# D1.4 Updated Data Management Plan

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| **Deliverable No.** | D1.4 | **Due Date** | 30/11/2024 |
| **Description** | An updated Data Management Plan having as a basis the first version produced in M6 and including changes as these have become evident from the design and development process | | |
| **Type** | Report | **Dissemination Level** | Sensitive |
| **Work Package No.** | WP1 | **Work Package Title** | Project Management and Coordination |
| **Version** | v1.0 | **Status** | Final |

This project has received funding from the European Union's Horizon Europe research and innovation programme under grant agreement N° 101057747

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## History

| Date | Version | Change |
|---|---|---|
| 23-10-2024 | 0.1 | Table of contents |
| 29-10-2024 | 0.2 | Introduction, Abstract, Statement of originality |
| 01-11-2024 | 0.3 | Updated Data Summary |
| 10-11-2024 | 0.4 | FAIR data, Allocation of resources |
| 20-11-2024 | 0.5 | Data security |
| 01-12-2024 | 0.6 | Ethical Aspects |
| 02-12-2024 | 0.7 | Conclusions |
| 09-12-2024 | 0.8 | Comments provided by UCL |
| 10-12-2024 | 0.94 | Deliverable finalised |
| 18-12-2024 | 0.95 | Final review by ICCS – minor changes applied |
| 23-12-204 | 1.0 | Deliverable approved by the PC and submitted |

## Key data


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|---|---|
| **Keywords** | Prospective data, retrospective data, cohorts, registries, data use and re-use, data management plan |
| **Lead Editor** | Themis Exarchos (UOI) |
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## Abstract

The TeleRehaB DSS project covers the development and validation of a tele-rehabilitation decision support system, which would aim at improving home-based rehabilitation programs for older adults at risk of falls. This is a multi-center clinical investigation involving patients between 40-80 years with diagnosed conditions like stroke, MCI, vestibular dysfunction, and long COVID-19. The main objective is the feasibility and acceptability of the home-based tele-rehabilitation program that could be beneficial in reducing risks from falls and balance-related problems. The sample size comprises 460 participants, which would be an adequate number for drawing conclusions on the overall effectiveness of the intervention. Baseline demographic information, primary outcomes such as quality-adjusted life years (QALYs) and functional assessments, secondary measures of cognitive function, incidence of falls, balance confidence, mood, and adherence could form the essential data points. Data are also collected on sensor-recorded physical activity, system usability, and real-life patient experiences. Furthermore, it involves retrospective data from different datasets to support the development of prognostic tools and enhance the scalability and generalizability of the tele-rehabilitation system. The project ensures data integrity and access in the future, with data stored securely and in a manner that is compliant with the FAIR principles and GDPR. The TeleRehaB DSS will focus on providing innovative, scalable solutions for fall prevention and rehabilitation in older adults, hence further developing the growing field of digital health.


## Statement of originality

This deliverable contains original unpublished work except where clearly indicated otherwise. Acknowledgement of previously published material and of the work of others has been made through appropriate citation, quotation or both.

# List of Abbreviations

| Abbreviation | Explanation |
|---|---|
| **AN** | Acoustic Neuroma |
| **BPPV** | Benign Paroxysmal Positional Vertigo |
| **BVW** | Bilateral Vestibular Weakness |
| **KCMH** | King Chulalongkorn Memorial Hospital |
| **CVD** | Central Vestibular Dysfunction |
| **DMP** | Data Management Plan |
| **FAIR** | Findable, Accessible, Interoperable and Re-usable |
| **MS** | Multiple Sclerosis |
| **MTBI** | Mild Traumatic Brain Injury |
| **NKUA** | National Kapodistrian University of Athens |
| **NPH** | Normal Pressure Hydrocephalus patients |
| **PD** | Parkinson patients |
| **PNP** | Polyneuropathy patients |
| **PPPD** | Persistent Postural-Perceptual Dizziness |
| **UCL** | University College London |
| **UKLFR** | Universitaet Klinikum of Freiburg |
| **UOI** | University of Ioannina |
| **UVW** | Unilateral Vestibular Weakness |
| **VM** | Vestibular Migraine |
| **WP** | Work Package |

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# About this deliverable

This deliverable highlights the extensive work conducted by the TeleRehaB DSS project to design, implement, and evaluate an innovative tele-rehabilitation decision support system aimed at enhancing home-based care for older adults at risk of falls. By integrating clinical insights, advanced digital health technologies, and data-driven approaches, the project addresses critical challenges in balance and fall risk management for individuals with conditions such as stroke, mild cognitive impairment, vestibular dysfunction, and long COVID-19. Conducted across multiple international sites, the study draws on the experiences of a diverse group of participants, ensuring that its findings are relevant to a wide range of individuals.

