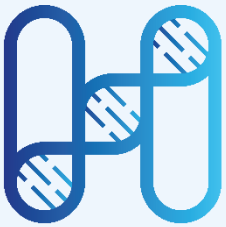

HEREDITARY

HetERogeneous sEmantic Data integratIon for the guT-bRain interplaY

Deliverable 6.2

HEALTH SOCIAL LAB ACTIVITIES

This project has received funding from the European Union's Horizon Europe research and innovation programme under grant agreement No GA 101137074. Views and opinions expressed are however those of the author(s) only and do not necessarily reflect those of the European Union. Neither the European Union nor the granting authority can be held responsible for them.

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EXECUTIVE SUMMARY

This report outlines how the Health Social Laboratory (HSL) was first developed and then implemented during the first year of the HEREDITARY project. As a result of a methodology designed to foster meaningful collaboration and generate actionable insights, the laboratory was successfully launched in the cities of Padua and Turin (Italy), and received positive feedback and provided valuable insights into the topics explored. Furthermore, three new laboratories will be established in the cities of Barcelona (Spain), Nijmegen (Netherlands) and Denver (United States), broadening the HSL impact and engaging more diverse perspectives.

The launch of the laboratories demonstrated the strength and adaptability of the framework while also highlighting opportunities for further refinement to meet evolving research needs. This report, thus, underscores the success of the initial phase of the HSL implementation and sets a clear direction for its continuous growth and development, ensuring it remains a dynamic and effective tool for collaboration for the future of the HEREDITARY project.

DOCUMENT INFORMATION

Deliverable ID	D6.2
Deliverable Title	Health Social Lab activities
Work Package	WP6
Lead Partner	Observa
Due date	28.02.2025
Date of submission	20.02.2025
Type of deliverable	R
Dissemination level	PU

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REVISION HISTORY

Version	Date	Author	Document history/approvals
V0.1	28/01/2025	Giuseppe Pellegrini, Chiara Lovati	First Draft
V0.2	02/02/2025	Rute Costa	Review of the document
V0.3	14/02/2025	Giuseppe Pellegrini, Chiara Lovati	Second Draft
V0.4	19/02/2025	Rute Costa	Second Review
V1.0	20/02/2025	Anna Romanovych	Final formatting of the deliverable

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LIST OF ABBREVIATIONS

Abbreviation	Expanded form
HSL	Health Social Laboratory
HSLs	Health Social Laboratories
MS	Multiple Sclerosis
ALS	Amyotrophic Lateral Sclerosis
FTD	Fronto Temporal Dementia
UNITO	University of Turin
UNIPD	University of Padua
RUMC	Radboud University Medical Centre
CRG	Centre for Genomic Regulation
UCD	University of Colorado Denver

1 INTRODUCTION

In year 1 of the HEREDITARY project, WP6 partners designed and launched a stakeholder engagement model series named Health Social Laboratories (HSLs). The design process lasted 8 months, and it involved a coordinated effort to integrate diverse expertise and perspectives, including those from medical researchers, medical professionals, patients and patient advocacy groups into a single co-creative solution aimed at supporting HEREDITARY innovative brain health research.

Prior to planning the methodology, researchers assessed the project consortium framework and landscape through a series of exploratory interviews with clinicians and researchers belonging to HEREDITARY partner institutions. These were located in Italy (*n*=4), Netherlands (*n*=2), United States (*n*=2), and Spain (*n*=1). The main aspects investigated through these interviews were: relationships and stakeholders; therapeutic process and clinical activities; technology and research; communication, expertise and policymaking. The aforementioned research efforts allowed us to observe how different HEREDITARY partner institutions engaged civil society in their specific field. It was in fact possible to observe varied levels of stakeholder engagement and science communication, different network configurations, and different research expertise, all of which were taken into account in the design of HSLs.

The laboratory initiative is aimed at fostering collaboration, aligning research priorities, and addressing key challenges in the field of neurodegenerative disorders and gut-brain interplay (details are shown in *Table 1*) through a series of workshops and collaborative discussion sessions.

