# From Complexity to Inclusivity: A Methodology for Drafting Patient-Centered Explanations of Gut-Brain Axis Concepts

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**Abstract**

Understanding specialized biomedical knowledge can be particularly challenging, posing significant barriers to the acquisition and use of medical information especially by patients. In this study, a methodology for drafting patient-centered explanations of concepts related to the gut-brain axis and related medical conditions is proposed. The explanations are specifically intended for patients affected by neurodegenerative diseases, who are experiencing cognitive decline. The methodology consists of the following steps: 1) the drafting of specialized definitions in the form of intensional definitions, which enable the structured representation of domain-specific knowledge, and 2) the simplification of specialized definitions into patient-centered explanations. In particular, explanations intended for patients are formulated using popular terms and plain language, considered as two complementary strategies aimed at enhancing the comprehension of specialized biomedical knowledge. This work lays the foundation for the future development of a terminology resource specifically designed to collect and systematically represent knowledge related to the gut-brain axis and associated health conditions.

**Keywords:** Medical Terminology, Patient-Centered Explanations, Intensional Definitions

## 1. Introduction

Medical language is characterized by a high level of complexity, which can hinder the comprehension of domain-specific knowledge by non-experts (Tercedor Sánchez and Prieto Velasco, 2013; Bernardis et al., 2025). Among the multiple factors underlying this complexity is the use of specialized terms in medical discourse, which can pose barriers to effective physician-patient communication (Giovagnoli et al., 2024; Wahrenbrock et al., 2025). The syntactic structures found in medical language could also be a source of difficulty for non-experts (Vecchiato and Gerolimich, 2013). Moreover, a limited degree of health literacy can affect the comprehension of medical terminology in individuals without domain expertise (Makhmutova et al., 2025).

These factors, which impact the understanding of domain-specific knowledge, are a subset of the broader challenges to consider in the popularization of specialized knowledge related to the gut-brain axis. Indeed, this domain of study, which investigates the potential link between the gut microbiota and different neurodegenerative diseases (Roy Sarkar and Banerjee, 2019; Li et al., 2024), has seen a rising volume of related PubMed biomedical publications over the last years (Martinelli et al., 2026, 2025; Nentidis et al., 2026). From a terminological standpoint, ongoing scientific advances have led to the emergence of new terms and concepts, and the reconceptualization of existing concepts. Thus, related knowledge requires systematic terminological analysis, accurate representation, and effective dissemination.

These objectives are included within the larger aims of the European-supported project HEREDITARY (HetERogeneous sEmantic Data integratIon for the guT-bRain interplaY).[1] The project aims to investigate the gut-brain axis and related medical conditions from a clinical perspective, integrating the use of machine learning and artificial intelligence for multimodal data management, and embedding a social dimension involving citizen science.

Within this social dimension, a central goal at the terminological level is to represent specialized knowledge on the gut-brain axis and related health conditions in a terminology resource. The resource will be publicly released, to enable the effective dissemination of knowledge related to the gut–brain interplay. The intended users are physicians, language professionals, and patients. In particular, inclusivity in specialized knowledge representation must be ensured, as the resource will be aimed at patients affected by different levels of cognitive decline due to neurodegenerative diseases. The varied audience of the resource calls for a tailored representation of specialized knowledge, to address the respective information needs of the users. In light of this, specialized definitions need to be drafted to convey domain-specific knowledge.

[1] https://hereditary-project.eu



*Proceedings of the 2nd Workshop on Evaluating Text Difficulty in a Multilingual Context (DeTermIt! 2026)*, pages 33–41
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However, patient-centered explanations also need to be formulated, to enhance comprehension of concepts among patients.

This preliminary study lays the foundation for the future development of the terminology resource, by presenting a methodology for drafting patient-centered explanations that builds on a previous related work of Bonato et al. (2025). Specifically, we consider the drafting of specialized definitions as the starting point for the creation of patient-centered explanations. The formulation of explanations will rely on two strategies aimed at promoting comprehension: 1) the use of popular terms, and 2) the adoption of plain language. These strategies aim to meet the needs of the specific category of patients that will be targeted by the resource.

