



**Advance
Care Planning
international**

ACP International

ACP Delphi Study

ACP-i Board

Email delphi@acp-i.org



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**International Society for Advance Care Planning
ACP-i e.V.**

Geschäftsstelle / Office

c/o Würdezentrum gUG (haftungsbeschränkt)

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Dear interested person,

Thank you for considering to contribute to the international Delphi Study on a **comprehensive global definition on advance care planning** (ACP). We are happy to inform you in detail about the study in order to support your decision if you like to participate.

What is this study about?

During the last decades, ACP has evolved as a concept fostering patient-centred care for future situations of care in which a person may not be able to decide for themselves due to non-existing, diminished, or lost decision-making capacity. As a complex, evidence-based intervention, building ACP research and practice on a well-founded definition is an important element of quality improvement. While several valuable Delphi studies on defining ACP have been conducted, they have been limited to certain areas of health and social care and/or countries. This is why ACP international has decided to launch a new Delphi Study on the definition of ACP. We focus on comprehensiveness and inclusiveness in this globally conducted study.

What is going to happen if I participate in this study?

This type of study is called a Delphi study. This is a highly structured form of anonymous group communication with several rounds. It aims at gathering and qualifying opinions of knowledgeable persons on a specific topic and ideally achieve consensus. We will conduct the Delphi rounds online. In this first round, you will answer mostly open-ended questions, as will several hundred other persons who have participated in ACP activities of ACP international or who have published on ACP. These responses will be synthesized and discussed in an in-person meeting at the ACP international conference in Queensland, Australia (<https://www.acp-i2025.org/>). If you are also participating in this conference on site, you are more than welcome to join the discussion. Based on results from the first Delphi round and the discussion on the ACP-i conference, responses on the concept and definition of advance care planning will be developed. At the beginning of the second Delphi round, which will start in the first quarter in 2026, we will inform you how the group responded in the first round and what was discussed in the in-person meeting. You will then rate how much you agree with each of the prepared statements and give comments.

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COMMITTEE: Tanja Krones (president), Craig Sinclair (vice president), Kornelia Götze (treasurer),
Cari Borenko (secretary). Extended Committee members: Cristina Lasmarius, Erik Fromme, Cheng-Pei Lin, Diah Martina.

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We will repeat this process of giving feedback and gathering new responses several (usually 2 or 3) times. Each time, you are free to participate and free to change your opinion. You will have three weeks to respond to each round at the time and place of your choosing. We expect it will take you 45-60 minutes for the first qualitative round and between 20 to 40 minutes to complete the upcoming quantitative rounds. You can take as many breaks as you need. You can also send our email with the participation link to other colleagues and peers who have experience with ACP so that they can participate.

What is going to happen with my data if I participate in this study?

The Delphi rounds will be conducted online on a specialized platform called Welphi which is based in Portugal. Welphi stores the data on servers in Frankfurt, Germany. Both Portugal and Germany have adequate levels of data protection according to Swiss legislation in which we have decided as ACP-i to conduct the study, as the current ACP-i President resides in Switzerland (see https://www.fedlex.admin.ch/eli/cc/2022/568/en#annex_1 for more information). To participate in the study, you must register on the platform. This is necessary so that Welphi can a) inform you when the next Delphi round starts and b) remind you what you responded to a given question in the previous round. Welphi guarantees the anonymity of your responses by storing your identifying information (your name and email address) separately from your responses to the Delphi rounds. We, the researchers, will only see whether you registered, started, or completed a given round, but not what you responded. Welphi will only give us access to participants' responses in anonymous form, both during and after the Delphi process. The other participants will neither learn your responses nor that you participated. Also, you are free to register on Welphi using a pseudonym (a false name) and an email address that does not contain your real name.

After each Delphi round, your anonymized responses will be uploaded to and processed on systems belonging to the University of Zurich. As these systems are cloud-based, it is not possible to state where your data will be processed. All data will be treated confidentially. Access to the data is only granted to approved members of the study team who are bound to confidentiality. Should you make use of the option to formulate your responses in a language other than English, we will use DeepL® to translate your anonymized responses to English. DeepL® is a free, artificial intelligence-based online translator (<https://www.deepl.com/de/translator>).

The findings of this study will be published in scholarly articles and public presentations without any reference to your identity. Depending on your preference, we will acknowledge your contribution in this article by name or anonymously. The data about you will be deleted from Welphi within a year after the last round. It will be stored for another 5 years on the local server at the University of Zurich. Data are available upon request to interested researchers in the field of ACP.

How will participation in the study affect me?

This is a low-risk study. We are collecting information through surveys. No medical procedures are involved in this study. Please keep in mind that you can stop participating in the study at any point. Also, participating means investing time and energy. We will acknowledge your contribution in all scholarly articles presenting the findings of this study either by name or anonymously, depending on your preference, which you can submit to the study email address delphi@acp-i.org. Apart from this acknowledgment, you will have no direct benefit from participating in this study, for example, you will not be compensated financially.

What rights do I have regarding this study?

Participation in this study is strictly voluntary. If you decide not to participate, this will have no consequences for you. Even if you give your consent and start participation, you can revoke your consent at any point - without giving reasons - via the Welphi platform or by emailing delphi@acp-i.org. If you revoke your consent, your identifying information (such as your mail address) will be removed from the Welphi platform. In addition, you have the right to demand the deletion of your responses to the Delphi rounds. However, this is only possible within 30 days after each round as they will already have been processed after this period.

At any point, you can request comprehensive information about the data that is stored about you and demand the correction or deletion of your identifying information. For data stored on the Welphi platform, please contact info@welphi.com, and for data stored on UZH systems contact delphi@acp-i.org.

Who is running and financing the study?

This study is coordinated by the ACP international board, supported by Dr. Anna Westermair and Laura Kim Sieber, Institute of Biomedical Ethics and History of Medicine, University of Zurich. Should you have any comments or questions, please contact the study address delphi@acp-i.org. This study is undertaken without external funding.

Thank you for your time to read and consider this information!

Tanja Krones, on behalf of the ACP international board

A handwritten signature in black ink, appearing to read 'JKrones', is positioned below the name of the representative.

P.S. If you would like to **know more about ACP-i**, go and visit our website: www.acp-i.org. And if you would like to help to sustain the works of ACP-i, participate in the network, and if you would like to use the online resources of the last webinars and congresses, **become a member!** We are looking forward to you! <https://acp-i.teamhub.de/application>