At its core, this deliverable emphasizes the project's dedication to using technology and data responsibly and effectively. With careful attention to data security and privacy, as well as a commitment to making the findings usable for future research, the team ensures that the project's impact extends far beyond its initial goals. By improving outcomes for those at risk of falls, the TeleRehaB DSS project not only addresses an important health issue but also opens doors to new possibilities in digital health and rehabilitation.

# 1 Updated Data Summary

## 1.1 Purpose of the data collection/generation and its relation to the objectives of the project

Data collection within this project is primarily focused within Work Package 5 (WP5) to support a comprehensive clinical study aimed at developing and validating a tele-rehabilitation decision support system (TeleRehaB DSS). The purpose of this data collection is to assess the acceptability and feasibility of a home-based balance tele-rehabilitation program for older adults, particularly those at risk of falls. This data generation is closely tied to the project's objectives, as it directly informs the development of a scalable, accessible, and effective digital solution that can improve patient outcomes through targeted interventions tailored to specific health conditions affecting balance and fall risk. The project aims to address fall prevention and rehabilitation needs for patients with multiple risk factors, leveraging innovative digital health technology to deliver therapy remotely.

Population to be studied and sample

Patients aged 40-80 years old with falls/at risk of falls AND/OR with chronic dizziness/imbalance AND with radiologically diagnosed stroke, OR diagnosis of mild cognitive impairment (MCI) OR peripheral or mixed (central and/or peripheral) vestibular diagnosis OR long Covid-19. By targeting these groups, the project aligns with its goal to develop interventions that address complex clinical needs through tele-rehabilitation.

The sample size for the pilot study will be 50 participants for each intervention group due to the number of variables included, with 50 stroke patients, 50 MCI, 50 vestibular, 50 long Covid in the intervention arm with an equal number of controls recruited at each site, with the control group matched to the experimental group for diagnosis, age and sex distribution, to account for country-specific factors.

The study will be conducted across multiple centres to enhance the generalizability of findings and account for variations in patient demographics and healthcare practices across countries. The targeted patient population and distribution of intervention and control group participants per site are as follows:

| | Site | Targeted patient population | Number of patients |
|---|---|---|---|
| Study 1 | University College London (UCL), UK | Stroke, MCI, long Covid-19 | 50 intervention + 50 controls |
| Study 2 | National and Kapodistrian University of Athens (NKUA), Greece | Vestibular, MCI | 50 intervention + 50 controls |
| Study 3 | University Medical Centre Freiburg Neurocenter (UKLFR), Germany | Stroke, MCI, long Covid-19 | 50 intervention + 50 controls |

| | | | |
|---|---|---|---|
| Study 4 | King Chulalongkorn Memorial Hospital (KMCH), Thailand | Stroke, MCI, Vestibular | 30 intervention + 30 controls |
| Study 5 | Secretaria Regional de Saúde e Proteção Civil da Região Autónoma da Madeira (SRS, Madiera) | Stroke, Vestibular, long Covid-19 | 50 intervention + 50 controls |
| **Overall:** | | | 230 intervention + 230 controls |

In total, the study will recruit 230 participants for the intervention group and an equal number of matched controls, bringing the overall sample size to 460 participants. This multi-centre approach not only facilitates a broad evaluation of the TeleRehaB DSS's effectiveness but also strengthens the external validity of the findings, providing insights into how such a program may be adapted and applied across different healthcare settings.

## 1.2 Types and formats of data the project generated/collected

This multi-centre, assessor-blinded, randomized control study is designed to explore the feasibility and acceptability of a home-based tele-rehabilitation program for older adults at risk of falls due to conditions such as stroke, mild cognitive impairment (MCI), long Covid-19, and vestibular dysfunction. Participants are randomized to either the intervention group (IG) or control group (CG) via a secure online platform (www.sealedenvelope.com). Given the study's comprehensive design, the TeleRehaB DSS project collects a diverse range of data types—from personal data necessary for participant management to specific health and functional metrics critical for assessing program outcomes

**Personal data**

Personal data (name, date of birth, address, contact details (email, phone number), GP name and contact details) will be kept for the duration of the study (in Data Safe Haven, UCL and in the data safe heavens of the other clinical partners for each clinical trial centre) in order to contact the participants throughout the course of the study, and the GP to notify of the participants' involvement in the study and any significant findings during it. The research team will also collect special category data – relating to the participants' health.