The work is organized as follows: Section 2 provides the theoretical background, focused on health literacy, the adoption of plain language in the medical domain, and studies that examine the linguistic difficulties experienced by patients affected by different neurodegenerative diseases. Section 3 outlines the methodology for drafting patient-centered explanations. Section 4 presents conclusions and future perspectives.

## 2. Theoretical Background

This section presents the theoretical background on health literacy, the use of plain language in healthcare, and studies on the linguistic patterns of patients affected by neurodegenerative diseases.

### 2.1. The Concept of Health Literacy

Health literacy represents a central concept in the framework of health communication and patient-centered healthcare. As defined by Berkman et al. (2010), health literacy is "[t]he degree to which individuals can obtain, process, understand, and communicate about health-related information needed to make informed health decisions".

Low health literacy can affect the understanding of medical texts, potentially impacting the safety of medical procedures. Smith et al. (2012) found that individuals with lower health literacy showed reduced comprehension of a colonoscopy preparation leaflet, and noted that inadequate understanding of the document may compromise the safety of the procedure. In relation to colonoscopy bowel preparation, Gwag and Yoo (2022) particularly highlight the need to account for the health literacy level of older patients.

Low health literacy can also influence the emotional sphere of people. As evidenced by Parikh et al. (1996), individuals with limited health literacy can experience feelings of shame, which in some cases lead them to choose not to mention their difficulties in reading medical materials to family members and healthcare professionals. As a result, shame prevents them from seeking help, and they lack the support to comprehend "prescriptions, follow-up appointments, recommended health care instructions, or informed consent documents".

### 2.2. Plain Language in Healthcare

In the healthcare setting, plain language can promote health literacy and foster immediate comprehension of medical information (Grene et al., 2017; Di Nunzio et al., 2024; Ermakova et al., 2024a,b). In ISO 24495-1, plain language is defined as "communication in which wording, structure and design are so clear that intended readers can easily find what they need, understand what they find, and use that information" (International Organization for Standardization, 2023). At the core of plain language is the aim of making medical knowledge accessible to non-experts, by adopting criteria that take into account the intended readers and their level of knowledge.

At the time of writing this article, ISO standard 24495-3 (International Organization for Standardization, in press), which provides guidelines for the use of plain language in science writing, is in the approval phase. However, ISO 24495-1 provides relevant principles aimed at drafting texts using plain language.

As indicated in the standard, from a linguistic standpoint, terms that are familiar to the reader and unambiguously designate concepts should be consistently used in texts. Specialized terms exclusively have to be used if readers can understand them and find them preferable, and "if readers need to learn them to achieve their goals". However, in the latter circumstance, specialized terms need to be accompanied by an accessible explanation at first mention.

At the syntactic level, sentences should ideally focus on a single notion, favoring unambiguous syntactic structures easily recognized by the reader. The use of the active voice is preferred, along with punctuation considered acceptable by readers.

Plain language has been adopted in the medical domain in numerous studies, also focusing on its positive impact on physician-patient communication (Peter et al., 2024). One of its applications is the creation of plain language summaries (PLSs), which are texts aimed at communicating medical research in a comprehensible way to non-experts, also generated through the use of large language models (Arias-Russi et al., 2025). For example, plain language summaries are provided on the web pages of scientific articles that present research on neurodegenerative diseases, such as Alzheimer's disease (AD) (Frederiksen et al., 2024) and Parkinson's disease (PD) (Chou et al., 2026).

Concerning plain language summaries, a notable example in the medical setting is Cochrane Plain Language Summaries (Pitcher et al., 2022; Whiting and Davenport, 2023). These texts, written in English language, summarize the key information and findings contained in medical systematic reviews published by the Cochrane organization. In these texts, terms that are easy to understand and syntactically straightforward sentences are used to facilitate comprehension of medical information by non-experts, favoring access to domain-related knowledge.

