



Survey of Health, Ageing and Retirement in Europe

Self-Administered Questionnaire 2015

Numéro de série:

Respondent ID										Respondent name
<input type="text"/>	<input type="text"/>	-	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	-	<input type="text"/>	<input type="text"/>

Date of interview: //

Interviewer ID: _____

Why this questionnaire?

Certain life phases are easier to discuss than others. The final life phase is one of the most challenging subjects to address and therefore often overlooked. However, this life phase is very important for many people, who hope to spend the end of their lives under the best possible conditions. The definition of the "best possible conditions" can vary widely from person to person.

This questionnaire was developed to obtain better information about individuals' end-of-life preferences, as well as their knowledge, attitudes, expectations and behaviors with regard to planning for their end of life. In order to broaden our knowledge of this subject, we are very interested in your opinion and your thoughts on this topic. We appreciate your contribution to our survey and thank you in advance for your participation.

How to complete the questionnaire?

- Mark your answer by placing an "X" in the corresponding box: ☒
- If you make a mistake, fill in the falsely marked box completely and then make a new "X" in the appropriate box for the correct answer: ☒ ☒
- Chose only one response per question, unless specifically instructed that several responses are possible.
- Answer the questions one after the other. Skip a question only if you are asked to do it.

EXEMPLE

Q73 Are you married?

Yes..... 1

No..... 2 → **If not, go to question Q76**

If you tick « Yes »,
go to the following
question **Q73**.

If you tick « No »,
go to the indicated
question **Q76**.

YOUR ANSWERS ARE CONFIDENTIAL AND VOLUNTARY.

How to send the questionnaire back?

If the interviewer is still at your home when you finish filling in the questionnaire, please give it back to him/her. Otherwise, please send it as soon as possible with the postage-paid envelope to:

LINK Institut
Spannortstrasse 7/9
CH-6000 Luzern 4

Q1 Some people think about the end of life often, whereas others claim to never think about this topic. How much you agree with the following statement: "I avoid thinking about death as much as possible."

I strongly agree 1
 I agree 2
 I disagree 3
 I strongly disagree 4

Q2 Prior to today, how often have you thought about your wishes for the last months of your life?

Often 1
 Sometimes 2
 Rarely 3
 Never 4

Q3 Some people make certain arrangements to plan for specific contingencies in the future. Do you have...

	Yes	No
Q3a ...a testament that details what should happen to your possessions in case of death?	<input type="checkbox"/> 1	<input type="checkbox"/> 2
Q3b ...a designated power of attorney in financial, legal or administrative matters in case you become incapable of making decisions for yourself?	<input type="checkbox"/> 1	<input type="checkbox"/> 2
Q3c ...an organ donor card stating your <u>consent</u> to donate (some of) your organs?	<input type="checkbox"/> 1	<input type="checkbox"/> 2
Q3d ...an organ donor card stating your <u>refusal</u> to donate your organs?	<input type="checkbox"/> 1	<input type="checkbox"/> 2

Q4 People differ in their opinion about what is important to ensure to spend best possible their last months of life. How important are each of the following potential end-of-life aspects for you when thinking about the last six months of your life?

	very important	important	not so important	not important
Q4a Spending time with family and friends	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
Q4b Feeling useful to others (giving time, sharing knowledge, etc.)	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
Q4c Avoiding to be a burden on society	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
Q4d Avoiding to be a burden on my family	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
Q4e Feeling that my family is prepared for my death	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
Q4f Being able to plan the events following my death (funeral, obituary, etc.)	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
Q4g Having my finances in order	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
Q4h Choosing where I die	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4

Q4 And also ...

		very important	important	not so important	not important
Q4i	Not dying alone	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
Q4j	Talking about my fears	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
Q4k	Being at peace with others	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
Q4l	Being at peace with myself	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
Q4m	Receiving spiritual or religious assistance	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
Q4n	Avoid over-treatment	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
Q4o	Having physical contact (e.g. hold hands)	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
Q4p	Being able to talk or communicate with others	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
Q4q	Being able to feed myself	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
Q4r	Using all available medical treatments to prolong life until the end	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
Q4s	Living without pain	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
Q4t	Keeping clean (personal hygiene)	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
Q4u	Being fully mentally aware	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
Q4v	Deciding in advance which medical treatments I would or would not like to receive	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
Q4w	Having confidence in my treating physician	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4

Q5 Some people communicate their preferences for the end of their life, while others do not. Have you ever had a discussion with someone about your wishes for the end of your life?

Yes..... 1

No..... 2 ➔ **If not, go to question Q8**

Q6 With whom did you discuss your wishes for the end of life? *Multiple responses possible*

Spouse or partner 1

Child 2

Sibling 3

Friend 4

Physician..... 5

Chaplain or other religious leader..... 6

Lawyer 7

Other person (*please specify*):

➔ **Go to question Q10**

Q7 Why haven't you ever discussed your wishes for the end of life? *Multiple responses possible*

- I don't like to think about it. 1
- It's too early to think about it. 2
- I tried but the person didn't want to discuss it..... 3
- I don't want to worry people..... 4
- I have no preference for end of life so far..... 5
- I have nobody to talk about it..... 6
- Other reason (*please specify*):

Q8 Please answer the following question only if you are living with your spouse or partner, if not skip to question **Q12**. How well do you think that you know...

	very well	rather well	not very well	not at all
Q8a ... <u>your spouse's or your partner's</u> wishes for the end of life in general?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
Q8b ... <u>your spouse's or your partner's</u> wishes for medical treatment at the end of life?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4

Q9 How well do you think that your spouse or partner knows...

	very well	rather well	not very well	not at all
Q9a ... <u>your wishes</u> for the end of life in general?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
Q9b ... <u>your wishes</u> for medical treatment at the end of life?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4

