OBTAINING INFORMED CONSENT FROM PEOPLE WITH DYSLEXIA: THE ROLE OF EASY LANGUAGE

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Abstract: *Obtaining informed consent is a standard procedure in research practice. However, it is not sufficient, even if an individual chooses to participate voluntarily in research process, for the researchers to be able to claim that they have obtained informed consent. The consent must be of sufficiently 'high quality': it must not only be informed, but also valid, i.e., it must contain the following three elements: adequate information, voluntariness, and competence. Although preparing informed consent is a difficult process in general, it is particularly challenging when working with certain populations, such as clinical groups who have language and literacy difficulties, e.g., dyslexia. A lack of understanding of the basis and specific characteristics of this disorder can have negative effects on people with dyslexia (PwD) such as in the form of unwanted misunderstandings, psychological stress, negative effects on their learning processes, as well as unethical treatment in the research process. Studies have shown that PwD can be particularly vulnerable to research that might exploit, imply, or attribute unsafe practices to them and their difficulties, especially in connection with research recommendations that require written informed consent. Easy language refers to the language adaptation of a text to facilitate both reading and comprehension, particularly for PwD. Therefore, the use of the easy language guidelines for language adaptation and graphical adjustment is important when obtaining informed consent from PwD.*

Keywords: *Informed consent, dyslexia, easy language, language adaptation, graphic adjustments*

INTRODUCTION

Ethics in clinical and academic research

For several decades, the ethical criteria for conducting research, especially studies involving human participants, including children and other potentially venerable groups, have been improved and tightened at the international level (Miteu, 2024). Nevertheless, there are additional regulations at the national level in some countries (e.g., Ubuntu philosophy of collectivism in living and decision making in Japan; Ekmerci & Arda, 2017) and in some individual institutions in order to ensure ethical conduct in research practice, particularly when dealing with certain user groups. For example, in Croatia, in addition to the general guidelines for ethics in research (Agency for Science and Higher Education, 2006), it is also important to follow the rules, guidelines, and recommendations of the individual institution or university (component) where the researcher works, i.e., research studies that they are a part of or where they were educated. For example, individual research institutes in Croatia (Institute for Social Research in Zagreb, 2012; Institute Ruđer Bošković, 2014) have their own ethical codes. In large clinical centres such as the University Hospital Centre, Zagreb, any access to patients for research purposes requires a written application and the approval of the internal Ethics Committee. Another example of this is the Code of Ethics of the University of Zagreb (2007), the Rules of Procedure of the Ethics Commission of Faculty of Education and Rehabilitation Sciences (2013), and the Rulebook of the doctoral study "Speech, Language and Hearing disorders" (2017). The PhD student in the mentioned study programme would need to fulfil all the conditions listed in the mentioned documents in order to obtain approval for the proposed research.

It is expected that institutions such as those mentioned above, whose main field of activity is research, have a high level of awareness of ethical principles in research. Ethics has long been integrated into research as an inseparable part of clinical medicine and associated research studies (Singer et al., 2001). On the other hand, research conducted in the fields of humanities and social sciences often focus on other aspects of ethics that are typically different from the traditional and integrated ethical principles seen in the medical field. Although there are clear codes of ethics developed for research in these fields, they evolve considerably with the growing knowledge of the human psyche and the potential indirect harm that can be caused by participation in research, among other things (Haimes et al., 2002).