Table 1 HEREDITARY Use Cases for Neurodegenerative Disorders and Gut-Brain Interplay

Use Case	Title	Disease(s)
1	Neurodegenerative diseases phenotyping & prognosis evaluation	ALS
2	Next-generation diagnosis and treatment response for neurodegenerative disease	ALS, MS, FTD
3	Signs of Parkinson's disease in multimodal data	Parkinson
4	Phenotyping of the gut-brain axis in healthy individuals	GUTBRAIN AXIS
5	Gut-Brain linkage and disease relevance	Multiple diseases

Stakeholder engagement has been proven to promote research adoption, improve the short and long-term relevance of research efforts, increase stakeholders' trust, and enhance stakeholders' and researchers' exchange and mutual learning (Concannon et al., 2014; Boaz et al., 2018).

In the case of HEREDITARY, engaging different stakeholders will help, on one side, to improve the understanding and communication of complex brain health data; and, on the other side, to ensure that scientific advancements are as accessible and as impactful for real-world health challenges as possible.

The remaining content of this report is structured as follows: *Section 2* is going to provide a summary of the Health Social Laboratory methodology as it was first consolidated; *Section 3* and *4* are going to describe concrete Health Social Laboratory events, both past and future; finally, *Section 5* will delve into the potential methodological evolution in line with the overall progress of the other HEREDITARY project components.

2 HEALTH SOCIAL LABORATORIES

Our Health Social Laboratory framework was the result of extensive research. It was designed to foster meaningful stakeholder engagement and bridge the gap between scientific research and public participation. While specifically tailored to the HEREDITARY project context, the model remains flexible enough to be implemented in different countries and contexts, and through different disciplinary fields and research topics.

The initial design efforts and careful planning resulted in a laboratory manual (available here) containing instruction regarding laboratories: *structure*, *activities*, *moderation*, *reporting*, and *evaluation* methods, along with the necessary forms and materials.

In particular, the methodology can be summarized as shown in *Table 2*.

Table 2 Health Social Laboratory Methodology Summary

Component	Summary Description
Structure	The laboratory lasts about four hours. It starts with an introduction to the project, the workshop and its objectives, and then continues with three sessions for thematic discussions, punctuated by two small coffee breaks offered by the host institution. It involves approximately 12 stakeholders, which are engaged in the discussion of selected topics, chosen on the basis of their relevancy to HEREDITARY project research, which can be updated or modified at need. The structured approach ensures that the sessions remain goal-oriented while allowing for flexibility in exploring innovative ideas.
Activities	Stakeholders are involved in discussions of around 45 minutes on a set of predetermined topics. In the case of the first HSLs, these topics were “technology”, “terminology”, and “ethics”. Each one of these sessions is supported by a written prompt (*Annex 3-5*) containing relevant sub-topics for discussion, effectively helping participants focus on specific issues and actionable insights. These prompts are designed to encourage critical thinking and foster meaningful dialogue, and include a space for participants to take notes.
Moderation	Moderation plays a vital role in the success of HSLs. In fact, two figures work collaboratively to ensure the success of all laboratory activities: a facilitator and an assistant. The facilitator guides the laboratory dialogue and encourages the collaboration between participants. The facilitator is responsible of active listening, impartial moderation, and conflict management. In this sense, a humanities background and previous experience in citizen science or group dynamics can be a valuable asset. The assistant manages organizational and logistical tasks, serves as the main contact for planning, and ensures the seamless execution of HSLs.
Reporting	The laboratory provides various reporting tools. Firstly, the discussion sessions prompt sheets include a space for notes which is then collected and recorded as laboratory material. Secondly, at the end of the event participants are asked to fill in an evaluation

Component	Summary Description
	questionnaire (*Annex 6*) on the activities. Thirdly, the entirety of HSLs are audio and video recorded (based on the consent form provided in *Annex 7*), allowing for the transcription of discussion content and the subsequent analysis of thereof.
Evaluation	The evaluation questionnaires are the primary resource analyzed following an HSL. The collected data is first entered into Excel and then thoroughly examined to extract meaningful insights including participants' interest in the topics discussed, their level of satisfaction, agreement, and other key metrics. A second key resource from the laboratories is their recording, in video and audio form. The audio recording is transcribed and later subject to a thematic analysis, helping uncover relevant insights.