**Types of data that will be generated from this project**

In addition to the personal data collected, as described, the following data will be collected:

**Baseline measures**

These will include demographic data (age, occupation, years of education, sex, married status) and all primary and secondary outcome measures

**Primary outcome measures:**

We will investigate the study's feasibility and acceptability, compared to the OTAGO and Meniere's dizziness booklet as standard care for balance rehabilitation. Acceptability will be measured via recruitment rate, compliance, drop-out rates, adverse events, and side-effects. Various other validated secondary outcome measures will be used to evaluate the programs efficacy, feasibility and safety, including measures of balance confidence, cognition, physical activity, falls risk, wellbeing, symptoms and user experience. Additional baseline measures will be collected to assess e-health literacy via questionnaires (STAM, e-heals and MDPQ). Acceptability and feasibility will be analysed using descriptive statistics, and trends for effectiveness will be explored using general linear model analysis of variance

We will calculate **quality-adjusted life years** (QALYs) with the EuroQol five dimensional descriptive system EQ-5D-5Linstrument (https://euroqol.org/eq-5d-instruments/) and QALY weights derived using cross-mapping to the EQ-5D-3L UK values and other European tariffs, as recommended by NICE and with an area-under-the curve approach, assuming linear change in EQ-5D-5L values over time with primary end point at the end of intervention. We will establish cost-effectiveness by means of the incremental cost-effectiveness ratio (ICER), that is the difference in mean costs divided by the difference in mean QALYs at the time of recruitment to the study and 1 year before the study and for 1 year after the end of intervention.

The **EQ-5D-5L**, a standardized, valid and reliable simple, generic measure of health status for clinical and economic appraisal. The respondent is asked to rate their health status on these five dimensions from 1 to 5 respectively as no problems, slight problems, moderate problems, severe problems, and extreme problems. The EQ VAS (Visual Analogue Scale) records the respondent's self-rated health on a 20 cm vertical, visual analogue scale with endpoints labelled 'the best health you can imagine' and 'the worst health you can imagine'. The respondent is asked to mark an X on the scale to indicate "how your health is TODAY". https://euroqol.org/eq-5d-instruments/sample-demo/

The 10-item **Functional Gait Assessment** (FGA) is a clinical test that assesses postural stability during complex gait tasks (e.g. walking with head turns or stopping and turning, 5 minutes). It is a modification of the Dynamic gait index, with improved reliability and a reduced ceiling effect. It consists of 10-items, scored from 0-3, Version 1.0 I 06.08.2024 I TeleRehaB DSS © 35 TeleRehaBDSS_WP5_DEL_5.5 Study initiation package v2.0_UCL_v1.0 z severe impairment to normal ambulation, respectively, scored out of a total 30 points, and takes 5-20 minutes to administer. https://geriatrictoolkit.missouri.edu/FGA/Wrisley-2007-FGA_PTJ_84-10-Appendix.pdf

**Secondary outcome measures:**

Secondary outcomes will include the same measures as per our published HOLOBalance protocol (https://clinicaltrials.gov/ct2/show/NCT04053829) to be collected at baseline (week 0) and end of intervention follow up (week 12). These will include functional measures of dizziness (such as Dizziness Handicap Inventory); balance and gait function (functional gait assessment), balance confidence (ABC Scale), fear of falling (FES-I) and prospective falls; cognitive impairment (MoCA); mood (hospital anxiety depression scale HADS); treatment adherence (patient exercise log diary); real life sensor recorded physical activity.

**a. Balance & orientation assessment measures:**

The **mini Balance Evaluation Systems Test BESTest**:a 14-item test that assesses dynamic balance with a total score of 28 points, 10 minutes. https://www.bestest.us/files/7413/6380/7277/MiniBEST_revised_final_3_8_13.pdf

**Subjective Visual Verticality (SVV)**: is a clinical assessment used to evaluate a person's perception of verticality. It is commonly used to diagnose and assess vestibular function, particularly involving the otolith organs (utricle and saccule) in the inner ear, which are responsible for detecting gravity and linear acceleration. The test will be performed using a computer program and a simple, validated bucket test: the subject is asked to adjust a visual line to what they perceive as vertical in various head positions to assess the effect of different body orientations on their perception of verticality.

**b. Falls**

Falls diaries will be collected weekly from participants during the intervention, and monthly for up to 12 months after completion of the intervention.

**c. Cognitive assessment measures:**

The validated **Montreal Cognitive Assessment** (MoCA) that includes sections on visuospatial/executive function, naming, attention, language, abstraction, memory and orientation to time and place (6 questions) (15 minutes). https://www.parkinsons.va.gov/resources/MOCA-Test-English.pdf

**d. Physical activity and social participation assessment**:

The 9-item self-administered **Rapid Assessment of Physical Activity** (RAPA) is a questionnaire that assesses levels of a wide range of physical activity level in adults older than 50 years (5 minutes). http://depts.washington.edu/hprc/programs-tools/tools-guides/rapa/

**e. Subjective questionnaires**

The 25-item self-report **Dizziness Handicap inventory** (DHI) validated questionnaire assesses' functional, emotional and physical domains. Responses are graded 0 (no), 2 (sometimes) or 4 (yes) with higher scores indicating greater impact of dizziness maximum and maximum score of 100 points (15 minutes). https://geriatrictoolkit.missouri.edu/vest/Dizziness-Handicap-Inventory.pdf