Informed consent

Nowadays, most researchers ubiquitously agree that the content and linguistic form of informed consent (Green et al., 2003; Zimmermann et al., 2021) are of the utmost importance in research ethics. Obtaining informed consent became a standard procedure in the research process after the Second World War, during which, from today's perspective, bizarre, unethical, and often illegal research involving human beings was carried out by the Nazis (Weindling, 2001). Documents such as the Nuremberg Code in 1947, the Declaration of Helsinki in 1964, and the Belmont Report in late 1970's were drawn up and published to completely rule out experiments that violated basic human rights. The Nuremberg Code emphasises the importance of voluntary consent. The first version of the Declaration of Helsinki states that the subject should be in a mental, physical, and legal state in which they can fully exercise their freedom of choice. The Belmont Report (National Institute of Health, 1979) contains at least two ethical convictions: firstly, that individuals should be treated as autonomous agents, and secondly, that persons with limited autonomy are entitled to protection. The principle of respect for the person is thus divided into two separate moral demands: the demand for recognition of autonomy and the demand for protection of people with limited autonomy. In the following decades, numerous other documents were published with the aim of guaranteeing the autonomy of people as research participants, among other things, precisely by obtaining informed consent. In the Charter of Fundamental Rights of the European Union (European Union, 2000: Article 3), free and informed consent of the person concerned is stipulated. The latest revision of the Declaration of Helsinki (World Medical Association, 2013) states that, in research involving human subjects, each potential subject must be adequately informed about the aims, methods, sources of funding, possible conflicts of interest, institutional affiliation of the researcher, the expected benefits and potential risks of the study, as well as the possible discomforts. The subject should be informed of the right to withdraw from participation in the study or to withdraw consent at any time without consequences. The Data Protection and Privacy document (The European Commission, 2009) emphasises the importance of specifying and explaining the research method and procedure in the consent form, as well as the justification for the collection of targeted data and the time limit on the use and storage of the data collected. It should also be ensured that they are used exclusively for the stated research purposes.

The requirement for informed consent is now included in various national laws (e.g., *Law on the protection of patients' rights 2004* in Croatia) and in the above-mentioned federal regulations. Official rules for the content and form of such documents are usually determined by national data oversight agencies or research ethics committees (Berget & MacFarlane, 2019). In addition, they are defined at the level of individual professions, scientific fields, universities, institutions, and so on.

So, for example, the Code of Ethics of the University of Zagreb (2007) defines informed consent as a person's conscious agreement to participate in research based on appropriate and sufficient information. Although ethics regulations vary between institutions and countries, most of the definitions and guidelines related to informed consent are similar, i.e., their content at its core is the same - the person participating in a research study or any kind of medical trial must be truly informed

about it. This means that the person has received sufficient information about the research and understood its objectives, and has been guaranteed the opportunity to refuse to participate in the research at any time before, during, or after the research process (Frankfort-Nachmias et al., 2015).

One would think that informed consent would be easy to wrap your mind around in terms of all the existing guidelines, but informed consent is an inevitably complex ethical issue when it comes to conducting research (Fouka & Mantzorou, 2011). Any researcher wishing to conduct research with human participants must prepare in advance and obtain informed consent from potential participants. Consent must be of sufficiently 'high quality': it must not only be informative, but also valid. This means that consent must be based on accurate and adequate information given to the individual in a form that allows them to understand what they are signing and/or agreeing to, while at the same time, knowing their rights during the research process and how to exercise those rights. The foundation of valid consent is based on three elements: adequate information, voluntariness, and competence (Directorate-General for Research and Innovation; European Commission, 2010). Adequate information refers to the quantity of information provided. It should be a reasonable amount of information that a person needs or wants to know to decide whether to participate, without leading to so-called information overload. Furthermore, the quality of the information must be presented in such a way that the language and style of the consent is understandable to participants, i.e., it does not include complicated technical terms and complex syntax that the average speaker would not understand. Simply put, voluntariness in practice means that consent cannot be based on coercion, manipulation, deception, or inappropriately high incentives that could act as manipulation. Competence means that the person giving consent has sufficient mental competence and capacity to understand and retain relevant information about the research, as well as to communicate their views about the research.

All these categories may seem logical and self-explanatory, but in practice, obtaining informed consent can be very complex. This is particularly the case when working with certain populations, where many dilemmas, challenges, and questions arise. Even today, when information on how to formulate good and valid informed consent is increasingly accessible, it seems that not all informed consent forms are truly informative or fully understandable (Lühnen et al., 2018; Pietrzykowski & Smilowska, 2021; Wu et al., 2024).