It is important to note that each HSL is organized collaboratively by the Observa association and a dedicated HEREDITARY partner, ensuring strong support through an established organizational framework and access to a local network. This partnership provides the necessary structure and resources to enhance the efficiency and effectiveness of the laboratory, leveraging local expertise and connections to achieve its goals.

2.1 Materials

Materials play a key role in HSLs. They can provide guidance, collect feedback, and facilitate dialogue.

A specific set of forms (*Annex 1-7*) guides the participants in their HSL experience. These are contained in a participant booklet, which is provided to each person during HSL events. It consists of:

- an info sheet on Health Social Laboratories, with a description of the sessions' agenda, goals, and other relevant information;
- a fact-sheet on the HEREDITARY project, with a description of the project's areas of action and citizen engagement efforts;
- three participant prompt sheets, one for each thematic session (technology, terminology, ethics);
- an evaluation form to collect important feedback about the participant experience and structure;
- a consent form for audio/video recording of the laboratory.

These forms are essential tools: by contributing to an organized and effective collaboration process, they help improve the overall participant's experience.

A second key element for the participant experience is represented by the brief report provided after each laboratory. This report helps summarize the main content that has emerged from the discussion sessions, and provides participants with a set of preliminary results, bypassing the long waits required for a more thorough thematic analysis discussion.

2.2 Participants and Outreach

HSLs are stakeholder engagement events. Its participants can be “individuals, organizations or communities that have a direct interest in the process and outcomes of a project, research or policy endeavour” (Deverka, et al., 2012). Based on principles of “inclusive” stakeholder engagement, stakeholder heterogeneity, diversity, and gender balance should be favored (C. Paleco et al., 2021).

The stakeholders identified for the HEREDITARY project, which provide a comprehensive and diversified set of perspectives that are critical for addressing complex health-related concerns, are:

- clinicians (physicians, nurses and other health professionals), who have firsthand expertise with patient care and practical insights into healthcare delivery;
- health and technology researchers, who can provide evidence-based expertise and cutting-edge knowledge about health technology innovation;
- patients and patients’ association representatives, who guarantee that lived experiences are included and encourage patient-centered solutions;
- caregivers, who can provide unique insights into the realities of patient care;
- health institution administrators, who can share strategic and operational views required to effectively implement projects;
- policy-experts, who can provide an awareness of the regulatory and systemic background, ensuring that the effort is consistent with broader healthcare policies and frameworks.

In the case of HSLs, stakeholders are engaged through a direct approach. The organizing team assistants and partner institute structure collaborate in contacting relevant organizations via email and phone to invite chosen stakeholders to participate in the event. The organizations (hospitals, research centers, patient associations) are selected based on their geographical relevance, within the province and region of the partner institution, and their expertise and focus on neurodegenerative disorders (*ALS*, *MS*, *Parkinson Disease*). If needed, an incentive in the form of a gift card is available to laboratory participants, as a token of appreciation for their time and contribution.

3 LABORATORIES, PAST ACTIVITIES

During the first year of the project, two Health Social Laboratories were activated. The first project partners involved were *UNITO* and *UNIPD*, respectively, in Turin and Padua (Italy).

The organization process began with an assessment of the partners relationship network and working team, to identify a point of contact for collaboration on the laboratory planning. Researchers utilized both face-to-face meetings and remote correspondence to identify a suitable representative from both organizations.

Once the point of contact was appointed, the team collaborated on the definition of a date and a location for the event. Finally, stakeholders were invited to the event.

After the event, the thematic sheets, evaluation questionnaires, and recordings of the laboratories were collected, and processed for analysis.

The laboratory evaluation began with two elements: the evaluation questionnaires and audio recordings. The questionnaire data was entered into an Excel file, and the audio recording was transcribed in Word. Following this operation, some key insights were extracted from the data, both from a quantitative and qualitative point of view.

Firstly, we assessed the distribution of participants roles (*Figure 1, Figure 2*). Secondly, we calculated the mean for several relevant questionnaire items (*Annex 6*). This included results for participant interest, perceived importance, and satisfaction with the discussion outcomes for each topic, which will be summarized in the following sections. Finally, for the transcriptions, the text was thoroughly reviewed, and the key points and insights were extracted and summarized (*Tables 3-8*). An in-depth thematic analysis of the discussions' transcriptions will be carried out in the following months, once the results from the first editions of all the laboratories are available.