The **Activities-specific Balance Confidence Scale** (ABC) that assesses patient's perceived confidence for 16-activities of daily living without losing balance. Scores ≤67/100% indicate increased falls risk (10 minutes). https://sites.temple.edu/rtassessment/files/2018/10/Activities-Specific-Balance Confidence-ABC-Scale.pdf

The **Hospital Anxiety and Depression Scale** (HADS), a 14-item scale which assesses non-somatic anxiety (HAD-A) and depression (HAD-D) symptoms. Scores range from 0-21 for each subscale and a score ≥8 identifies depression and anxiety. https://www.svri.org/sites/default/files/attachments/2016-01-13/HADS.pdf

**Fatigue Severity Scale** (FFS; Long covid-19 cohort only): a 9-item instrument designed to assess fatigue as a symptom of a variety of different chronic conditions and disorders. The scale addresses fatigue's effects on daily functioning, querying its relationship to motivation, physical activity, work, family, and social life, and asking respondents to rate the ease with which they are fatigued and the degree to which the symptom poses a problem for them. https://www.sralab.org/sites/default/files/2017-06/sleep-Fatigue-Severity-Scale.pdf

**Warwick-Edinburgh Mental Wellbeing Scale (WEMWBS)**: The Warwick-Edinburgh Mental Wellbeing Scales were developed to enable the measuring of mental wellbeing in the general population and the evaluation of projects, programmes and policies which aim to improve mental wellbeing. The 14-item scale WEMWBS has 5 response categories, summed to provide a single score. The items are all worded positively and cover both feeling and functioning aspects of mental wellbeing, thereby making the concept more accessible. The scale has been widely used nationally and internationally for monitoring, evaluating projects and programmes and investigating the determinants of mental wellbeing. https://warwick.ac.uk/fac/sci/med/research/platform/wemwbs/using/howto/

**Situational Characteristics Questionnaire (SCQ)**: The SCQ is 20-item questionnaire designed to assess discomfort in situations of intense visual salience of visual vestibular conflict. It was originally developed as a measure of space and motion discomfort. The questions are graded on a scale from 0 (not at all) to 4 (very much).

https://neuropt.org/docs/vestibularsig/situational_vertigo_questionnaireA068B2C6D4D5.pdf?sfvrsn=ef974640_4

**f. Treatment adherence:** We will also collect treatment adherence through patient exercise log diary (control group) and real-life sensor recorded physical activity (intervention group)

**g. System usability and experience:** We will also assess usability of the TeleRehaB DSS system by collecting the following two questionnaires from research team members and participants enrolled in the intervention group only:

The **system Usability Scale (SUS)** (collected at week 12 only). From: https://www.usability.gov/how-to-and-tools/methods/system-usability-scale.html

User Experience Questionnaire (UEQ) (Collected at weeks 0,12 and 8). From: https://www.ueq-online.org/

h. **System performance**: We will also compare the TeleRehaB DSS predicted versus observed patient outcomes on the EQ-5D-5L, and secondary outcome measures, to assess the system performance.

i. **e-health literacy**: we will also assess patients' knowledge and proficiency with using electronic devices as well as their understanding of health information.

**eHealth Literacy Assessment** (eHEALS): is a 10-item Likert scale questionnaire that evaluate' s patients' skills in finding, evaluating and applying electronic health information. Responses range from 1 (strongly disagree, to 65 (strong agree), with total scores indicating levels of eHealth literacy. This will be used to help validate the AI-model in terms of participant allocation into the high-tech versus low-tech solution.

**Senior technology acceptance & adoption model** (STAM-14): is a 14-item validated questionnaire, short version of the full 38-item STAM, with items rated on a 1-10 Likert scale to measure factors influencing technology acceptance among older adults, with a higher score indicating greater perceived digital literacy.

**Mobile Device Proficiency Questionnaire** (MDPQ) and the short 16-question version (MDPQ-16). The MDPQ, its subscales, and the MDPQ-16 were found to be highly reliable and valid measures of mobile device proficiency in a large sample. We conclude that the MDPQ and MDPQ-16 may serve as useful tools for facilitating mobile device training of older adults and measuring mobile device proficiency for research purposes.

**Exit interviews**

Exit interviews will be held to collect qualitative and data to explore participants' experience of the exercise programme and will be recorded, transcribed verbatim and subjected to thematic analysis to determine commonalities in their experiences.

## 1.3 Update on the re-use of existing data in TELEREHAB DSS and their origin updated

The pre-clinical evaluations in TeleRehaB DSS focus on the development of tools necessary to assess the patient's current status and, critically, to evaluate their risk for imminent deterioration in well-being and the likelihood of adverse incidents, such as falls, in the near future. Retrospective data is key to achieving this, allowing for the alignment of clinical modules across sites and the extraction of critical risk and prognostic factors. These include indicators for fall risk, treatment effectiveness and side effects. As previously outlined in the D1.1 Data Management Plan, the retrospective data will encompass both questionnaires and physical activity records from previous studies and partner institutions.