Informed consent in specific and clinical populations

The Data Protection and Privacy document (European Commission, 2009) emphasises that the individual's decision to participate in a study must be made after obtaining an accurate and complete understanding of all the information contained in the informed consent form. Such a guideline opens numerous ethical dilemmas when it comes to obtaining informed consent from certain groups. One of the most frequently mentioned groups of participants in this context are children. There is much debate about the cognitive and moral/ethical maturity of children when deciding to participate in research studies (see e.g., Coyne, 2010; Lambert & Glacken, 2011). Although parents or legal guardians are typically required to sign an informed consent statement on behalf of their children, it is becoming increasingly important in research practice to obtain consent from minors as well. In the literature, this is referred to as "assent" (or "dissent" if they refuse to participate, e.g., Abramovitch et al., 1991; Dockett & Perry, 2011). Assent is defined as a relational process whereby the children's actions and adults' responses are taken together in order to reflect the children's participation decisions (Dockett & Perry, 2011). Previous studies have reported that children are apparently cognitively capable of providing meaningful consent to research participation by the age of 12 or 14 years (Cortim et al., 2021; Abramovitch et al., 1991), which some states consider when prescribing age for obtaining consent from children (e.g., in Croatia from 14 years of age; Ajduković & Keresteš, 2020). However, besides the cognitive capacity for decision making, there can be other significant problems

in ensuring that minors are free to make this decision (Abramovitch et al., 1991). For example, most children appear to know that they can withdraw from participation in the study, but they are not clear about the details of how to do this or whether there are any negative consequences. In addition, while it seems like obtaining prior parental consent appears to be a protection measure for the children, it also seemed to put additional pressure on the children to agree to participate in the study and to continue once they had consented. Similar questions arise, for example, in relation to cognitive decision-making abilities in the clinical population of people with dementia (Cacchione, 2011). Their capacity to provide their own informed consent to participate is significantly and negatively associated with cognitive impairment (Beattie et al., 2018). Another question that arises when considering the possibility of deciding about participation in research is connected to people whose chronological or mental age alone may not necessarily be an obstacle in the decision-making process, but their language abilities and skills could pose a significant problem in obtaining valid and informed consent. In this context, special attention was mostly given to people with aphasia (Hersh et al., 2021; Shiggins et al., 2023). Aphasia is an acquired language disorder resulting from brain injury typically affecting the left hemisphere after a cerebrovascular insult. Here, language can be affected at all its levels and modalities, but cognitive status usually remains intact (American Speech-Language-Hearing Association – ASHA, 2024; National Aphasia Association – NAA, 2024). Although the ability to make decisions may be preserved in aphasia, patients' ability to read the informed consent or to fully participate in a dialogue, such as about a proposed medical procedure, is often impaired (Stein & Brady Wagner, 2014). Brady et al. (2012) emphasised that excluding participants from the decision to participate in certain research and clinical trials is not a solution. Instead, a different form of flexible approach should be adopted and tailored to the individual's needs. In this context, they emphasised the role of supportive communication techniques, such as those highlighted in Penn et al. (2009) and used within the model for improving informed consent in aphasia. All these adjustments should be implemented in collaboration with a speech and language pathologist (SLP) who is an expert on communication and language adaptations. In the case of specific groups, such as the one described here, in addition to the general documents listed above, research in different scientific fields may have its own guidelines, e.g., the scientific field of speech and language pathology adheres to a set of standards and codes relevant to the profession and research work with clinical populations (ASHA, 2010).