3.1 Padua

The first HSL of the first year of the project was held in Padua on November 11th, 2024. A total of 15 participants attended the event. Their roles are detailed in *Figure 1*.

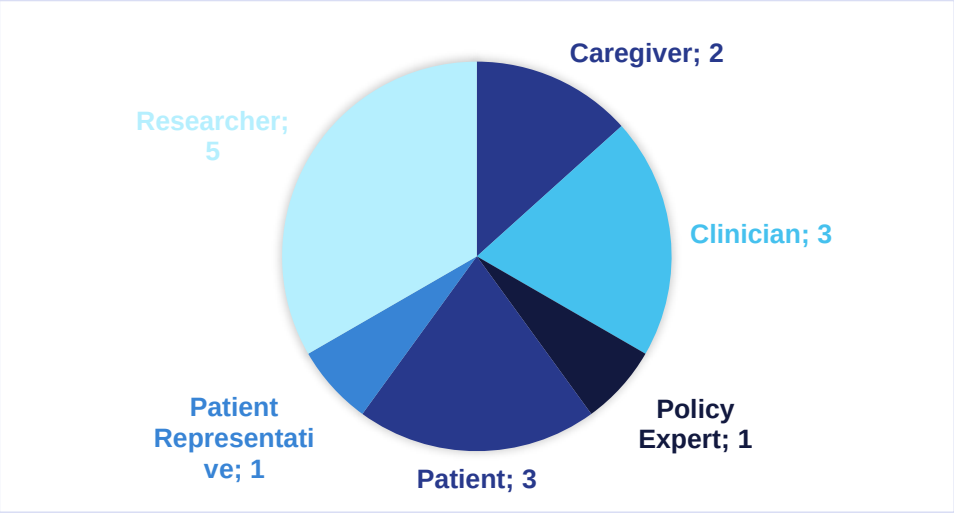

Figure 1 HSL Padua Participant Roles Distribution

The laboratory was facilitated by Giuseppe Pellegrini, from Observa. It had a total duration of 3 hours and 15 minutes, and it included a 20-minute coffee break instead of two 15-minute ones.

Based on the evaluation questionnaires, participants expressed the highest satisfaction and interest in the "Ethics" topic, viewing it as both important and engaging. The "Technology" topic ranked highly in interest and perceived importance, while the "Terminology" topic was seen as relatively important but had slightly lower ratings in both satisfaction and interest.

The technology discussion lasted around 40 minutes.

Table 3 Insights from HSL Turin Technology Session

Insights Summary
Medical-technological progress is not uniform, due to different data collection practices and different applications of technologies.
Technology, telemedicine, and telemonitoring can help the doctor-patient relationship but we must be careful: there is a gap in the digital skills of the population, especially in relation to age. The lack of digital skills also prevents some patients from accessing continuous care.
It is important to include people's lived experience in research databases, to capture symptoms and discomforts that are not easily detectable in the clinical setting. The study of progression trajectories could also contribute to advancing research.
In treatment pathways, but especially at the time of diagnosis, it would be good to inform patients of the associations, specialists and treatment centers available.
It would be important to standardize and make accessible health data (for example online), especially in relation to the results of clinical tests, both to allow exchange between different clinical specialists and to promote communication between different research centers. However, data accessibility is limited by the European Regulation on privacy.
In terms of data standardization, the bottom-up approach to research means that different research centers, even if they work on the same topics, do not communicate and do not share data; this constitutes an obstacle to the progress of knowledge. With the use of artificial intelligence, this problem is amplified since large amounts of data are processed.
Hospitals and professionals should be coordinated in the effort to collect data in a standard way, and to improve collaboration in research.

The terminology discussion lasted around 30 minutes.

Table 4 Insights from HSL Padua Terminology Session

Insights Summary
In doctor-patient communication, it is best to avoid anglicisms (outside of English-speaking countries), acronyms, approximate indications such as "as needed", excessive simplifications or generalizations.