### 2.3. Language in Neurodegenerative Diseases

Patients affected by neurodegenerative diseases, however, may experience particular difficulties in language-related tasks (Cummings, 2025). As affirmed by Gumus et al. (2024), this category of patients "tend[s] to use simpler vocabulary and syntax; shorter words and fewer prepositional phrases, reflecting cognitive impairment". Thus, these patterns are linked to the underlying health condition.

Pan et al. (2024) evidence that patients affected by Parkinson's disease manifest impairments at different linguistic levels, namely "morpho-syntactic, lexical-semantic, and pragmatic". Some patients find it difficult to understand sentences with complex structures (Angwin et al., 2006).

Complexity in understanding sentences due to syntax is likewise observed in patients affected by Alzheimer's disease (Nasiri et al., 2022). From a terminological viewpoint, it is particularly interesting to note that "attributes which are more salient for the identification of a given concept are also those most resistant to semantic memory degradation in AD pathology" (Perri et al., 2019).

Taken together, these considerations are relevant for the formulation of patient-centered explanations, as the specific linguistic features of these patients need to be reflected in both the linguistic and conceptual dimensions of terminology.

## 3. A Methodology for Drafting Patient-Centered Explanations

As outlined above, in the terminology resource that will be developed within the HEREDITARY project, knowledge related to the gut–brain axis will be provided to healthcare professionals, language professionals, and patients affected by neurodegenerative diseases. These users manifest different information needs, especially with regard to the level of specialization of the medical information they need to access.

To understand the specific needs of patients, within the HEREDITARY project, interaction with them takes place during the Health Social Labs (Pellegrini et al., 2025), which are events designed to facilitate dialogue among researchers, physicians, patients, patient representatives, and caregivers.

During the meeting held in Padua in 2024, it has been possible to explore the difficulties that patients experience with medical terminology. In that occasion, terminology experts engaged with patients, asking them for examples of terms used by clinicians in communication that were unfamiliar to them, or domain-specific concepts that are difficult to understand. However, understanding the needs of patients requires more than identifying inadequately explained concepts used in physician–patient communication. As a matter of fact, it is fundamental to ask them which information they actually consider useful. For instance, patients emphasized the need for physicians to use terms that makes it easier for them to understand the exact prescribed dosage of medications, given its practical implications for managing symptoms in daily life. However, patients also expressed the necessity to access specialized knowledge on the medical conditions they are experiencing, to gain a clear and exact understanding of their health status. Indeed, patients do not seek an over-simplification of the conceptual dimension of medical terminology; rather, they need to access domain-specific knowledge with the support of explanations that aid the comprehension of concepts, making information clearer and more accessible. Moreover, they wish to acquire knowledge of the specialized terms used by healthcare providers, so that these terms are familiar to them when used in physician–patient communication. More specifically, their key requests are: 1) the use of specialized terms in physician–patient communication, 2) the use of terms that physicians typically use to communicate with patients who are not affected by neurodegenerative diseases, and 3) access to explanations of medical concepts.

Based on this, in the future terminology resource, the specialized definitions of medical concepts will be supplemented by patient-oriented explanations, the latter aimed at facilitating the popularization of knowledge on the gut-brain axis. In particular, providing patients with access to specialized definitions of biomedical concepts enables them to gain insight into specialized knowledge as well as the terms used by healthcare professionals to convey that knowledge. At the same time, patient-oriented explanations, which constitute a simplification of specialized definitions, make it easier to understand specialized information, thereby supporting the dissemination of knowledge. Patient empowerment is therefore achieved through terminology, as specialized knowledge is made inclusive and accessible.