The updated version of the TeleRehaB DSS changes many of the sources of retrospective data as presented in Deliverable D1.1. In effect, these changes introduce quantities and reliabilities of different clinical research projects and partner databases. The changes are very crucial to the project since they affect the range

and depth of analyses, especially for balance, gait, and fall risk factors. Below is a description of the changes to the previous data sources:

**HOLOBALANCE**: In the original dataset there were 160 people, but this was lately reduced to only 129. The requirement of a specific number of participants was instrumental to the success of the module harmonization, and hence the adjustment was made. Even though the original number of participants has been lessened, the dataset is still a useful tool for investigating the data from both balance and rehabilitation interventions.

**EMBalance**: This dataset has seen an increase in the number of participants from 200 to 989. This growth makes it one of the largest and most diverse data sets for the research of balance-related health challenges and assessment of rehabilitation results.

**Smartbear**: Currently, the Smartbear dataset consists of 116 participants due to the ongoing trial. These numbers will grow as the trial will go on.

**NKUA (Greece):** The dataset from the NKUA has undergone refinement from 250 to 248 participants. This decrease of 2 participants out of 250 is mainly caused by the proper data quality checks and new eligibility criteria, which are, of course, the guarantees of the precision and truthfulness of the data.

**UKLFR (Germany):** The University Medical Centre Freiburg (UKLFR) dataset now includes 207 participants, down from 214. This adjustment is part of an ongoing effort to follow up with participants and refine the data collection process.

**KCMH (Thailand):** Initially encompassing 9,200 participants, this dataset has been refined to 8,414 participants to meet the project's strict eligibility and data quality standards. This ensures that only the most relevant and accurate information is used, strengthening the overall analysis.

**UCL (UK):** The UCL dataset has been updated from 414 to 397 participants. This change reflects adjustments made during data validation and participant eligibility reviews, ensuring consistency and precision.

**UK Biobank (UCL):** The planned contribution from the UK Biobank, originally set to include 500,000 participants, remains pending as part of the updated dataset.

**ACTIVAGE**: Initially expected to include 574 participants, the ACTIVAGE dataset will no longer be used. This decision was made due to unexpected challenges with data availability but does not significantly impact the project's overall data pool.

These updates reflect the project team's commitment to ensuring that all datasets meet high-quality standards and align with the TeleRehaB DSS project's goals. While some datasets have been refined or removed, others, like EMBalance, have expanded significantly to provide deeper insights. Together, these datasets form a robust foundation for delivering meaningful results in tele-rehabilitation research.

| Source of retrospective data | Subjects |
|---|---|
| HOLOBALANCE | 129 |
| SMARTBEAR | 116 |

| | |
|---|---|
| EMBalance | 989 |
| NKUA (Greece) | 248 |
| UKLFR (Germany) | 207 |
| KCMH (Thailand) | 9,200 used 8414 |
| UCL (UK) | 397 |
| UK Biobank (UCL) | 500,000 pending |

### 1.3.1 Updated Types and formats of retrospective data

The types and formats of retrospective data used in the TeleRehaB DSS project remain consistent with those described in Deliverable 1.1, with no significant changes to the data types or formats. The only updates are related to the number of subjects in some of the datasets, where minor adjustments have been made as we see in the previous section. These adjustments reflect the updated criteria and the selection of relevant datasets for the study, ensuring the data remains aligned with the project's objectives.

UK BioBank has >10,000,000 datapoints on 5000, 000 participants. We have applied to review data from all UK Biobank participants who gave a positive answer (subjects) and a negative answer (controls) to the following question "In the last year have you had any falls?" and we will document the number of falls reported by positive respondents.

We will assess: medical information (eye problems/disorders, vascular/heart problems diagnosed by doctor, long-standing illness, disability or infirmity, other serious medical condition/disability, hearing difficulty/problems diagnosed by doctor medication for cholesterol, blood pressure or diabetes, participants BMI, height, weight, pulse, overall health rating); physical and socioeconomic characteristics; genetic principal components;

Biomarkers: cognitive; behavioural; psychological/psychiatric/mental health; imaging data.

We aim to find which factors or characteristics may contribute to falls or increase the risk of falls. We have requested tier 3 (highset tier) data access.

## 1.4 To whom might the datasets be useful ("data utility")

As we described in Deliverable 1.1, the data collected in the TeleRehaB DSS project holds significant utility for a wide range of researchers and professionals in various fields. These datasets can be particularly useful to researchers studying:

- Vestibular disorder
- Long COVID-19

- Mild Cognitive Impairment
- Stroke
- Neurologists
- ENTs
- Human balance and its rehabilitation
- Human-machine interactions
- Signal processing
- Medical data mining

# 2. FAIR data

Architecture and data storage will be designed to fully comply with the FAIR principles, but also adopt the EOSC Interoperability Framework for technical, semantic, organizational, and legal interoperability. The FAIR principles represent a set of rules which enhance the discoverability, accessibility, interoperability, and reusability of data, as defined in Deliverable D1.1 Data Management Plan. In the context of TeleRehaB DSS, conformity to the FAIR principles is achieved by using Zenodo (https://zenodo.org/) as the repository both for publications and data and by implementing the DataCite Metadata Schema https://schema.datacite.org/. The Zenodo community for TeleRehaB is available here:

https://doi.org/10.5281/zenodo.14265573.

