

Help us find out which outcomes for Best Care for the Dying Person are the most important to measure in research and as goals of care by sharing your views!

Participant Information

You are being invited to take part in a research project. Before you decide whether or not to take part, it is important for you to understand why this research is being undertaken and what it will involve. Please take time to read the following information carefully and discuss it with others, if you wish.

The purpose of this study is to develop a core outcome set for best care for the dying person focused on the most critical aspects of care during the last days of life. This is undertaken through a Delphi Study. Further information on this process and on what a Core Outcome Set is can be found below.

You have been invited because you are either a family member of a deceased patient, a patient representative (e.g. a volunteer), a clinician or a researcher working with patients at the end of life. Your participation in this research project is entirely voluntary and it is up to you to decide whether to take part. If you decide to participate, please proceed to the survey. If you decide not to take part, you do not have to explain your reasons and this will not affect you in any way.

You are free to withdraw from the research project, without giving a reason, up to the point at which you have submitted your responses. Although you will be asked to provide us with your email address, your responses will remain anonymous and confidential and only looked at by the study team. Feel free to skip any of the items by choosing the 'unable to score' option while answering the survey.

Taking part will involve completing two online surveys. The first one takes around 15 minutes to complete. About 4 to 6 weeks later, you will be asked to complete the second online survey, which should take about 20 minutes to complete. There will be no reimbursements for taking part in this study.

No direct benefits or advantages are expected from participating in this study. We also do not expect there to be any risks involved in taking part, given that participants are only completing two online surveys in their own time. However, some participants may find it upsetting

thinking about the care of their dying relative, or of dying patients. If you do feel uncomfortable, you can stop taking part at any time and provide feedback to the research team if you would like.

Your contact information will be saved for the sole purpose to contact you for participation in the second survey, to receive the study results, or for participation in further research, however this will only be done if you consent to each of those purposes. Providing your contact information will not affect the anonymity of your survey answers.

If you are unhappy with any aspect of the survey or are having a technical difficulty when completing the surveys then please contact the researchers at: i-live.study@insel.ch

Information on the Delphi process

How are health care treatments developed?

To help patients, doctors and other health professionals make decisions about treatments, we need evidence about what works best. Treatments are developed and tested by researchers to make sure they work and are safe. To do this researchers need to look at the effects those treatments have on patients. Researchers do this by measuring an 'outcome'. For example, at the end of a life, in a study of how well a new treatment for pain works, 'outcomes' might include:

- a measure of the level of pain a patient has before and after receiving the medication
- how fast the medication works to relieve the pain
- changes to the patient's cognitive function

How do researchers decide on what outcomes are important to measure in research studies?

When researchers design research studies to investigate treatments for health conditions they need to measure outcomes that are important and relevant to those people affected by the condition. To decide which outcomes are important researchers need to get everyone's opinion and try to reach agreement, or "consensus", on the most important outcomes. In order to do this, researchers carry out a 'consensus exercise'. One way of doing this is by using something called a 'Delphi' study. In a Delphi study researchers identify groups of people who are "experts" in the health condition they are interested in. "Experts" are:

- People with personal experience of the condition, for example, patients, patient representatives, or family caregivers.

- Health professionals with expertise in treating and caring for people with the condition, or researchers with a experience on the condition.

Experts taking part in a Delphi study are asked to give their opinion on what outcomes are most important. The study is anonymous to make sure everyone has an equal say.

What happens early on in a Delphi Study?

The research team has developed a long list of possible outcomes that we want to ask the experts about. To develop the list we first did a systematic review to extract all the outcomes that have been studied in the last month of a person's life. Then, we interviewed patients, caregiver/family members, and health care professionals and asked them about outcomes that were important in the care delivered to the patient and family in the last month of the patient's life.

This list contains outcomes from both quantitative and qualitative research.

The level of detail of each item/outcome may vary. This heterogeneity comes from the raw data. In order to remain faithful to the raw data, we have preserved this heterogeneity for the first round of the Delphi.

What happens next?

Each expert is sent the list in the form of a survey by email and asked to score the importance of each outcome. If, in their opinion, there are key outcomes missing from the list, they are encouraged to add these to the list. We refer to this as "Round 1" of the Delphi study.

Each expert sends their ratings back to the research team, who then summarise the responses from the group as a whole and send this summary back to each expert in what we refer to as Round 2 of the Delphi process. At this stage each expert is given a reminder of how they scored the outcome last time and the range of scores of the rest of the group. No-one in the group can see another individual's scores; they can only see the overall results for the group as a whole. Using this information each expert is asked to reflect on their own view and on the view of the group and to decide whether to stick with their original rating or change it. Through the whole process no-one is under any pressure to change their rating if they don't want to. It is perfectly fine for people to stick with their original rating even if they rated the outcome differently to the rest of the group.

The responses of the experts are then sent back again to the research team who again collate the information.

After collecting the information, the researchers invite the experts to get together in a virtual meeting to discuss the results. This is called a consensus meeting. At the end of this process the research team produce a report on what the experts have agreed as the most important outcomes. These are called the 'core outcomes' for a particular health condition. You will be asked, if you would like to participate in the consensus meeting. However, as

the number of Delphi participants may be too large, it is possible that only a few of those participating in the Delphi are invited to the consensus meeting. The selection will be made at random, so not everyone may receive an invitation. If you receive an invitation and do not want to participate, you are free to not attend the meeting. Instructions and dates for the consensus meeting will be sent well in advance.

The delphi process summary

ROUND 1

A list of outcomes is produced by the research team and sent to each participating patient representative, family member, health professional, and researcher to score the importance of each outcome



ROUND 2

Round 1 results are summarised and sent back to each person, together with a reminder of the person's own score for each outcome. Each person is asked to think about the group's results and decide if they want to change their score



CONSENSUS MEETING

Virtual meeting of people taking part to discuss the results



REPORT

Report produced identifying agreed outcomes of importance (Core Outcomes)

Publication of the results

After the consensus meeting and once the Core Outcome Set (COS) is agreed, the COS will then be published in a medical journal and disseminated at academic conferences. You will not be identified in the publications unless you have told us at the end of the second survey that you would like to be acknowledged for your contribution. If this is the case, your name will be included in an acknowledgement section of the publication. We will not present your individual views about outcomes in the publication and will not present how you individually responded during the survey. Instead results from the survey will be presented by group (e.g. results from patient representatives, from family members, followed by results from healthcare professionals and researchers).

When you register you will be able to tell us if you would like to be sent the results of the study by email. Please note that this may be several months after you have taken part, as it takes time to analyse the results and write the report.

Further research

After the Core Outcome Set (COS) is agreed, a follow-up study will be set up to agree on how each of the outcomes should be measured. For example, if one of the outcomes is 'pain level' then we will look at how to best measure this outcome. Although this work will be done in the future, you can already indicate if you would like to be contacted for this part of the study. You will be asked this at the end of Survey 2.

Your opinion in both Survey 1 and Survey 2 is extremely important in developing the Core Outcome Set. It is therefore essential that you complete both surveys.

If you are ready to take part please visit the link below to register and complete the Delphi Survey 1.

<https://delphimanager.liv.ac.uk/bestcare-dyingperson/>