SUPPLEMENTARY MATERIAL 1.

SURVEY FOR ESTABLISHING PATIENT KNOWLEDGE REGARDING INFORMED CONSENT

Dear patient, I would like to ask you several questions regarding your participation in the Early Onset Rheumatoid Arthritis Clinic (Clínica de Artritis Reumatoide Temprana - AR-TE) and how you feel about the treatment that has been provided over the years. Would you be willing to devote 10 minutes of your time to complete a questionnaire on these issues? If you do not wish to do so (at this or any other time), you can say no without affecting your medical care.

You first visited the Early Onset Rheumatoid Arthritis Clinic a number of years ago.

1. When you first visited the Early Onset Rheumatoid Arthritis Clinic, do you remember signing a document called Informed Consent?
   YES___ NO___

2. How do you rate your knowledge regarding the informed consent form you signed?

Poor	Average,	Superior

Regarding the content of the informed consent form that you signed at the time, indicate which of the following statements you consider to be true or correct (Please try to answer based on what you remember and understood regarding the document you signed)

3. * The procedures that will be performed at the Clinic will include physical examination, laboratory studies (blood samples), radiographs and questionnaire administration.
   _____

4. The objective of the clinic is to research rheumatoid arthritis.
   _____

5. * Based on the physician's evaluation in the consultation, he or she will propose a treatment, which we can discuss.
   _____

6. * Every so often, I will be asked for blood samples that will be frozen and stored in a blood bank and used to study genes, proteins and substances that may help to better understand my disease.
   _____

7. My blood samples will be saved after my personal data are removed to preserve my anonymity.
   _____

8. Being a patient of the Clinic will not place me at any additional risk except for the risk of discomfort or bruising as a result of blood sample collection.
   _____

9. My participation is voluntary, and I may withdraw from the research program at any time without affecting my patient rights.
   _____

10. * Being a patient of the Clinic will not entail any additional cost, and I will pay the costs of my medical care according to my socioeconomic status.
    _____

11. As a patient of the clinic, I could benefit from the information generated from research.
    I may also have no direct personal benefit.
    _____

12. * As a patient of the clinic, I was asked to maintain close contact with the Clinic team and to attend my appointments.
    _____

13. I was given four authorization options regarding the use of my data for research: 1) Only for research on RA, 2) For research on RA and other diseases, 3) For research on RA and other diseases only when I am informed beforehand and 4) Refuse permission.
    _____

14. Currently, how do you rate your knowledge regarding the informed consent form you signed when you first visited the Clinic?

Poor	Average,	Superior

15. Do you remember which option you selected when you signed the consent form? YES___ NO___

16. If you do, please indicate which option you selected by circling the corresponding letter.

A) Only for research on RA.
B) For research on RA and other diseases.
C) For research on RA and other diseases only when I am informed beforehand.
D) Refuse permission.

17. Do you remember if you were provided a copy of the information sheet or the informed consent form you signed? YES___ NO___

18. Have you shown the document to someone you trust to share information or ask for an opinion? YES ___ NO___

19. If you showed it to someone, to whom? _____

20. If we asked you to bring the informed consent form you signed the last time, could you bring it?
YES, I could. ____
NO, I have not kept it. ____
NO, I do not know where it is. ____
NO, I lost it. ____
NO, I was not provided a copy. ____

21. To resolve doubts before signing a new informed consent form, would you like another opportunity to discuss with a Clinic team member what it means to be a patient of the Clinic? YES____ NO_____

22. If you were willing to sign the informed consent form again, which option would you authorize on this occasion?
A) Only for research on RA.
B) For research on RA and other diseases.
C) For research on RA and other diseases only when I am informed beforehand.
D) Refuse permission.

23. How often would you like an opportunity to re-discuss your participation in the study to resolve doubts before signing a new informed consent form?
_____

24. Indicate the degree of agreement with the following statements, selecting only one answer option.

	SD Strongly disagree	**D** Disagree	**U** Undecided: Neither agree nor disagree	**A** Agree	**SA** Strongly agree
My values and beliefs must be respected by my attending physician in everything related to my disease(s) and how it affects my health.	**SD**	**D**	**U**	**A**	**SA**
My preferences should be respected by my attending physician in everything related to my disease(s) and how it affects my health.	**SD**	**D**	**U**	**A**	**SA**
I have the right to participate in the treatment that my attending physician proposes to me.	**SD**	**D**	**U**	**A**	**SA**
I may not agree with the treatment plan my attending physician proposes to me, and that disagreement should not affect my medical care.	**SD**	**D**	**U**	**A**	**SA**
I must be well informed regarding my disease and the consequences it may have for my body.	**SD**	**D**	**U**	**A**	**SA**
I consider myself a patient with the ability and the right to make decisions regarding my health.	**SD**	**D**	**U**	**A**	**SA**
I consider myself sufficiently informed regarding my disease to make decisions about my health.	**SD**	**D**	**U**	**A**	**SA**