Insights Summary
Support desks for patients and their families can contribute to patient support, diagnosis processing, and language understanding.
It is best not to undermine the specialized nature of medical reports, as their purpose is to communicate medical data to other professionals in the sector. However, at the same time it would be useful to ensure that the message is understood (not simplified) in doctor-patient communication.
Communicating research results between professionals is different from public communication, where the quality of information risks being lost. Furthermore, in public communication of science, sensationalism must be avoided. Scientific citizenship could be promoted by communicating research in a simple way, alongside professional communication.
There is a gap in the standardization of terminology in different fields of application of medicine (e.g. cardiopulmonary resuscitation vs. neurodegenerative diseases) so it could be useful to create specific dictionaries for some diseases.

The ethics discussion lasted around 45 minutes.

Table 5 Insights from HSL Padua Ethics Session

Insights Summary
It is important to discuss palliative and end-of-life care from the beginning of the disease pathways, not only in the final part.
People should be informed about the importance of sharing data for the benefit of the individual and the community, and about the processes for protecting the privacy of clinical data.
All actors involved in medical research should participate in the processes in an organized manner and with equal dignity, according to a multi-actor model. This process would make research accessible and aligned with the needs of all stakeholders.
Correct data management requires large resources, which associations often do not have. The state could meet this need. The sharing of health data could also be promoted through a circular economy.
Patient privacy must be guaranteed in the context of caregiving relationships, honoring professional secrecy. However, it is good to encourage caregiver-patient communication, and evaluate each case based on its specificities.
Intransigent ethics committees and a restrictive application of the GDPR in Italy make several research efforts difficult.
The figure of the caregiver in Italy is neither recognized nor supported in the phase of understanding the disease, despite the valuable role it plays.
Transparency is needed in doctor-patient communication, even in the case of difficult therapeutic choices that can significantly modify the course of the disease and/or the quality of life.

3.2 Turin

The second HSL of the first year of the project was held in Turin on November 21st, 2024. A total of 10 participants attended the event. Their roles are detailed in Figure 2.

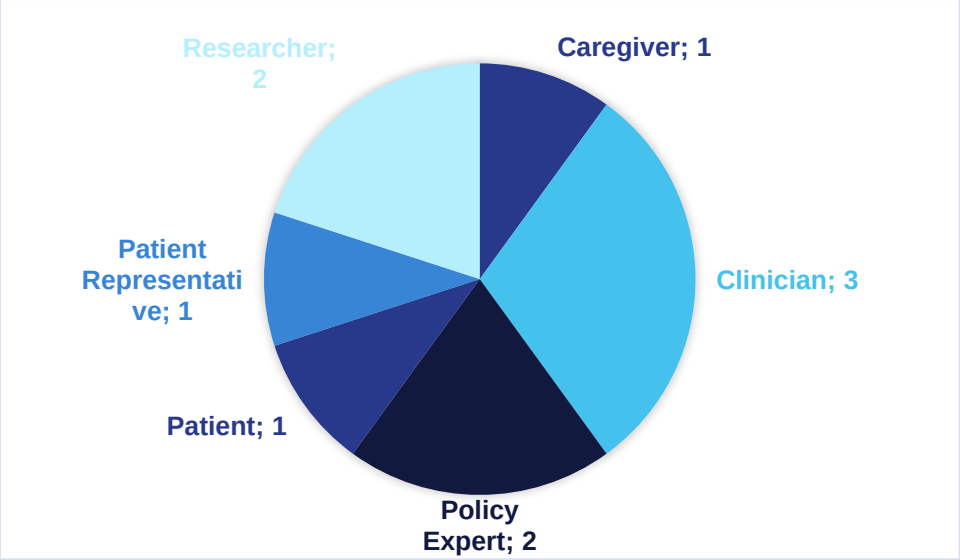

Figure 2 HSL Turin Participant Roles Distribution

The laboratory was facilitated by Giuseppe Pellegrini, from Observa. Just as the Padua event, it had a total duration of 3 hours and 15 minutes, and it included a single 20-minute coffee break instead of two 15-minute ones.

Based on the evaluation questionnaires, participants expressed a high level of satisfaction, interest, and perceived importance across all three discussion topics, with "Ethics" clearly standing out. The "Technology" and "Terminology" discussion topics were also rated positively, reflecting strong interest and perceived relevance.

The technology discussion lasted around 45 minutes.