To be even more in line with the principles of Open Science and to guarantee that the FAIR(Findable, Accessible, Interoperable, and Reusable) data standards are met, this deliverable has also been created and managed using the OpenAIRE Argos service for Data Management Plans. The Argos tool provided a structured format for documenting and organizing the project's data management practices, enhancing both transparency and accessibility. The DMP is publicly available via the Argos platform and can be accessed using the DOI:10.5281/zenodo.14289431.

# 3. Data security

## 3.1 Data storage

During the RCT study, all personal data collected for the TeleRehaB DSS dataset will be securely stored under the responsibility of ICCS, the project coordinator. Data storage will adhere to GDPR requirements and relevant legal frameworks to ensure participant confidentiality and data integrity.
Pseudoanonymized data, where participant identifiers are replaced with unrelated character sequences, will be shared within the consortium for analysis and processing via a secure, encrypted cloud platform. Access to this pseudoanonymized data will be strictly limited to authorized consortium members based on their role and need.
ICCS will implement secure backup systems to prevent data loss and ensure availability in the event of unforeseen circumstances. Physical access to premises where sensitive data is stored will be restricted to authorized personnel, with appropriate surveillance and access controls in place. Digital access will require strong authentication mechanisms, including two-factor authentication (2FA), to prevent unauthorized access.

Upon completion of the study, ICCS will retain the pseudoanonymized dataset for the legally required retention period, during which it will remain encrypted and protected. This dataset will only be accessible under strict protocols for quality control, audits, and approved analyses. After the retention period, all data will be securely destroyed following GDPR-compliant procedures.

## 3.2 Data Access

Data access during the RCT study will be managed to ensure compliance with GDPR, ethical standards, and participant confidentiality. Access protocols will differentiate between consortium partners and external parties, with oversight provided by the Data Management Board (DMB).

**Access for Consortium Partners During the Study**

Consortium partners requiring access to the TeleRehaB DSS dataset must notify the DMB, detailing the purpose of access, such as conducting analyses or preparing publications, and specifying the exact subset of data needed. The DMB will evaluate these requests to ensure alignment with the project's objectives and to prevent redundant or conflicting usage. Only coded and pseudoanonymized data will be shared, and access will be granted through secure and encrypted channels to protect data integrity and confidentiality.

**Access for External Researchers Post-Project**

After the project's conclusion, external researchers may request access to the dataset through a formal application process managed by the DMB. Applications must include:

- The purpose and intended outcomes of data use.
- Details of the requested subset of the dataset.
- Documentation of compliance with ethical and legal standards.

The DMB will assess these applications to ensure compliance with GDPR and project-specific policies. Approved access will be granted under strict licensing agreements that safeguard participant confidentiality and ensure proper usage of the data.

All access to the dataset, whether internal or external, will be logged and monitored to maintain transparency and traceability. These logs will be periodically reviewed by the DMB to ensure adherence to data access policies and protocols.

## 3.3 Data Management Board (DMB)

To oversee the governance and accessibility of the TeleRehaB DSS dataset, a **Data Management Board (DMB)** will be established. The board will function as the central body for managing data requests and ensuring compliance with legal, ethical, and security standards during and after the project.

Composition of the DMB

The DMB will comprise representatives from key consortium partners:

- **ICCS (Coordinator):** Responsible for overall data governance and ensuring GDPR compliance.
- **UCL (Clinical Manager):** Ensures ethical handling of clinical data and monitors adherence to participant confidentiality protocols.
- **UOI (Technical Manager):** Oversees the technical aspects of data security, storage, and sharing.

**Responsibilities During the Project**

During the study, the DMB will manage data access requests from consortium partners. Each partner must notify the DMB about their intended use of the data, such as for specific analyses or publications, and specify the required subset of the dataset. The DMB will evaluate these requests to confirm alignment with the project's objectives, ensure proper data use, and avoid redundant or conflicting analyses. The DMB will also ensure that all shared data is pseudoanonymized and transferred securely.

**Responsibilities Post-Project**

After the project concludes, the DMB will handle external data access requests. Researchers or organizations outside the consortium must submit a formal application detailing the purpose, intended outcomes, and data subset required. The DMB will assess these requests based on compliance with GDPR, ethical considerations, and licensing agreements. Data access will only be granted under strict terms that protect participant privacy and ensure appropriate use.

