag u daar ten alle tijden vanaf zien. Ook kunt u nog achteraf (binnen 24 uur) weigeren dat uw gegevens voor het onderzoek mogen worden gebruikt. Dit alles blijft zonder nadelige gevolgen.

#### Vertrouwelijkheid

Wij delen geen persoonlijke informatie over u met mensen buiten het onderzoeksteam. Er zullen audio-opnamen gemaakt worden tijdens het interview. Deze zullen niet worden doorgegeven aan anderen. Ze zullen uitsluitend worden afgespeeld in het bijzijn van de onderzoekers. Het materiaal wordt uitsluitend gebruikt voor wetenschappelijke analyse. De informatie die we met dit onderzoek verzamelen wordt gebruikt voor het schrijven van wetenschappelijke publicaties. Alles gebeurt geheel anoniem en niets kan naar u herleid worden.

#### Nadere inlichtingen

Als u nog verdere informatie wilt over dit onderzoek, dan kunt u zich wenden tot Myrthe Plaisier (email: M.A.Plaisier@tue.nl)

Voor eventuele klachten over dit onderzoek kunt u terecht bij de projectleider, Astrid Kappers (A.M.L.Kappers@tue.nl).

#### Instemming onderzoeksdeelname

Bij dezen verklaar ik, (NAAM)..... dat ik dit document heb gelezen en begrepen en dat ik de gelegenheid heb gehad om vragen te stellen. Ik stem ermee in om vrijwillig deel te nemen aan dit onderzoek van de Technische Universiteit Eindhoven.

\_\_\_\_\_  
Handtekening Participant

\_\_\_\_\_  
Datum

The consent form used for the interviews with the users within WP2 (in English)



**Consent form to take part in a Research Project on new technologies for Deafblind People**

**SUITCEYES (Smart User-friendly Interactive Tactual Cognition-Enhancer that Yields Extended Sensosphere)**

Name of Interview Researcher: Dr. Adriana Atkinson

*To give written consent, please sign alongside each of the following statements. To give verbal consent, please state your name and if you agree or disagree with each of the following statements*

- 1 I confirm that I have read and understand the information sheet dated June 2018 explaining the above research project and I have had the opportunity to ask questions about the project.
- 2 I understand that my participation is voluntary and that I am free to withdraw before the dates specified in the information sheet without giving any reason and without there being any negative consequences. Should I choose to withdraw, data collected from me will be removed from the research. In addition, should I not wish to answer any particular question or questions, I am free to decline.
- 3 I give permission for members of the research team to have access to my responses. I understand that my name will not be linked with the research materials, and I will not be identified, or identifiable in outputs from this research. I understand that my responses will be pseudonymised before they are shared with anyone other than the research team.
- 4 I understand that an audio or video recording will be taken of the interview, but that this recording is only for the purposes of enabling detailed notes to be taken of the interview. I understand that the recording will not be shared outside of the University of Leeds research team. I give my permission for the interview to be recorded.
- 5 I agree that the data collected from me can be shared in a pseudonymised form for use in relevant future research.
- 6 I understand that relevant sections of the data collected during the study, may be looked at by auditors from the University of Leeds where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.
- 7 I agree to take part in the above research project.

_____	_____	_____
Name of participant	Date	Signature
_____	_____	_____
Name of person taking consent	Date	Signature

***To be signed and dated in presence of the participant***

**Copies:**

Once this has been signed by all parties the participant should receive a copy of the signed and dated participant consent form, the letter/pre-written script/information sheet and any other written information provided to the participants. A copy of the signed and dated consent form should be kept with the project's main documents which must be kept in a secure location.

The form of Non-Disclosure Agreements that were signed with the advisors, symposia participants, and e.g. persons who helped in transcribing some parts of the interviews



### NON-DISCLOSURE AGREEMENT

Whereas I, the undersigned,

Declare that I have been engaged as an external advisor by:

HOEGSKOLAN I BORAS, with organisation number 202100-3138, having its registered office at Allégatan 1, 30190 Borås, Sweden; and,

ETHNIKO KENTRO EREVNAS KAI TECHNOLOGIKIS ANAPTYXIS, with VAT number EL099783242, having its registered office at 6<sup>th</sup> Km Charilaou-Thermi Road, 57001 Thessaloniki, Greece; and,

HOCHSCHULE OFFENBURG, having its registered office at Badstr. 24, 77632 Offenbourg; and,

UNIVERSITY OF LEEDS, with registration number RC000638, having its registered office at Leeds, LS2 9JT United Kingdom; and,

STICHTING VU, with VA number 8510.29.279.B.01, having its registered office at De Boelelaan 1105, 1081 HV, Amsterdam, The Netherlands; and,