In the following, we present a methodology for drafting patient-centered explanations. We con-

sider intensional definitions as the first step toward the drafting of explanations of concepts, serving systematically as the source of knowledge on which explanations are based. This methodology has been adopted to build a dataset of over 1,200 intensional definitions of concepts related to the gut–brain interplay and related medical conditions. Therefore, intensional definitions for more than 1,200 biomedical concepts have been drafted. The dataset also includes patient-centered explanations of biomedical concepts and is currently being further expanded.

### 3.1. Drafting of Intensional Definitions

The intensional definition is defined in ISO 704 (International Organization for Standardization, 2022) as a "definition that conveys the intension of a concept by stating the immediate superordinate concept and the delimiting characteristic(s)". Thus, in this type of definition, the first concept mentioned helps to precisely situate the defined concept within the concept system, establishing a hierarchical relation with respect to it. The delimiting characteristics, instead, perform a dual function: 1) they allow the comprehension of the defined concept, and 2) they differentiate the defined concept from other concepts that, within the same concept system, share the same generic concept.

In this study, intensional definitions are used to represent specialized knowledge related to the gut-brain axis. As a matter of fact, in the ISO standard, this type of terminological definition is recommended for the purpose of terminology work, since it enables the identification of the characteristics that distinguish one concept from others.

However, representing knowledge specific to the biomedical domain presupposes that terminologists have already gained this knowledge. To achieve this, it is essential to acquire information about the concepts to be defined relying on specialized resources, within which the specialized knowledge shared by experts is conveyed.

Taking this into account, the process of drafting intensional definitions for each concept involves three distinct sequential steps: 1) collecting multiple definitions from reliable biomedical sources to acquire specialized knowledge about the concept, 2) identifying the immediate generic concept, and 3) determining the delimiting characteristics.

The resources consulted include biomedical ontologies, with particular reference to the NCI Thesaurus (NCIT),[2] the Chemical Entities of Biological Interest (ChEBI) ontology, [3] and the Gene Ontology (GO)[4]. Other sources are the Medical Subject Headings (MeSH),[5] the Unified Medical Language System (UMLS),[6] the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition, Text revision (DSM-5-TR) (American Psychiatric Association, 2022), and the International Classification of Diseases, 11th Revision (ICD-11)[7]. In addition, scientific papers are also considered as a reference, mainly retrieved from PubMed.[8] We specifically prioritize recently published scientific papers, to ensure that the representation of knowledge related to biomedical concepts is aligned with the constant scientific evolution that characterizes the domain of the gut-brain axis.

The consultation of multiple sources is also fundamental to identify the immediate generic concept and the delimiting characteristics of the concept to be defined. As a matter of fact, in many cases, different sources respectively provide different definitions of the same concept, and may each state a different generic concept. Comparing the definitions, thus, proves to be a crucial process for identifying the immediate generic concept. This comparison also allows for the identification of the essential and delimiting characteristics needed for comprehending the concept, distinguishing them, for instance, from non-essential characteristics.

An example of an intensional definition is the following definition of the concept <Bacterium>:

> microorganism that is unicellular, prokaryotic, and reproduces by cell division

In our concept system, the characteristics stated in this intensional definition are sufficient to distinguish bacteria from other types of microorganisms. The definition is specifically formulated according to the guidelines established in ISO 704, as it is “a statement in the form of an incomplete sentence without a full stop”. Moreover, it contains specialized terms, known to experts who are already familiar with the concepts linguistically designated by the terms and used by them in the medical setting.