The DMB will also be responsible for monitoring the use of the dataset, maintaining access logs, and addressing any issues related to data security or misuse. Periodic reviews of the dataset and access policies will be conducted to ensure continued compliance with evolving legal and ethical standards.

## 3.4 Data Storage After the Project

Once the RCT study is concluded, the TeleRehaB DSS dataset will continue to be managed securely under the oversight of the Data Management Board (DMB) to ensure compliance with ethical, legal, and project-specific requirements.

### 3.4.1 Long-Term Data Storage and Security

The dataset will remain coded and pseudoanonymized, with any identifying information replaced by unrelated character sequences. ICCS, as the project coordinator, will be responsible for the secure storage of the dataset for the legally required retention period. During this time, the data will be stored in an encrypted environment with access restricted to authorized personnel. Physical data, if any, will be archived securely at clinical trial sites, complying with national and international regulations.

To enhance security, the linking codes used to associate pseudoanonymized data with participant identifiers will be stored separately in an encrypted and password-protected system. These codes will only be accessible to authorized DMB members and will not be shared externally under any circumstances.

### 3.4.2 Data Access Post-Project

The pseudoanonymized dataset will be retained for secondary analysis, quality control, and audits. Access to the full dataset will be strictly limited to the DMB and granted only upon approval of formal requests. External researchers requesting access to the dataset must submit applications reviewed by the DMB, ensuring the requests align with legal and ethical guidelines. All approved data access will be provided through encrypted and secure transmission protocols.

### 3.4.3 Data Confidentiality

Data confidentiality will be maintained throughout the retention period through robust encryption mechanisms and access controls. Regular audits will ensure compliance with GDPR and evolving data security standards. Access logs will be maintained to track all data-related activities and prevent unauthorized use.

### 3.4.4 Data Destruction

At the end of the legally required retention period, the dataset and all associated records will be securely destroyed. ICCS will ensure the complete and irreversible deletion of all digital records and the shredding or incineration of physical documents. A detailed record of the destruction process will be documented and made available for auditing purposes, ensuring compliance with GDPR and other applicable regulations.

## 3.5 Availability for Use by Other Researchers

After the completion of the project, a subset of the pseudoanonymized TeleRehaB DSS dataset will be made available to the broader research community under open science principles. This process will balance the promotion of scientific collaboration with the protection of participant confidentiality and consortium members' rights to publish their findings.

### 3.5.1 Data Subset Selection

The data shared publicly will be a curated subset of the full dataset, ensuring that no personal or sensitive information can be inferred. This subset will be selected based on its relevance to the broader scientific community and its ability to support secondary analyses while safeguarding participant anonymity.

### 3.5.2 Embargo Period for Publications

To respect the efforts and intellectual contributions of the consortium, an embargo period will be implemented during which external researchers will not be permitted to publish findings using the shared data. This embargo period, set by the Data Management Board (DMB), will allow consortium partners sufficient time to publish their primary findings before the dataset becomes fully available for unrestricted use.

### 3.5.3 Access via Zenodo Repository

The selected data subset will be uploaded to the Zenodo repository (https://zenodo.org/records/14265573), a secure and widely recognized platform for sharing research data. Access will be governed by clear licensing terms, which will specify the permitted uses of the data and the requirement to acknowledge the original project and data providers in all subsequent publications and analyses.

### 3.5.4 Licensing and Compliance

External researchers accessing the data must comply with the licensing terms and conditions set by the DMB. These terms will include:

- Proper acknowledgment of the dataset and the TeleRehaB DSS project in all publications.
- Restrictions on the re-identification of participants or unauthorized data sharing.
- Adherence to GDPR and other applicable data protection regulations.

### 3.5.5 Monitoring and Enforcement

The DMB will oversee the use of the dataset to ensure compliance with the licensing terms. Violations of these terms will result in penalties, including revocation of data access and reporting to relevant ethical and legal bodies. Monitoring mechanisms, such as data usage tracking, will be employed to uphold these policies.

This framework ensures that the TeleRehaB DSS dataset contributes to advancing scientific knowledge while protecting the rights and confidentiality of participants and the consortium's intellectual contributions.

# 4. Ethical aspects

## 4.1 Ethical and Legal Framework

The Legal And Ethical Environment has been reviewed extensively in deliverable D7.1 Ethical and Legal Framework. The deliverable document outlines the legal and ethical framework and environment that applies to the project and lists the relevant areas that will be further analysed. Each area contains ethical principles on which rules and regulations are based.