LES DOIGTS QUI REVENT (LDQR), with organization number 404 871 196 000 30, having its registered office at 11 bis rue de noailles, 21240, Talant, France; and,

HARPO SP. Z O.O., with company registration number 0000119733, having its registered office at ul. 27 Grudnia 7, 61-737 Poznań, Poland

(the "Beneficiaries") in connection with the project "Smart, User-friendly, Interactive, Tactuel, Cognition-Enhancer, Yielding Extended Sensosphere - Appropriating sensor technologies, machine learning, gamification and smart haptic interfaces" - SUITCEYES (Project ID: 780814) and I am duly authorized by the Beneficiaries to provide non-binding advice and guidance on issues related to either deaf-blindness, the applicability of research results, technical evaluation or ethical aspects of the project, based on my knowledge and expertise.

For providing accurate professional advice, the Beneficiaries, individually or collectively, may disclose proprietary information or Confidential information, with the Project Advisory Board, which cannot be disclosed under any circumstances to any other third party.

Therefore, I solemnly undertake:

(i) to use the Confidential Information solely in connection with purposes contemplated between the Beneficiaries in the Grant and Project Consortium Agreement and not to use it for any other purpose or without the prior written consent of the Disclosing Party. The Confidential information will only be used for the preparation of reports addressed to the Beneficiaries, containing findings and conclusions.

(ii) not to copy (in any format, physical, digital or otherwise) or remove any Confidential Information from databases or premises, and to fully abide by the internal procedures for management of Confidential Information of the Beneficiaries.



(iii) not to disclose, transmit or communicate Confidential information provided by the Beneficiaries or contained in reports (or any observations, comments, inferences or conclusions drawn from such information or such Reports) available in any manner, shape or form to any other person.

(iv) to ensure that the reports of the Project Advisory Board do not contain any business secrets and other confidential information supplied by the Beneficiaries, and do not in any way reveal any such business secrets and other confidential information, whether directly, indirectly or by implication.

(v) to procure the full compliance with the terms of this agreement by any and all persons who work with me in any capacity in reviewing and analysing the information received by the Beneficiaries and/or preparing the corresponding reports, and to provide a list of all such persons to SUITCEYES Project Management Board and their signed acceptance of the terms of this agreement.

(vi) to return or destroy all copies (in whatever form reproduced or stored), including all notes and derivatives of the Confidential Information disclosed under the Project, upon the earlier of (i) the completion or termination of the dealings contemplated in this Agreement; (ii) or the termination of this Agreement; (iii) or at the time the Disclosing Party may request it.

The above shall not apply for disclosure or use of Confidential information if:

- The Confidential Information becomes publicly available by means other than a breach of the duty of confidentiality.
- The Confidential Information has rightfully received from a third party without confidential obligations.
- The disclosure is required by law or regulation with reasonable opportunity for the owner to oppose disclosure.

For the avoidance of doubt, the Project Management Board's approval of making a report public shall imply that the Beneficiaries have agreed that information compromised in the report has ceased to be Confidential Information already at the time of the approval.

This Agreement shall remain in effect during the implementation of the Project and shall survive for an additional period of five years after the termination of the Project. Notwithstanding the foregoing, my duty to hold in confidence Confidential information that was disclosed during the term of the Project shall remain in effect indefinitely, save otherwise agreed.

This Agreement shall be construed and interpreted by the laws of Belgium. The court of Belgium shall have jurisdiction.

Name:

Function:

Date:

Place:

## The informed consent forms used for experiments in the Netherlands (in Dutch)



### Instemming onderzoeksdeelname

Dit document geeft u informatie over het onderzoek 'Temporal grouping of vibration pulses'. Voordat het onderzoek begint is het belangrijk dat u kennis neemt van de werkwijze die bij dit onderzoek gevolgd wordt en dat u instemt met vrijwillige deelname. Leest u dit document a.u.b. aandachtig door.

### Doel en nut van het onderzoek

Het doel van dit onderzoek is om te meten hoe mensen series vibratiepulsen het makkelijkst kunnen verwerken. De verkregen informatie wordt gebruikt om ondersteunende apparatuur voor mensen met een beperking in het horen en zien te ontwikkelen.

Het onderzoek wordt uitgevoerd door dr. Myrthe Plaisier van de Dynamics & Control groep van het departement Werktuigbouwkunde samen met prof Astrid Kappers van de Dynamics & Control groep en Systems Control groep van het departement Werktuigbouwkunde en de Human-Technology Interaction group.

### Procedure

Er wordt straks een vibratiemotor op je arm geplakt. Deze zal een serie van trillingen laten voelen. De vraag aan jou is hoeveel trillingen je hebt gevoeld. We gaan dit eerst even oefenen zodat je kunt wennen aan de taak.

### Risico's

Dit onderzoek brengt geen risico's met zich mee, en ook geen nadelige bijwerkingen.