Another example of intensional definition is the following definition of the concept <Multiple sclerosis>, which is regarded as one of the diseases showing an association with the gut–brain axis:

> demyelinating disease of the central nervous system that is characterized by destruction of myelin by the immune system

In this definition, the immediate generic concept <Demyelinating disease> is followed by the delimiting characteristics of the defined concept. The

[2] http://purl.obolibrary.org/obo/ncit.owl

[3] http://purl.obolibrary.org/obo/chebi.owl

[4] http://purl.obolibrary.org/obo/go.owl

[5] https://www.ncbi.nlm.nih.gov/mesh/

[6] https://uts.nlm.nih.gov/uts/umls/home

[7] https://icd.who.int/en/

[8] https://pubmed.ncbi.nlm.nih.gov

information provided concerns the affected anatomical site, namely the central nervous system, and the fact that the disease involves the destruction of myelin by the immune system. In particular, to formulate the intensional definition, the terminologists considered essential to include the information regarding the anatomical site specifically affected by demyelination in multiple sclerosis, as demyelination may also involve the destruction of myelin located in the peripheral nervous system. The definition conveys the specialized knowledge held by experts, who do not need, for instance, to understand what a demyelinating disease is or the concept of myelin.

In this work, we consider the formulation of intensional definitions as the first crucial step that provides the foundation for the drafting of patient-centered explanations. This reasoning is informed by different considerations. In the first place, to effectively convey specialized knowledge to patients, it is essential to first analyze, understand, and represent domain-related knowledge, particularly by identifying the delimiting characteristics of defined concepts. Intensional definitions precisely allow to unambiguously define a concept and, in doing so, to clearly distinguish it from other concepts that share common characteristics.

Secondly, using intensional definitions as the starting point for drafting explanations ensures that the delimiting characteristics of each defined concept are also represented in the explanations. This can be particularly important for patients, as it can help them gain a clearer understanding of the condition they are affected by, and distinguish it from other conditions.

The distinction between intensional definitions and explanations is grounded in their respective purposes. Intensional definitions are specifically aimed at defining concepts and establishing precise boundaries between them, as each concept is regarded as "a unit of knowledge created by a unique combination of characteristics." (International Organization for Standardization, 2019). The aim of intensional definitions, therefore, is not to simplify specialized knowledge, but rather to convey and represent it faithfully by listing the characteristics that distinguish concepts. Explanations, in contrast, are intended to make specialized knowledge understandable to a non-expert audience, given that their purpose is to explain specialized knowledge and make it more comprehensible. In light of this, the future terminology resource will provide patients with both intensional definitions and patient-centered explanations. The integration of both specialized definitions and patient-centered explanations is intended to accurately represent and disseminate specialized knowledge, thereby enabling patients to become informed patients. Additional information that may support and further enhance the understanding of biomedical concepts by patients will also be provided in the future terminology resource, presented as supplementary notes within the respective concept entries.

### 3.2. Formulation of Patient-Centered Explanations

As previously mentioned, unlike intensional definitions, patient-centered explanations are designed to facilitate the understanding of the concept. For this reason, it is necessary to simplify the definition, limiting the use of specialized terms and adopting a recognizable syntactic structure. In the work by Bonato et al. (2025), two strategies are used to draft patient-centered explanations. The first strategy is the use of popular terms, that are more easily understood. Secondly, plain language is adopted, to ensure that the text is also structured in a way that allows patients to clearly comprehend medical information.

Based on the knowledge contained in the intensional definition of <Bacterium>, by adopting these strategies, the following explanation is proposed:

> A bacterium is a microscopic organism composed of a single cell. This cell does not have a nucleus. It also does not have organelles that are surrounded by a membrane, that can be considered the organs of the cell. The bacterium can reproduce by dividing into other cells.

As can be observed, several changes have been made compared to the intensional definition. At the textual level, the intensional definition consists of one sentence, whereas the explanation contains four separate sentences. The text is therefore longer; however, it aligns with the guidelines provided in ISO 24495-1, according to which sentences should contain a limited amount of information and focus on a single idea. Notably, this allows for greater clarity in explaining the different characteristics of the concept. The sentences are short and include popular terms, which allow patients to understand the text at the linguistic level, while providing access to specialized knowledge.

