



PARTICIPANT INFORMATION SHEET

TITLE OF THE STUDY

Pain in blind and low vision people – Let's Make Pain Visible (MAPAVI)

PRINCIPAL INVESTIGATOR

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CENTER

Facultat de Ciències de l'Educació i Psicologia – Universitat Rovira i Virgili (URV)

RESEARCH GROUP

ALGOS; Càtedra de Dolor Infantil (Chair in Pediatric pain)

INTRODUCTION

This study has been approved by the Universitat Rovira i Virgili's Ethics Committee for Research in People, Society and Environment.

This "Participant information sheet" is to provide you with information so that you can decide whether or not you want to participate in this study. Please read this information sheet carefully, and we will clarify any doubts that you may have. Moreover, we inform you that you are free to consult with anybody you feel appropriate before deciding on whether to take part.

VOLUNTARY PARTICIPATION

You should be aware that your participation in this study is voluntary and that you can decide not to participate, change your decision and withdraw your consent at any time.

GENERAL DESCRIPTION OF THE STUDY

This study aims to help improve the quality of life of blind and low vision people suffering from pain.

If you agree to participate in this study, we will ask you to complete a questionnaire of approximately 5 minutes. This is phase 1.

If you so wish, you can also participate in phase 2, which is complementary. It involves answering another questionnaire of approximately 10 minutes.

You can participate only in phase 1 and answer the questionnaire. If you want to participate in phase 2, you can say so in the last question.

BENEFITS AND RISKS

This study will serve to inform health professionals, the scientific community, health managers and politicians to help them make decisions and take effective measures to promote health and well-being in blind and low-vision people with regard to pain.



Participation in this study requires completing a questionnaire. It is highly unlikely that participating involves any risk or damage. If you wish, you can contact the principal investigator, Dr Jordi Miró (jordi.miro@urv.cat) who will answer your questions and help you if necessary.

DATA CONFIDENTIALITY AND PROTECTION

All information collected about the participants in this study will be kept strictly confidential, and strict security measures will be followed to guarantee not only its confidentiality, but also its integrity, availability, authenticity and traceability.

Participants will never be identified in any report, presentation or publication arising from this study. Therefore, their identity will not be disclosed to any person, except when required by the Ethics Committee to which the study is submitted in order to check the data and procedures of the study.

The information systems of the Universitat Rovira i Virgili, subject to the information security measures established by Royal Decree 3/2010 that regulates the National Security Scheme, will be used for data processing.

The research staff of the study is committed to complying with Organic Law 3/2018, of 5 December, on the Protection of Personal Data and Guarantee of Digital Rights, in addition to Regulation (EU) No. 2018. 2016/679, of the European Parliament and of the Council, of 27 April 2016, on the protection of natural persons with regard to the processing of personal data, and will sign a commitment to participation and confidentiality.

Participants may interrupt their participation in the study or related future studies by withdrawing their consent at any time, without the need for justification. In this case, the data may not be deleted in order to guarantee the validity of the results and comply with the legal obligations applicable to the study, but they will be encoded so that it is not possible to link them to your person.

EXTENDED INFORMATION ON THE PROCESSING OF PERSONAL DATA

In accordance with the provisions of current legislation on data protection applicable to the Universitat Rovira i Virgili (URV) and published in the "Applicable legislation" section of the "Protection of personal data" in the e-Office (<https://seuelectronica.urv.cat/rgpd/>), the following information is made known to interested parties:

a) Who is responsible for processing your data?

• Identification	Universitat Rovira i Virgili CIF: Q9350003A
• Postal Address	Carrer de l'Escorxador, s/n 43003 Tarragona
• Contact details of the DPO	DPO - Data Protection Delegates of the URV Email: dpd@urv.cat



b) What personal data do we process and for what purpose?

Personal data is processed for the purpose of participating in the URV's research project under the terms described in the participant's information sheet. In the event that the study foresees the publication, dissemination and reuse of the data obtained, including personal data, they will be used for this purpose provided that the interested party has given his or her consent.

c) To which recipients will your data be communicated?

In the framework of the aforementioned processing, your data will not be transferred to third parties unless there is a legal obligation.

d) What is the legitimacy for the processing of your data?

The legitimacy of this treatment is based on the consent given by the interested party.

e) What security measures do we apply when processing your data?

The University is responsible for applying security measures and other obligations arising from the legislation on the protection of personal data, in accordance with the National Security Scheme, Royal Decree 3/2010.

In this regard, the Rovira i Virgili University has its own Security Policy that can be consulted in the section on "Legislation and regulations" of the University's website within "Own Regulations" and "Other rules", <http://www.urv.cat/ca/universitat/normatives/altres-normes/>.

In addition, the Participant Information Sheet specifies some specific security measures that will be taken into account during the study.

f) What are the rights of the interested parties?

All interested parties have the right to access their personal data; to request the rectification of inaccurate data; to request cancellation and deletion; to oppose processing, including profiling; to limit processing to a particular date; and to have their data transferred in electronic format.

The participant may interrupt participation in the study by withdrawing his or her consent at any time, without giving explanations. In this case, the data may not be deleted in order to guarantee the validity of the results and comply with the legal obligations applicable to the study, but it will not be possible to link them to his or her person.

You may exercise your rights of access, rectification, cancellation, opposition, limitation and portability by written communication, detailing the reasoned request, addressed to the General Registry (Carrer de l'Escorxador, s/n, 43003 Tarragona) or by submitting it to the General Registry of the University, in person or online, as indicated at <https://seuelectronica.urv.cat/registre.html>.



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Likewise, we inform you that you have the right to file a claim with the Catalan Data Protection Authority. You may find more information at <https://apdcat.gencat.cat/en/inici/index.html>.

Finally, we inform you that you may request information about our data protection delegates at dpd@urv.cat.

g) How long will we keep your data?

The data retention period is 5 years once the study has been completed, unless the participant's information sheet establishes a different period. In any case, the data will be kept until the consent is revoked by the interested party.