### Duur

Het onderzoek duurt ongeveer 60 minuten.

### Participanten

U bent geselecteerd omdat u als participant geregistreerd staat in de participantendatabase van de Human-Technology Interaction group van de Technische Universiteit Eindhoven. Of omdat heb gereageerd hebt op onze oproep via e-mail.

### Vrijwilligheid

Uw deelname is geheel vrijwillig. U kunt zonder opgaaf van redenen weigeren mee te doen aan het onderzoek en uw deelname op welk moment dan ook afbreken. Ook kunt u nog achteraf (binnen 24 uur) weigeren dat uw gegevens voor het onderzoek mogen worden gebruikt. Dit alles blijft te allen tijde zonder nadelige gevolgen.

Paraaf participant: \_\_\_\_\_

### Vergoeding

De vergoeding bedraagt 10 euro (€2.00 extra indien u niet op de TU/e of Fontys Eindhoven studeert of werkt.)

### Vertrouwelijkheid

Bij alle onderzoeken van Human-Technology Interaction wordt gewerkt volgens de ethische code van het NIP (Nederlands Instituut voor Psychologen).

Wij delen geen persoonlijke informatie over u met mensen buiten het onderzoeksteam. Er worden geen video- of audio-opnames gemaakt die u zouden kunnen identificeren. De informatie die we met dit onderzoek verzamelen wordt gebruikt voor het schrijven van wetenschappelijke publicaties en wordt slechts op groepsniveau gerapporteerd. Alles gebeurt geheel anoniem en niets kan naar u herleid worden.

### Nedere inlichtingen

Als u nog verdere informatie wilt over dit onderzoek, dan kunt u zich wenden tot Myrthe Plaisier (email: m.a.plaisier@tue.nl).

Voor eventuele klachten over dit onderzoek kunt u terecht bij de projectleider, Astrid Kappers (a.m.k.kappers@tue.nl)

### Instemming onderzoeksdeelname

Bij dezen verklaar ik (NAAM)..... dat ik dit document heb gelezen en begrepen en dat ik de gelegenheid heb gehad om vragen te stellen. Ik stem ermee in om vrijwillig deel te nemen aan dit onderzoek van de onderzoeksgroep Human-Technology Interaction, Technische Universiteit Eindhoven.

Handtekening Participant

Datum

The informed consent form (in English) used by HB for taking photos, filming and publishing (for various university applications, also used in the project)



UNIVERSITY OF BORÅS  
Akademi/enhet  
Namn, titel

2018-xx-xx

**Consent for [specify photography and/or filming]**

University of Borås would like to [specify photograph and/or film] you, and use this material in [specify purpose, e.g. the University's marketing].

The material will be published in [specify in which media channels the material will be published, e.g. Magasin 1866, printed brochures, billboards, ads in Borås Tidning, Göteborgs-Posten (newspaper) and Channel 5 (TV), the University's website, Facebook, Instagram, Twitter and YouTube]. The material may reach a large audience, and the University is not able to control others use of the material.

The publishing of the material on [Facebook, Instagram, Twitter, LinkedIn and YouTube] means that the material is transferred to companies based in the United States. These companies are members of the "Privacy Shield"-agreement, and are thus considered to ensure an adequate level of protection of your personal data.

The material will be published together with information about you [specify any additional personal data that will be published together with the photo or film].

//The photographer is entitled to use the material him/herself. The photographer is responsible for his/hers own use.//

It is your decision whether or not we may [specify photograph and/or film you]. It is entirely voluntary to give your consent. If you give your consent, the consent may be withdrawn at any time whereby we will stop using the material. This does usually not affect material that have already been made public however.

I give my consent to the University of Borås to [specify photograph and/or film] me and use this material as described above.

Signature

Name in block letters

Place and date

Email address

To be filled in by the photographer or communicator:

The picture/film shows (content)

Photographer and date for the photo shoot

**Privacy Notice**

Your privacy is important to us at the University of Borås. We are committed to protect your personal data and only process it according to applicable laws and regulations such as the General Data Protection Regulation ("GDPR").

The University of Borås is the controller (in Swedish "personuppgiftsansvarig") of all processing of personal data at the university. If you have any questions about how we process your personal data, you are welcome to read more about this on our website, <http://www.lhb.se/datskydd>, or contact your contact person.