Almost all guidelines on obtaining informed consent emphasise that the informed consent itself should be given in a written form and signed (verbal consent to participate in research is not sufficient). Otherwise, it is not possible to involve a person in research without violating the fundamental ethical principles of research work. Consent documents, therefore, purely aim to cover ethical guidelines and will often require extensive reading. Considering these factors, the present study raises the issue of valid informed consent for a population group who, despite exhibiting proper cognitive functioning, can have significant difficulties with reading and reading comprehension, namely people with dyslexia (hereinafter referred to as PwD). This group is of particular importance in the context of the investigation of ethical informed consent. In addition, unlike aphasia, which is an acquired language disorder affecting adults, there are many studies on children with dyslexia, which makes this group doubly vulnerable - as a group of underage participants and as a group of participants belonging to the clinical population of people with language disorders. The aim of the present study is to propose a set of guidelines for academic researchers and sponsors for the creation of accessible and valid informed consent forms for PwD.

INFORMED CONSENT OF PWD

Dyslexia

Dyslexia is a language-based disorder. It is a specific learning disorder characterised by dif-

ficulties in mastering reading techniques, inadequate reading comprehension, and difficulties in writing (Snowling, 2013), although the person functions well, both intellectually and perceptually (so-called exclusion criteria from APA's DSM-V, 2013). However, public awareness of dyslexia and its characteristics is still inadequate (Knight, 2018; Subramaniyan et al., 2020; Worthy et al., 2016), especially in the Balkan countries (Duranović et al., 2018). Although these results are from the general population and do not necessarily reflect the situation in the academic community, experience shows us that PwD represent an interesting population for many scientific fields, not all of which necessarily understands the depths of their pathology and its characteristics. For example, teachers in Croatia report themselves that they lack confidence, and the relevant knowledge required to work with children with dyslexia (Martan et al., 2017), even though teachers in general often have a research interest in students with specific learning disorders from a methodological point of view. Elliot (2020) also pointed out that even scientists, researchers, and clinicians dealing with dyslexia lack a complete understanding of its characteristics, and this can have a variety of practical consequences for PwD. Any lack of understanding of the basic and specific characteristics of this disorder can have negative effects on individuals with dyslexia, such as unwanted misunderstandings, psychological stress, negative effects on their learning processes, and even unethical treatment in the research process (Gillin, 2015). Research has shown that PwD are particularly vulnerable to research that might exploit, imply, or attribute unsafe practices to them and their difficulties (Berget & MacFarlane, 2019; Coleman et al., 2021; Gillin, 2015), especially in connection with research recommendations that require written informed consent. As the informed consent is usually, as mentioned before, given in written form, researchers cannot be sure whether the participant has comprehended all the written information before signing, which may result in a serious violation of research ethics (Berget & MacFarlane, 2019). Reduced short-term and/or working memory of PwD (Jeffries & Everatt, 2004) may also be a challenge, because participants may quickly forget the information that they read (for example, those mentioned at the beginning of the written informed consent documented, especially if the text is very long and complex) and any related questions about research procedure they may have had.

Despite these factors, as well as the reasons outlined above that can make PwD particularly vulnerable research participants in terms of obtaining informed consent, it is clear that this subject has not been studied in detail. To our knowledge, apart from the few authors mentioned earlier, there are no other studies that deal with the ethical issues of informed consent and other research aspects of having participants with specific learning disorder such as dyslexia. Special consideration should be exercised when researching this population. However, to be able to do so, more detailed reviews and expert papers, as well as empirical research are required to further improve the informed consent process for research participants with dyslexia (Coleman et al., 2021).

Easy language

Easy language (EL) refers to the language adaptation of a text in order to facilitate both reading and comprehension. The theoretical background of EL stems from socio-political principles that focus on the importance of developing an inclusive society and ensuring language accessibility (Lindholm & Vanhatalo, 2021). Consistent with ethical norms and values, as well as modern society's goal of "leaving no one behind", all individuals must be given the opportunity to understand spoken and written languages. EL therefore "can bring the luxury of understanding to everyone, but is essential for those for whom standard language is not an option" (Lindholm & Vanhatalo, 2021, pp. 22-23). In some European countries, this form of language is recognised at a national level, while in others, it remains at the level of recommendations by academics and experts. Nevertheless, it has an undisputed value for approaching people with language disorders. Most of the principles of EL (and the associated standards from which they emerged) overlap with what is expected of

well-formulated informed consent form. This is precisely why it is necessary to apply the rules of EL when drafting and preparing consent forms, especially when working with different clinical groups. One of the populations that can benefit most from the use of EL is PwD (Lenček, 2012; Lenček & Kuvač Kraljević, 2021; Lenček et al., 2022).