In particular, the concept designated by the term "prokaryotic" that appears in the intensional definition is explained through a sentence that makes the concept more understandable: "[t]his cell does not have a nucleus. It also does not have organelles that are surrounded by a membrane, that can be considered the organs of the cell". This sentence partly adopts the wording used in the MSD Manual Consumer Version, a medical resource for non-experts, in which it is stated that organelles "could

be considered the cell's organs".[9] In addition, the term "cell division" is not included in the explanation, replaced by the expression "dividing into other cells", to easily explain the cellular process.

The same strategies are used to draft the patient-centered explanation of the concept <Multiple sclerosis>, based on the information conveyed in the respective intensional definition:

> Multiple sclerosis is a disease. This disease affects the brain, the spinal cord, and the optic nerve. In this disease, the immune system destroys the substance that surrounds nerve fibers.

As exemplified in the previously proposed explanation, the text is composed of more than one sentence, to facilitate the understanding of the different delimiting characteristics of the defined concept. As can be noted, the specialized terms "demyelinating disease", "central nervous system" and "myelin" are excluded from the explanation, as they may be unfamiliar to the patients. In particular, this explanation also adopts the text simplification strategies and wording used in the MSD Manual Consumer Version, where the concept of <Multiple sclerosis> is presented as follows: "In multiple sclerosis, patches of myelin (the substance that covers most nerve fibers) and underlying nerve fibers in the brain, optic nerves, and spinal cord are damaged or destroyed".[10]

In the explanation, the terminologists likewise decided to specify the parts of the central nervous system that are affected by demyelination in multiple sclerosis. The information provided immediately afterward concerns the fact that the immune system destroys myelin. Myelin is referred to as a substance, using the generic concept <Substance> rather than <Myelin>, which may facilitate understanding of the concept. The function of myelin is also mentioned, which is essential for helping the patient understand the specific type of substance referred to, avoiding the use of the specialized term "myelin".

To draft explanations, thus, it is also relevant to consult existing medical resources aimed at non-experts, as they can help in identifying terms that are considered more easily understood.

This methodology is therefore characterized by the contextual consultation of medical resources aimed at both experts and non-experts. This combination allows for the creation of patient-centered explanations that reflect the needs of patients, which concern both the linguistic and conceptual dimensions of terminology.

## 4. Conclusions and Future Work

In this work, we outlined the methodology for the formulation of explanations of concepts related to the gut-brain axis, targeted at patients affected by neurodegenerative diseases. Building on intensional definitions, explanations can convey specialized knowledge to patients, facilitating the understanding of biomedical concepts.

We plan to further refine the methodology presented. In particular, we will explore the adoption of easy language (Maaß, 2020; Pedrini, 2022) to draft patient-centered explanations, as easy language targets users that present cognitive decline and intellectual difficulties. We will focus on the drafting of different patient-centered explanations tailored to the respective varying levels of cognitive decline experienced by patients. We plan to conduct a study in which patients are presented with the drafted explanations and asked to provide feedback on the syntax and the terms used. For this purpose, questionnaires could be used to collect patient feedback. This process will allow the terminologists to identify any challenges that could hinder the comprehension of medical knowledge. In addition, we plan to engage health professionals in the validation of both intensional definitions and patient-centered explanations. In this context, we consider the evaluation of patient-centered explanations within shared tasks and benchmarking initiatives, such as DETECH 2026,[11] to assess the effectiveness of different strategies for improving accessibility and comprehension of specialized knowledge. Specialized intensional definitions and patient-oriented explanations will be included as terminological data in the future terminology resource. Within the resource, intensional definitions and explanations will be provided in multiple languages, to further support the dissemination of knowledge about the gut–brain axis.

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[9] https://www.msdmanuals.com/home/fundamentals/the-human-body/cells?query=cells

[10] https://www.msdmanuals.com/home/brain-spinal-cord-and-nerve-disorders/multiple-sclerosis-ms-and-related-disorders/multiple-sclerosis-ms

[11] https://detech2026.dei.unipd.it/

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