

# Patientenverfügung in der Schweiz

Survey: Google form distributed with link. All german-speakers above 16 years of age were invited to participate, no prior knowledge required. 3 sociodemographic questions (age, gender and chronic diseases).

Small questions with branching logic (depending on answer different follow-up question)  
N=226 (last question, N=212)



## 1. General Analysis

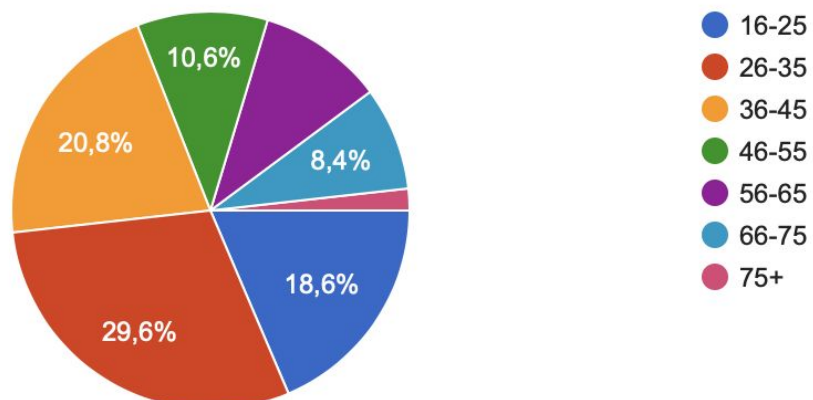
### Age

N=226

Most of the respondents have an age of 25-46 years (~50%). Groups represented more than ~10% are age group 16-25, 46-55 and 56-65. This means our survey was able to cover a large life span of respondents. Groups 66-75 and 75+ are underrepresented.

Wie alt sind Sie?

226 Antworten



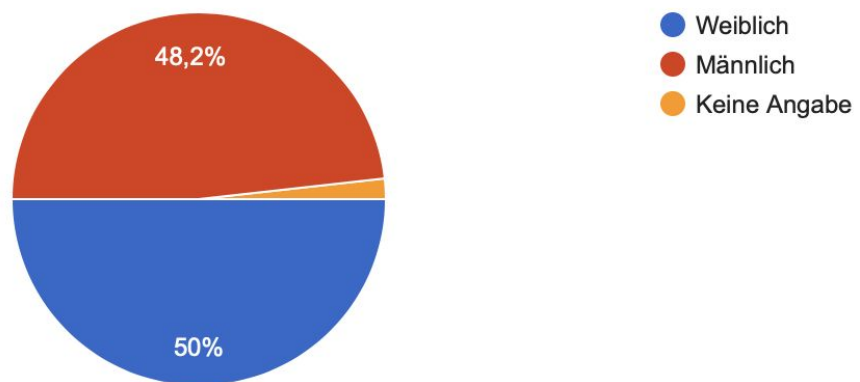
## Gender

N=226

Women and men respondents are nearly represented equally in the survey (~50% vs. ~48).  
A minority of <2% did refuse to answer this question.

### Geschlecht

226 Antworten



## Chronic diseases

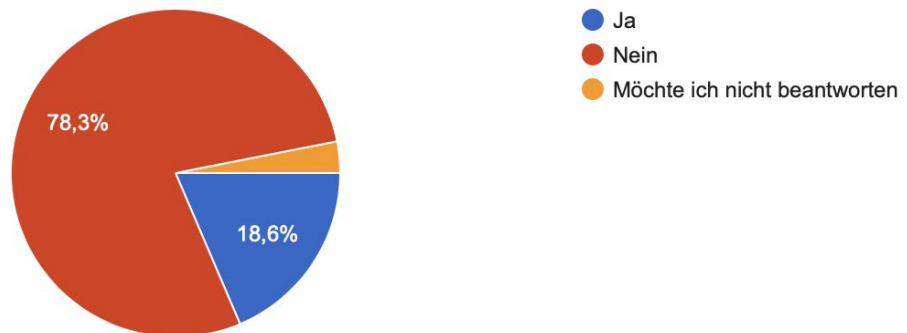
Diseases mentioned as example: high blood pressure, diabetes, cardiovascular diseases, respiratory diseases (e.g. asthma), cancer

N=226

Around 78% of respondents do not have any chronic diseases, ~20% have one or more of the mentioned diseases, and 4 people (1.8%) refused to answer.