The principles of translation and adaptation from standard language into EL include language-independent sections and certain general and language-specific rules (Maaβ, 2020; Lenček et al., 2022). Language-specific rules refer to the specifics of each language. They consider the differences between languages and the fact that linguistic complexity is conditioned by the structure and script of the language under study (Juola, 2008; Sinnemäki, 2011). Some of the principles can even be culturally specific (Ahrens & Fioravanti, 2022). Language-independent adjustments (but in the function of EL) are typically related to content (informational) and graphics - 1) paratextual, 2) textual (discourse), 3) visual, and 4) the ones including images (pictures, photographs, and illustrations). In addition, general and specific language adaptations can be carried out at the level of different language components - 1) semantic, 2) morpho(syntactic), and 3) pragmatic.

Paratextual elements accompany, support, or frame the main text of the publication such as front cover, (sub)headings, and appendix. They must be simple, clear, and meaningful. In the case of informed consent, subheadings are applicable. It is even recommended to use more (sub)headings to indicate or "summarise" the content of the following paragraphs (Inclusion Europe, 2024; Lindholm & Vanhatalo, 2021).

At the textual (discourse) level, Maaß (2020) pointed out the need for complementary reduction and addition strategies. The reduction strategy refers to reducing the available linguistic inventory in standard texts to a minimum (e.g., avoiding foreign terms and stylistic devices) so that the subject matter of a text remains complex (e.g., a text on inheritance law still needs to explain the order of succession), while keeping the linguistic devices basic/simple(r). The addition strategy refers to the use of explanations, exemplifications, and illustrations of the content. Both strategies are used together to foster comprehension at the word and sentence levels. Finally, one must consider the target group and adjust the information structure to its users (in this case, PwD).

At the lexical level, EL focuses on shorter, high-frequency, and familiar words and tries to avoid the use of unfamiliar words (Rello et al., 2013b; Maaβ, 2020). Additionally, Gala & Ziegler (2016) recommended using regular words (high grapheme-phoneme consistency), which is especially applicable in languages with transparent orthography where the phoneme-grapheme correspondence is direct (one-to-one or close). When considering semantics, it is best to use words that are concrete (avoiding the use of abstract words) and unambiguous, and therefore, unquestionably clear (Coleman et al., 2021). Figurative language (e.g., metaphors, metonymies, and so on) should be avoided. Adjectives or adverbs can be omitted if the information provided is repetitive and/or not relevant for the comprehension of the sentence (Gala & Ziegler, 2016). Another strategy is the substitution of the combination of the support verb and a deverbal noun by the corresponding verb alone (Rello et al., 2013c). Lexical-semantic simplification following these guidelines can significantly improve reading speed and accuracy, as well as comprehension in readers with dyslexia (Gala & Ziegler, 2016; Rello et al., 2013b; 2013c).

At the level of morphosyntax, it is recommended to use shorter sentences, simplify complex structures, avoid negations since they are cognitively more demanding, and use active, rather than passive constructions (Gala & Ziegler, 2016; Maaβ, 2020). As far as the word order in the sentence is concerned, the prototypical canonical order in each language facilitates reading comprehension (del Rio et al., 2012; Gala & Ziegler, 2016; Rayner et al., 2013).