**Your Right:**

- The university is transparent with how we process your personal data. If you want to know what personal data we process about you, you can request a copy of the personal data and information about the processing free of charge once per year. To order a copy of your personal data and information about the processing, you can use the form for this that is available on our website, <http://www.lhb.se/datskydd>.
- If you consent to processing of your personal data you may withdraw the consent at any time. We will then not continue to process your personal data. Personal data that have been made public, e.g. published on social media, is usually not affected by a withdrawn consent however. Because of legal provisions we may also be prevented from immediately erasing your personal data.
- You have a right not to be subject to a decision based solely on automated processing, including profiling, which produces legal, or other significantly effects. The University of Borås does not make such decisions.
- You have a right to have the processing of your personal data restricted.
- You can request rectification or supplementation of personal data that is inaccurate or incomplete.
- You have a right, under certain circumstances, to have your personal data erased.
- You have a right to receive your personal data in a structured, commonly used and machine-readable format to transmit those data to another controller.
- You have a right to lodge a complaint to the supervisory authority (Datinspektionen).

**Contact us:**

**Controller**  
Högskolan i Borås/University of Borås  
501 90 BORÅS  
Sweden  
Tel: +46 33-435 40 00  
Email: [registrator@lhb.se](mailto:registrator@lhb.se)  
Org.nr: 202100-3138

**Data Protection Officer**  
Ann Drysalins  
Email: [datskydd@lhb.se](mailto:datskydd@lhb.se)

Letter of consent regarding video/audio recording or photos in German



**Einverständniserklärung Mitwirkende im Rahmen von  
Foto-/Video- und Tonaufnahmen durch das  
Affective and Cognitive Institute der Hochschule Offenburg**

**Produktion: Foto-/Video- und Tonaufnahmen  
im Zusammenhang mit dem Projekt SUITCEYES**

(nachfolgend „Produktion“ genannt)

**Datum/Aufnahmeort:**

Hiermit erkläre ich mein ausdrückliches Einverständnis, im Rahmen der Interviews der o.g. Produktion, als TeilnehmerIn mitzuwirken.

Ich räume dem *Affective and Cognitive Institute* das Recht ein, Ton- und Video- bzw. Fotoaufnahmen (nachfolgend „Aufnahmen“ genannt) von meiner Person im Rahmen des Interviews zu machen.

Ich übertrage dem *Affective and Cognitive Institute* an diesen Aufnahmen ausschließlich zeitlich, räumlich und inhaltlich unbegrenzt sämtliche im Zusammenhang mit meiner Mitwirkung bei mir entstehenden oder von mir hierfür erworbenen urheberrechtlichen Nutzungs-, Leistungsschutz- und sonstigen Schutzrechte.

Ich gestatte dem *Affective and Cognitive Institute*, die Aufnahmen unter Wahrung der Persönlichkeitsrechte ganz oder teilweise zu bearbeiten, umzugestalten, zu kürzen, zu synchronisieren oder in andere Werkformen zu übertragen.

Diese Erklärung unterliegt ausschließlich deutschem Recht.  
Ausschließlicher Gerichtsstand ist Stuttgart.

TeilnehmerIn (Name in Druckbuchstaben):

.....

TeilnehmerIn (Unterschrift):

Ort, Datum .....

Universal consent form created in the second year of project in accordance with the project identity



**Consent for [specify according to "we would like to..." section]**

SUITCEYES is an Information and Communication Technologies project, financed by the European Union's Horizon 2020 Research and Innovation programme (2018 - 2020).

With the purpose of creating dissemination material and/or for internal use of project members, we need your consent to register material in the following formats and to publish this material in the following channels:

**We would like to...**

- Take pictures of you
- Take video clips of you
- Record our conversation
- Other: \_\_\_\_\_

**The material will be published in the project's...**

- Website
- Twitter and YouTube accounts
- ResearchGate site
- Publicity material (posters, leaflets)
- Internal use repositories
- Other: \_\_\_\_\_

The material published in other than "project's internal use repositories" may reach a large audience, and SUITCEYES is not able to control others use of the material.

If needed, the material will be published together with information about you, such as [for example name, affiliation or other].

It is entirely voluntary to give your consent and decide if you grant us permission to register this material. If you give your consent, the consent may be withdrawn at any time, and from there on, we will stop using the material. This does usually not affect material that have been already made public.

I give my consent to the SUITCEYES project to register and use this material as described above.

\_\_\_\_\_  
Name

\_\_\_\_\_  
Place and date

\_\_\_\_\_  
Signature

\_\_\_\_\_  
E-mail address @

**Information about the material:**

\_\_\_\_\_  
The registered material contents

\_\_\_\_\_  
Photographer's name and date for the photo shoot

We are committed to protect your personal data and only process it according to applicable laws and regulations such as the General Data Protection Regulation (GDPR).

For additional information, please contact us:

<https://suitceyes.eu/contact/>



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University of Borås, Sweden  
Centre for Research & Technology Hellas, Greece  
Offenburg University of Applied Sciences, Germany  
University of Leeds, United Kingdom  
Eindhoven University of Technology, Netherlands  
Les Doléts Qui Réveit, Talant, France  
Harjo Sp. z o.o., Poznań, Poland