Leiden Sie an einer der folgenden chronischen Erkrankungen (Bluthochdruck, Diabetes, Herz-Kreislauferkrankungen, Atemwegserkrankungen [z.B. Asthma], Krebsleiden)

226 Antworten



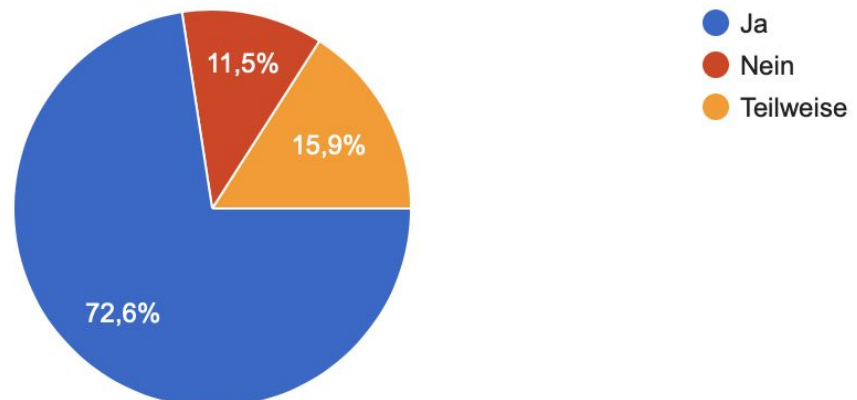
### Do you know what an advance directive is?

N=226

A majority of respondents know what an advance directive is (>70%). Around 16% know partially what it is and around 12% responded that they don't know what an AD is.

Wissen Sie was eine Patientenverfügung ist?

226 Antworten



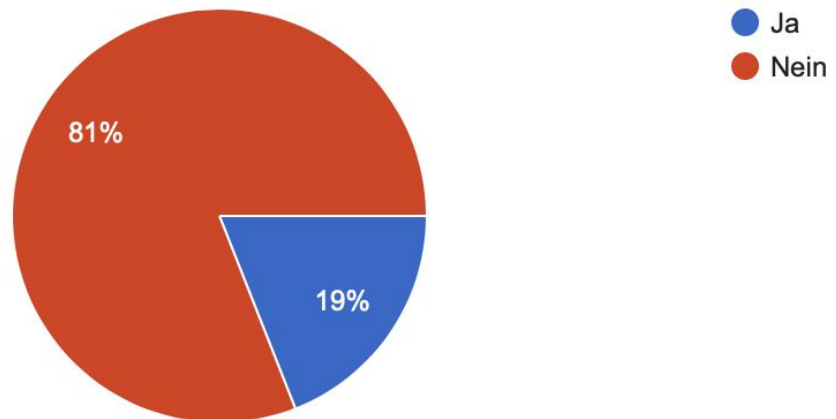
### Do you have an AD?

N=226

A huge majority, nearly 80% of all respondents, do not have an AD. Only a minority of around 20% have an AD.