The graphic design of the text is also very important to make the text readable and ensure the hierarchy of information, which is especially important for individuals with reading difficulties. Graphic adjustments refer to the formatting and organisation of the text and images (Lenček et al.,

2022; Maaβ, 2020). These adjustments are made according to the guidelines of the so-called universal design (Praiser & Smith, 2011; Rao et al., 2014), which overlaps with the principles of EL for graphic adjustments (Maaβ, 2020). Rello et al. (2013a) recommended the use of a black font on a cream background and an almost black colour font (10% grayscale) on a white background. Graphic adjustments include wider margins, a minimum line spacing of 1.5, aligning text to the left, indenting the beginning of a new paragraph in the text, separating sentences with a double space, starting a new sentence at the beginning of a new line when possible, and choosing the correct font size and type. Font size should be at least 12, but 14 is recommended. The best fonts are graphically simple and visually recognisable fonts, i.e., the ones excluding unnecessary lines and other parts of the graphemes, e.g., from the Sans-Serif series, which must be used consistently throughout the text. It is recommended not to underline and/or italicise the text. The graphic organisation of the text also refers to the division of the text into smaller units, using columns and text boxes (Coleman et al., 2021), separating sections with a thin line, and the use of images (photos and illustrations) to visually support the text, although it is important to know where and how the visual support is used. The images should not "decorate" the text, but add additional or independent information (e.g., about the device that is being used to conduct the research), without interrupting the text and making it more difficult to read. Graphic adjustments also include bolding negations and keywords (to highlight important information) in order to make them easier to recognise. Although the latter adaptation is essentially based on a language adaptation, it has a graphical manifestation (Lenček et al., 2022). A practical example of the translation of the standard language into EL can be found in Appendix 1, where we have used the original and the adapted copy of the informed consent form for the collection of clinical data in our Teaching and Clinical Centre (Faculty of Education and Rehabilitation Sciences).

Paying attention to such language adaptations and graphical adjustments makes it much easier for PwD to read and understand written texts (Hargreaves, 2007; Rello et al., 2013a; 2013b; 2013c; Weinstein & Mayer, 1986). Therefore, the application of the above guidelines when obtaining informed consent of PwD is clearly necessary. It ensures that ethical standards are met when informing people who will potentially participate in research, therapy, or similar professional procedures. However, such adaptations must be made in consultation with a specialist SLP (in the best case, the specialist himself makes the adaptations), since this is a compulsory part of basic training for these specialists in many countries. The difficulties in generalisation may be related to the specificities of each language and script. While much of the EL guidelines are generally applicable, there are also a number of specific adaptations related to what is simple or complex in a particular language (in terms of the structure of the language and the course of language development and literacy), which in turn is related to cultural specificities and legal requirements (e.g., curriculum, age of school entry, and so on). Building on the limitations described above, it is recommended that future EL research must focus on its specificities in different languages and scripts. In this way, the application of specific guidelines, while adhering to the general guidelines, would allow for the relevant adaptation of informed consent, as well as a wide range of other content for PwD.

CONCLUSION

This paper has attempted to provide a brief overview of the issue of informed consent in PwD. PwD have typical intellectual and cognitive abilities, but limited literacy skills (reading and writing). Therefore, the most common and recommended form of obtaining written informed consent presents a challenge for this population, as well as for the researcher. Due to the lack of public awareness and all the characteristics and linguistic basis of this disorder, some researchers may be tempted to simply read out the informed consent to the person with dyslexia in the belief that this removes all barriers. However, based on what we know from research and practice about

dyslexia today, it feels necessary to point out that approaching PwD in that manner in order to obtain informed consent is not sufficient. The aim of the preset study was therefore to propose a set of guidelines for academic researchers to develop informed consent documents for PwD that are more accessible and therefore, valid. Adherence to these guidelines is consistent with the general understanding on the linguistic complexity of consent forms (at (upper) primary school level). All the factors and recommendations described in this paper refers to PwD, but it can also be applicable to other groups with language disorders (e.g., people with development language disorder, or people with aphasia), but also to other populations (children in general, people with intellectual disabilities, and so on). Ultimately, to conduct research that complies with ethical standards from start to finish is not easy, but the language used can be (easy). It is important to note that, the SLPs, who are experts in the assessment and treatment of dyslexia and the adaptation of material from standard language to EL, have a special role to play in this entire process.