Table 6 Insights from HSL Turin Technology Session

Insights Summary
Wearable technology, home automation, and telemedicine have many potentials, for example in terms of increasing sociability, mobility, or the perceived quality of life of the patient (or person). But they can also create various risks in terms of safety, privacy, and individuality of the patient (or person).
Technology is a precious element in terms of relationship opportunities, but it is important to know its limits and risks. Furthermore, technological aids are not always easily available for patients, and require support for their use.
Technology must be a tool, not an end.
Advancement in knowledge does not always translate into progression in the clinical-therapeutic approach, and it is important to know how to communicate the difference between these steps, especially in the doctor-patient relationship, and/or in the case of invasive or particularly impactful tests.

Insights Summary
It is important to have the courage to explore new clinical approaches, even if they are uncertain or risky.
Uncertainty in the medical field is as difficult to communicate as it is to accept. But transmitting uncertainty is essential to ensure effective communication.
Technological innovation requires the collaboration of a very broad network of actors and relationships.
The speed of technological progress risks generating mistrust and fear. However, excessive distance can slow down innovation processes. It is therefore necessary to promote an informed debate on the topic.

The terminology discussion lasted around 35 minutes.

Table 7 Insights from HSL Turin Terminology Session

Insights Summary
It is best to avoid technicalities to make medical communication more accessible while using specific language.
It is important to know how to modulate different elements of communication in the doctor-patient interaction, such as terminology, distance and timing based on the needs of the interlocutor.
Both the right to know and the right not to know of the person and/or patient must be respected, even in treatment planning.
Great care is needed in medical communication, both to avoid making it difficult to understand and to avoid adding frustration to the patient in a difficult journey.
It is useful to encourage students, or aspiring medical specialists, to reflect on communication through ad hoc opportunities in their study paths.
The time elapsed since diagnosis can influence the need for understanding and the ability to accept new medical information of the patient.
Doctors do not always have enough time during visits to explore in depth the communication needs of each patient.
In multi-professional medical teams, a harmonization of communication practices leads to greater synergy.
Personal communication in the clinical field is very different from public communication of science, it is not always clear how to use the two types of communication.
Truthfulness of the source and accreditation of the doctor are very important in medical communication, especially in the case of social communication.

The ethics discussion lasted around 55 minutes, it was the longest discussion session recorded so far in the HSL series.

Table 8 Insights from HSL Turin Ethics Session

Insights Summary
In terms of data protection, neither an excessive desire to protect the privacy of the individual, nor an excessive desire to protect the research center, should limit research opportunities, as often happens.
The population should be informed about the real procedures for data processing, and shared management of data between different research centers should be promoted.
There is a general distrust towards the processing of personal data, for this reason it would be useful to be able to better explain to the public how research, with its interests and efforts in terms of data protection, is a very protected environment from the point of view of security and privacy.
To investigate certain diseases in more depth, the creation of large databases is necessary, with particular attention to transparency.
Social and political research can provide credibility to patient advocacy movements and valuable support for medical innovation.
Marginalizing patients as a “separate category” prevents them from being an active part of the medical research process.
Excessive suspicion of data processing procedures in the medical field harms not only the clinician, but also the patient.
It would be useful to involve patient representatives in ethics committees.
Political and cultural blocks on issues such as end-of-life research or banned therapeutic substances should be overcome to promote patient well-being.
It is important to respect the individuality of the patient in terms of needs, desires and life path by using personalized medicine rather than standardized medicine.
It is important to educate the population on the strengths and weaknesses of public health, in order to adequately support it.

4 LABORATORIES, FUTURE ACTIVITIES

Year 2 of the project will begin with the establishment of the remaining HSL base reference networks: Barcelona (Spain), Nijmegen (Netherlands), and Denver (USA). The aforementioned cities present several key differences which are going to enhance the heterogeneity of results and findings from future HSLs.

The Barcelona edition of the HSLs event series will be realized in March 2025 in collaboration with the Centre for Genomic Regulation and European Genome-phenome Archive (CRG - EGA), a biomedical research institute with a service for the permanent archiving and sharing of personally identifiable genetic, phenotypic, and clinical data generated for the purposes of biomedical research projects or in the context of research-focused healthcare systems.

The Nijmegen edition of the HSLs series will be realized in April 2025 in collaboration with the Radboud University Medical Center (RUMC), specialized in patient care, scientific research, teaching and training.