Q10 In Switzerland, people can plan how their possessions and medical situation should be handled if they become incapable of making decisions due to disease or accident. Are the following statements about current law in Switzerland true or false? In Switzerland, ...

	true	false	don't know
Q10a ... it is allowed to legally name somebody as one's healthcare proxy.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
Q10b ... it is possible to indicate on one's health insurances card that one has completed a document about one's wishes and refusals for medical treatment (advance directives).	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
Q10c ... a physician can continue a treatment that the patient has refused in writing (advanced directive) if the physician thinks that the treatment is necessary to prolong the patient's life.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
Q10d ... the closest relative is in charge of medical decisions for an incapacitated person if this person did not name anybody in advance.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3

Q11 Concerning health care at the end of life, are the following statements true or false to your knowledge?

	true	false	don't know
Q11a Palliative care means stopping all medical treatment and giving morphine to ensure a peaceful death.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
Q11b Palliative care should start early in the disease course and can prolong life significantly.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
Q11c Assisted suicide is also possible in demented patients if they explicitly state so in their advance directive.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
Q11d In Switzerland, doctors are not allowed to directly inject a lethal substance to a patient in order to end his life, even if he asks them to do so.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3

Q12 In your opinion, what fraction of people persistently experience the following conditions during the last month of their lives?

	<10%	10-25%	25-40%	40-60%	60-80%	>80%
Q12a Being in severe pain	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6
Q12b Being incapable of making decisions for themselves	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6
Q12c Being unable to perform basic activities by themselves such as eating, dressing, washing or walking across a room	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6

Q13 Suppose that you had a serious illness and your doctor told you that you are likely to die within the next few months. If your remaining life expectancy would be six months irrespective of the place of treatment, would you prefer to be treated at a hospital or at home?

Hospital 1
 Home 2

Q14 Now suppose your remaining life expectancy would depend on the place of treatment with a remaining life expectancy of six months at hospital, but only three month at home. Which place of treatment would you prefer?

6 months of life expectancy and treatment at hospital. 1
 3 months of life expectancy and at home. 2

Q15 Advance directives are a written statement in which an individual can describe his/her preferences for medical treatments and care in case he/she become incapable of making decisions. Individuals can also designate someone who can make medical decisions for them if necessary. This written statement is binding for medical providers and relatives. Prior to today, have you heard about advance directives?

Yes..... 1
 No 2

Q16 Have you completed a written statement about your wishes and refusals for medical treatments and care (advance directives)?

Yes 1

No 2 → **If no, go to question Q21**

Q17 When did you do this for the first time?

Please fill out the year:

Q18 Have you spoken to somebody about your written statement (advance directives)?

Yes 1

No 2 → **If no, go to question Q23**

Q19 Who is this person? *Multiple responses possible*

Spouse or partner 1

Child 2

Sibling 3

Friend 4

Treating physician 5

Chaplain or other religious leader 6

Lawyer 7

Other person (*please specify*):

→ **Go to question Q23**

Q20 If you have not written a statement about your wishes and refusals for medical treatments and care (advance directives), why is this the case? *Multiple responses possible*

I was previously not aware of the existence of advance directives. 1

I have not yet completed advance directives, but I intend to do so 2

I do not think that I need advance directives. 3

It is too early for me to make advance directives. 4

I am afraid of receiving lower quality of health care if I have advance directives. 5

It is pointless to prepare for a hypothetical situation that one cannot judge well in advance. 6

Other reason (*please specify*):

Q21 How likely is it for you to have a written statement about your wishes and refusals for medical treatments and care some day in the future?

For sure 1

Very likely 2

Not very likely 3

Certainly not 4

Q22 Is there someone who you would trust to make medical decisions for you if you were not able to make them for yourself?

Yes 1

No..... 2 → **If no, go to question Q27**

Q23 Who would that person be? *Multiple responses possible*

Spouse or partner 1

Child..... 2

Sibling 3

Friend..... 4

Treating physician 5

Chaplain or other religious leader 6

Lawyer 7

Other person (please specify):

Q24 Have you appointed someone in writing to make medical decisions for you should you not be able to make those decisions for yourself?

Yes 1

No..... 2 → **If no, go to question Q27**

Q25 Who did you appoint?

Spouse or partner 1

Child..... 2

Sibling 3

Friend..... 4

Treating physician 5

Chaplain or other religious leader 6

Lawyer 7

Other person (*please specify*):

Q26 There are associations in Switzerland, such as "Exit" or "Dignitas", that offer assisted-suicide. Are you a member of such an association?

Yes 1

No..... 2 → **If no, go to question Q29**

Q27 When did you become a member of this association?

Please fill out the year:

→ **Go to question Q30**

Q28 How likely is it for you to become member of this association some day in the future?

For sure 1

Very likely 2

Not very likely 3

Certainly not..... 4

Q29 Do you support the legality of assisted suicide as it is currently the case under Swiss law?

Yes..... 1

No 2

Q30 Can you imagine circumstances under which you would consider asking for assisted suicide yourself?

Yes..... 1

No 2

Q31 The decisions that we make or the way we view the world can be influenced by personal experiences. Have you ever participated in making medical decisions for a relative or close friend?

Yes..... 1

No 2

Q32 While some people have high degrees of confidence in certain persons or institutions, others are more suspicious of them. To what degree do you have confidence with regard to end-of-life issues in...

	very confident	quite confident	not very confident	not at all confident
Q32a ... relatives	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
Q32b ... the Swiss legal system (justice)?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
Q32c ... the Swiss healthcare system (hospitals)?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
Q32d ... healthcare providers (physicians, nurses)?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
Q32e ... healthcare insurances?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
Q32f ... religious authorities?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4

Q33 I am...

a man 1

a woman 2

Q34 I was born in (year)