## Haben Sie eine Patientenverfügung

226 Antworten



### 1. Questions for people that reported to HAVE an AD (branching logic)

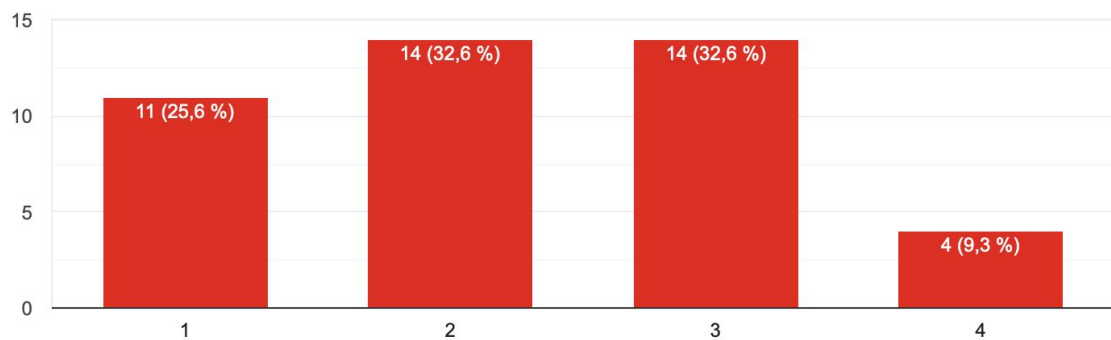
#### Understandability (content):

N=43

Most respondents reported that the understandability (content) is partially easy to partially complicated. A minority reported that the understandability is complicated, more respondents reported that it is easy to understand than complicated.

Verständlichkeit (Inhalt)

43 Antworten



### Availability of the form:

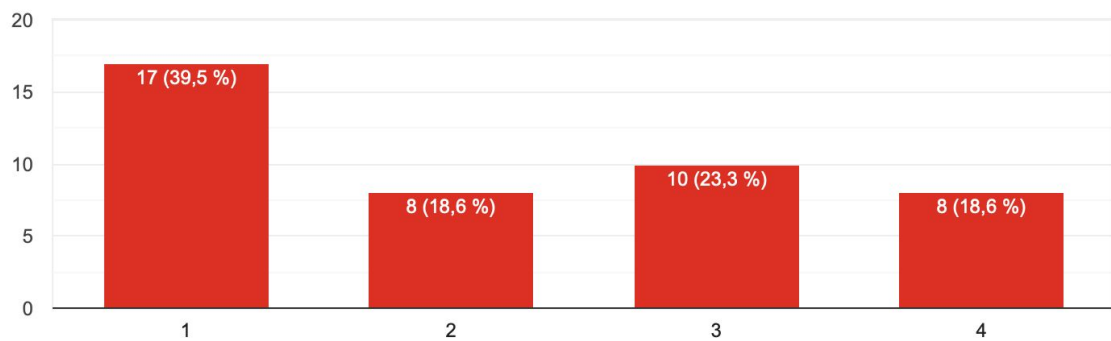
N=43

Most respondents reported that the availability of the form is easy (~38%). However, 25% reported that the availability of the form is rather difficult.

Verfügbarkeit des Formulars



43 Antworten



### Understandability (language):

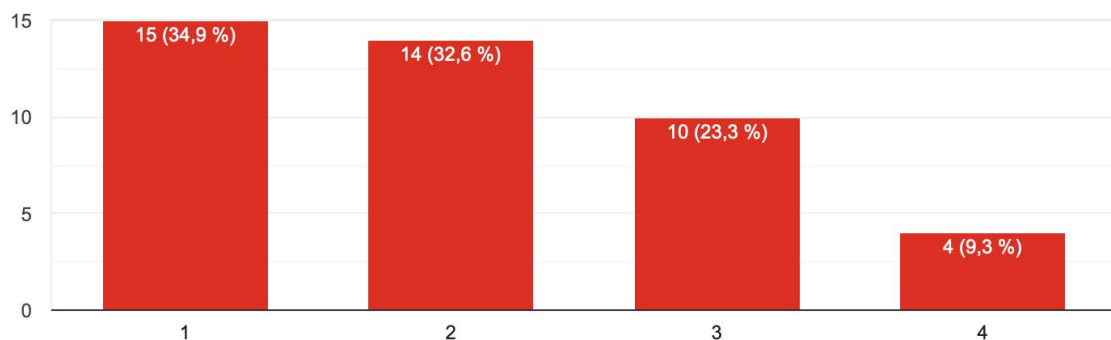
N=43

A majority of respondents (combined >60%) responded that the language used in the forms is easy to partially easy. However, around 25% had some difficulties understanding the form.