The Denver edition of the HSLs series will be realized in collaboration with the University of Colorado Denver (UCD) and, more specifically, with the support of the CU Anschutz, a leading academic medical campus driving innovation in education, research, medicine, and healthcare.

The introduction of HSLs in these three new stakeholder networks in collaboration with HEREDITARY partners will significantly enhance its global impact, and the diversity of participant perspectives will foster richer, more inclusive feedback on the project research processes. Furthermore, working with varied healthcare and research landscapes will help generate insights that better represent global challenges and opportunities, strengthening the relevance of our findings.

5 METHODOLOGICAL FRAMEWORK EVOLUTION

As part of our commitment to foster meaningful citizen engagement and advance neurodegenerative and gut-brain interplay collaborative research, we designed our methodological framework to be adaptable and responsive to the emerging needs of the different HEREDITARY research process components. Furthermore, this approach responds well to the dynamicity of the interaction between scientific progress and societal needs.

Whether we are focusing on semantics, visualization or terminology, the HSL flexibility can ensure that the citizen engagement efforts remain aligned with the overarching goals of the project, maximizing their impact.

Following this direction, we will now illustrate some ways in which the HSL framework is able to evolve:

a. by focusing on a single, well-defined topic, rather than several at once, stakeholders would be able to conduct an in-depth exploration and analysis of the issue at hand, a process that would encourage a more focused discussion and, consequently, targeted problem solving;
b. by introducing shorter sessions, HSLs could better accommodate participants' need for flexibility and make it easier for them to engage while maintaining focus and productivity; this adjustment would enhance accessibility and participation without necessarily compromising the quality of outcomes;
c. by introducing innovative laboratory components, such as scenario-based discussions, interactive digital tools reviews, visualization element evaluation, HSLs could collect more focused, actionable feedback and enable real-time adjustments to the project research trajectory based on stakeholders' insight.

All of these elements can be tailored on a case-by-case basis during the planning phase of the HSL to optimize stakeholder engagement and outcomes.

5.1 Terminology research

One critical focus of the HEREDITARY project is developing and validating a common terminological framework to support its collaborative research efforts, that can provide stakeholders and end users with a comprehensive and accessible set of terminological knowledge related to neurodegenerative and gut-brain diseases and medical research. In fact, HEREDITARY aims to simplify medical language and concepts, making these more understandable to the general public.

The HSL methodology can play a key role in this task by providing an adaptable and flexible approach that facilitates the validation process. Its ability to accommodate face-to-face interactions can support engagement and dialogue efforts between experts and non-experts, enabling collaborative refinement of the terminology.

6 CONCLUSIONS

HSL were designed in year 1 of the HEREDITARY project to encourage a collaborative approach to neurodegenerative diseases and gut-brain interplay clinical research. Their development and implementation have proven to be a significant success.

Through careful design, extensive research, and the organization of the first two sessions in Padua and Turin, we have gained valuable feedback and uncovered meaningful insights on how stakeholders understand technology, terminology, and ethics within the HEREDITARY project scope. The positive reception and outcomes of the first HSLs confirm the strength of the approach while also highlighting areas for potential refinement.

As we move forward, plans are already underway to expand the initiative to the cities of Barcelona, Nijmegen, and Denver, broadening the laboratories' impact and engagement. Furthermore, we remain committed to continuously adapting the methodology to meet evolving research needs, ensuring that the HSL framework remains a dynamic and effective tool to foster meaningful collaboration.

This iterative approach will allow us to remain responsive to the project progress while ensuring that the HSLs continue to serve as an effective platform for citizen engagement in neurodegenerative disease and gut-brain interplay clinical research.

REFERENCES

The bibliographic entries are arranged in lexicographical order based on the key, following the APA style. This enables us to place the entries and citations in the table and text in any sequence, allowing for later sorting while ensuring consistency.

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7 Annex

Annex	Name
Annex 1	HEREDITARY Factsheet
Annex 2	HSL Info Sheet
Annex 3	Participant Sheet – Thematic Session A
Annex 4	Participant Sheet – Thematic Session B
Annex 5	Participant Sheet – Thematic Session C
Annex 6	Evaluation Questionnaire Participant
Annex 7	Participant Video Audio Consent Form