The document delves into a more detailed analysis of each specific area and examines it in the context of the regulatory framework that applies to it. By doing so, the objective is to gain a comprehensive understanding of how these areas function and the impact those ethical principles have on the project,like :

- **Overview Of Data Ethics And Principles**. The document covers the overview and the introduction of the general ethics and principles of data.
- **Principles Of Data Ethics**. The document analyses further all the general ethics and principles on data mentioned in the previous overview.
- **Overview Of Ethics In The Development And Use Of AI**. The document covers the overview and the introduction of the ethics and principles of AI applications.
- **AI Ethics And Data Stewardship Values and AI Ethics And Ethical Principles**. The chapter analyses further all the ethics and principles of AI applications mentioned in the previous overview.
- **Ethics In Data Processes**. The chapter lists all ethics and principles applied in the major data processes of the project: Data Collection (gathering), Processing, and Sharing.

## 4.2 Informed Consent (IC)

The data will be collected from consenting patients that will be fully informed that their de-identified and pseudoanonymized data may be used for research also after the end of the project.

An essential condition for acquiring a subject's (person's) Informed Consent to participate in clinical research is the satisfaction of the scientific and ethical rigor principles.

With regard to ethical principles and their application to the IC the following must be taken into particular consideration:

- the principle of respect for the dignity of the subject (person);
- the principle of respecting the right to self-determination of the competent subjects involved in the trial;
- the fairness of the risk/benefit ratio

It is crucial to ensure that the consent request and information documents are worded in a manner that guarantees complete compliance and application of the principles that guide the practice of Informed Consent. The aim is to make the participant aware that they are not merely being subjected to the experiment, but are actively choosing to participate in it.

The IC and the patient information form tend to guarantee the alliance or therapeutic agreement between doctor/investigator and patient; they should take a formulation that explicitly declares and specifies the positions of the subjects in question, their respective obligations, and rights, commitments, and waivered required and

expected. From an ethical and deontological point of view, these aspects do not have a value. They are only theoretical, but they imply a practical commitment in the doctor / patient relationship context.
The IC has been reviewed and analysed extensively in deliverable D7.1 Ethical and Legal Framework.

## 4.3 Data Gathering, Processing and Sharing

As previously stated, the TeleRehaB DSS project aims to conduct a clinical study involving participants. The study will involve processing their personal information to provide customised rehabilitation interventions, assessing prognostic factors, and offering automated balance intervention planning and management.

Given that the project is funded by the EU and will mostly take place within the EU, the regulatory environment of the EU has been taken into account. Therefore, the following legal and ethical aspects must be incorporated into the framework:

- **Clinical Ethical Standards and Guidelines and relevant Regulation,**
- **AI Act and relevant Regulation,**
- **Data Transfers,**
- **General Data Protection Regulation,**
- **Gender Equality,**
- **CE Mark.**

The document D7.3 Data Gathering, Processing and Sharing, presents a comprehensive and detailed report on the Ethical and Legal Framework of the TeleRehaB DSS project, which includes an overview of relevant regulatory, privacy, and ethical initiatives.

The report aims to provide a thorough understanding of the current landscape, identify any gaps, and propose potential solutions that can help improve the overall effectiveness and compliance of the Framework.

The document also focuses on specific areas with significant impact, such as:

- **Joint Controllers and Data Processors Agreement,**
- **Security and Privacy Measures.**

# 5. Conclusions

The main goal of the TeleRehaB DSS project is to enhance balance and the management of fall risk in older adults by developing a tele-rehabilitation decision support system. The data collected and generated within this study is important for reaching the aims of the project, which include establishing the feasibility, acceptability, and effectiveness of home-based rehabilitation programs tailored for individuals at risk of falls. The data collected across various clinical sites represents a diverse population, including persons with conditions such as stroke, MCI, vestibular disorders, and long COVID-19. This guarantees not only the broad generalizability of the intervention but also strengthens the results.

The datasets generated from this study provide a rich resource for future research in areas such as vestibular disorders, stroke rehabilitation, cognitive impairment, and human balance. Furthermore, the integration of both primary and retrospective data ensures completeness of understanding of the intervention effect on health outcomes. By following the FAIR principles, the project guarantees that this data is findable, accessible, interoperable, and reusable; thus, it is open to transparency and the opportunity for secondary usage, making it so useful for any future studies and healthcare innovation.

Regarding security and data protection, the research makes use of tight protocols for protecting personal data or health information, meeting GDPR and the laws on data protection. It will securely store pseudoanonymized data, allowing for subsequent research into these data, which supports principles of open science.

In total, the TeleRehaB DSS project represents a significant step forward in the integration of digital health technologies within fall prevention and rehabilitation, and the data generated will be pivotal to advance knowledge and improve patient outcomes in this domain.

# Appendix

## A.1.1 Data

The dataset contains a variety of information that has been accurately fielded into various fields, all of which are mentioned in detail below. This list provides an overview of the data currently stored, offering insights into the structure and scope of the dataset. Every field represents one aspect in which this dataset is comprehensive, with a view to increasing its utility.


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    "QUEST_COHORTSTROKE_5",
    "QUEST_COHORTSTROKE_6",
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  "cohort_mci": [
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  "cohort_vestibular": [
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    "QUEST_VESTIBULAR_100"
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