Verständlichkeit (Sprache)



43 Antworten



## Length of form/AD:

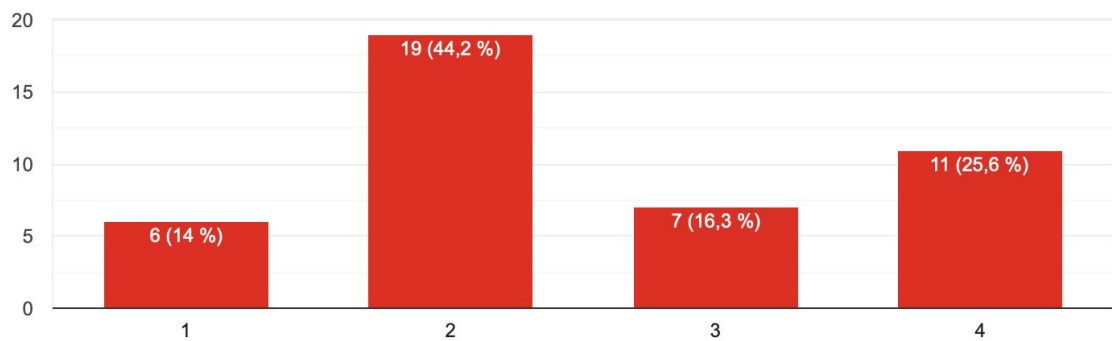
N=43

45% of respondents reported that the form is not short, but manageable. But more than 27% reported that they think the form/AD is too long.

Länge der Verfügung/Formular



43 Antworten



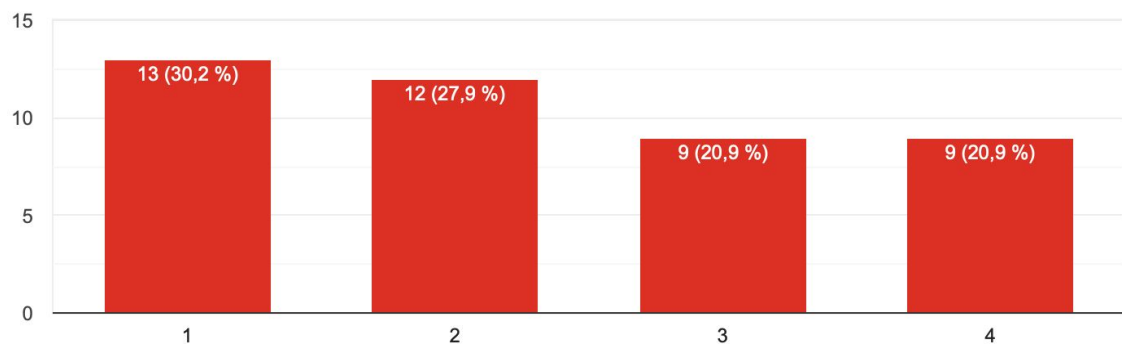
## Legal usability of form/AD:

N=43

Each category has been reported by more than 20%, meaning that it is for some people very clear how such a form/AD is used from a legal viewpoint. But nearly 43% reported that it is hard to understand how the form/AD works from a legal viewpoint.