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CONFLICT OF INTEREST STATEMENT

The authors declare that there are no potential conflicts of interest in relation to the authorship and/or publication of this article.

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Appendix 1. *Practical example of adaptation of standard language to easy language – language adaptations*

VERSION A: STANDARD LANGUAGE

CONSENT TO THE COLLECTION AND USE OF DATA

As part of the educational, research, and clinical work of the Teaching and clinical Centre (hereinafter: the Centre), it is important to regularly collect relevant data for the progress and improvement of services for our users. The data collected helps the Centre's experts to carry out the assessment and diagnostic process as accurately as possible, determine therapeutic goals, evaluate progress in therapy, and plan the addition of goals during the intervention.

The data collected by the Centre's experts will be used exclusively for the following purposes: for the provision of a professional service of the highest quality, for research purposes carried out to improve the quality of professional services, and for the training of future professionals to ensure the best possible professional service in the future.

You will be informed about the specific types of data being collected and the data collection procedure. As part of the assessment and intervention procedures, we collect personal data, medical data relating to the reason you or your child is attending the Centre, as well as data on the general condition and functioning in your everyday environment, or in your child's environment if they are involved in our services.

We collect data in a variety of ways: through interviews, by downloading copies of medical and other records, by completing questionnaires and protocols, and through audio and video recordings. All data that we collect from you, including audio and video recordings, are subject to confidentiality, regardless of the method of collection. The Centre's employees are obliged to record the data confidentially and in accordance with the rules of their profession.

The data collected will be stored securely and used exclusively for the stated purposes. Any person involved in any of the above activities is obliged to protect your personal data and privacy.

You have the right to withdraw your consent at any time and you will always find us fully understanding of your decision.

DECLARATION OF CONSENT FOR DATA COLLECTION AND USE

_____

(surname, first name and date of birth, if the consent relates to a full age adult)

_____

(surname and first name of the parent/legal guardian and date of birth, if the consent relates to a minor)

_____

(surname, first name and date of birth of the child ,if the consent relates to a minor)

I agree to the collection of data <u>for the purpose of inclusion in the database, the improvement of diagnostic procedures and therapy goals, the performance of research work, and the training of experts and students</u>. I consent to the <u>collection of data through interviews, downloading copies of medical and other records, completion of questionnaires and protocols, and audio and video recordings</u>.

_____

(signature)

In _____

VERSION B: EASY LANGUAGE

NOTION ON DATA COLLECTION

As experts from the Teaching and Clinical Centre Centre (in short: the Centre), we collect relevant data to advance the quality of research, clinical, and educational services at the Centre.

We will use the data collected to provide highest quality professional services through further education of our students.

In assessment, diagnostics, and therapy, we will collect:

a. personal data

b. medical data that led you to our Centre

c. data on general condition and everyday functioning

We will collect the data through:

1) interviews

2) copies of medical records

3) questionnaires and testing protocols

4) audio and video recordings

All **your information** is **confidential** and **protected**. This information will **not** be used for anything, except for the purposes that are stated under 1), 2), 3), and 4).

You have **the right to withdraw** your consent **at any time** and you will always find us fully understanding of your decision.

CONSENT TO COLLECT AND USE OF DATA

I **agree** to the **collection of data** for the purposes stated above.

Chose an option A **or** B:

A. If you are **full age adult**, please write **your first name, surname, and date of birth** on the line below:

_____

B. If the **data is of a minor or a child**, and you are the parent or legal guardian,

please write **your first name, surname, and date of birth** on the line below:

_____

Please write the **child's first name, surname, and date of birth** on the line below:

_____

_____

(Sing on the line above)

_____

(Write the name of the city where you signed this document.

Write today's date on the line above).