Angaben zur rechtlichen Verwendbarkeit des Formulars

43 Antworten



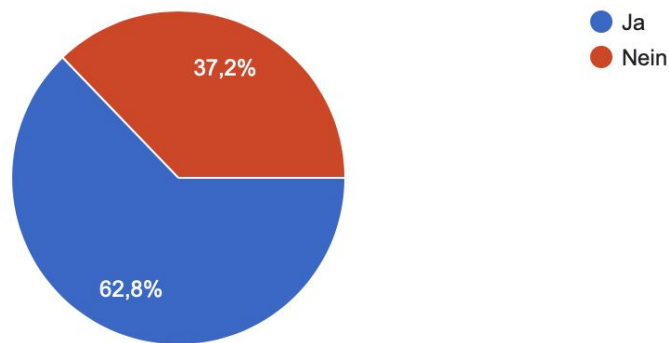
### **Possibility to do it online:**

N=43

A majority of more than 60% of respondents that have an AD report that they would prefer it if the process of filling out an AD could be done online. Nevertheless, nearly 40% report that they don't prefer an online solution.

Heute muss man das Formular online ausfüllen oder ausdrucken und per Hand ausfüllen, unterschreiben und dann einsenden oder hinterlegen. Fänden Sie es besser, dies online machen zu können?

43 Antworten



### **Other remarks from people that filled out an AD:**

N=14

Some responses:

- include more information (blood type) and combine it with organ donor pass
- raise awareness and communication
- not clear why so many different forms, which is the best one?
- think about people without online access and think about people that want to do it online

## Further:

N=14

Interestingly, >85% report that they did not use a form.

Weiteres

16 Antworten



### Remark (copied of responses):

Was ich noch los werden möchte, mir viel während dem Arbeiten auf das 1 viele keine pat. Verfügung besitzen und 2. Diese häufig nicht im altersheim oder beim Hausart gelagert wird. Würde ich wirklich jedem empfehlen. Ein weiter Aspekt, wo ich an meine Kollegen vom Spital appellieren möchte, ich würde es begrüßen wenn die Pat. Verfügungen im Doppel mitgeben werden, auch im Doppel oder zumindest ein Exemplar es auf die Station schafft. Das gleich mit Medikamentenlisten, in 9 von 10 Fällen krieg ich einen Anruf ob ich noch etwas Mailen könnte. Empfehlung diese Dinge entgegen nehmen Scannen und ab ins Kartext oder Dok. System

→ *Translation*: "Something I want to mention. 1) I noticed while working that many people don't have an AD and 2) that they are often not stored in the nursery home or at the doctor. I would really suggest this to everyone. Something else I want to tell my colleagues at the hospital: I would prefer it if every patient decree we hand out is distributed two times meaning that at least we get both or at least on of the two forms back. The same is happening with medication lists. In 9 out of 10 cases I get a call if I can email something. Suggestion: Notice these things, scan it and put it into the Kartext or Doc. System.



## 2. Question for people that reported that they DON'T have an AD (branching logic)

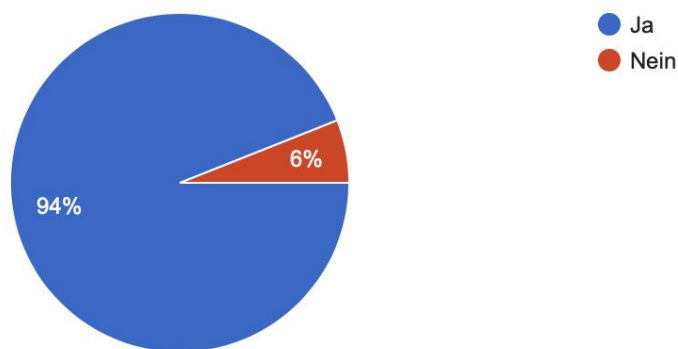
Would you be willing to fill out an AD (with regard the current circumstances)?

N=183

An overwhelming majority of nearly 94% of people that reported to not have an AD would be willing to fill out an AD! Only 6% would not fill out an AD.

Wären Sie grundsätzlich bereit (unter gegebenen Umständen) eine Patientenverfügung auszufüllen?

183 Antworten



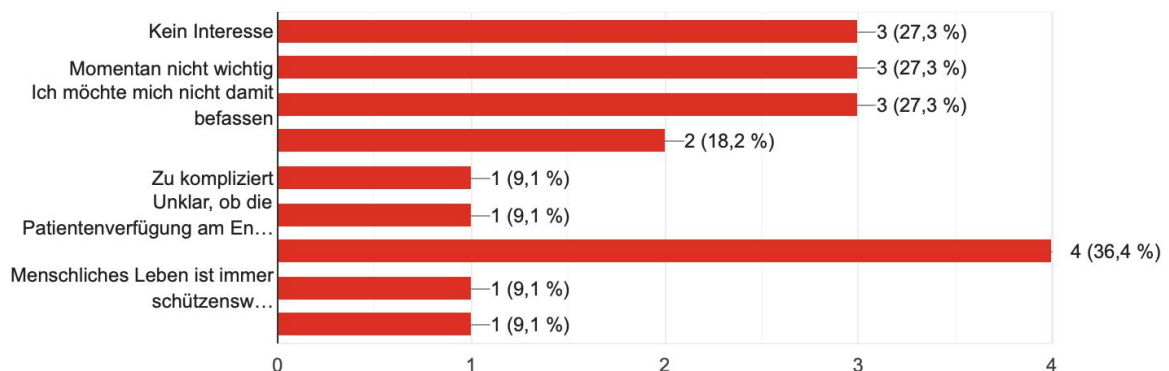
### 2.1 Question for people to not fill out an AD under the current circumstances Why would you not fill out an AD? (multiple responses possible)

N=11

36.4% of respondents state that they did not think about this topic enough to fill out an AD. Each of the following statements have been reported by more than 25%: no interest, not important right now, I don't want to think about it & I want someone else to decide for me.

Wieso möchten Sie keine Patientenverfügung ausfüllen? (Mehrfachantwort möglich)

11 Antworten



**Questions for all respondents again:**  
**With who would you discuss this AD topic? (multiple responses possible)**

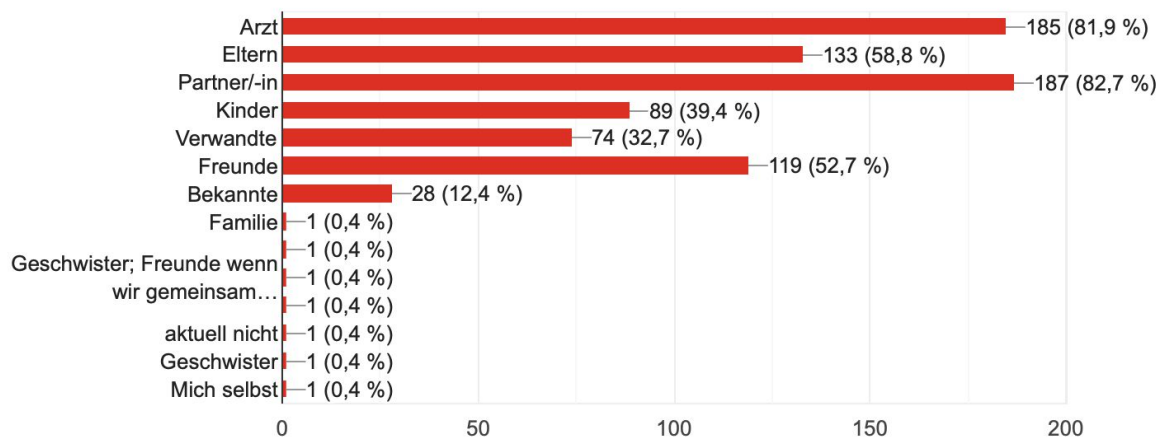
N=226

People stated that they would discuss this topic with their doctor (~80%), their partner (~83%), their parents and friends (both around 50%). Some would discuss this topic with their relatives (33.3%).

Mit wem sind Sie bereit Gesundheitsthemen (Patientenverfügung) zu besprechen?  
(Mehrfachantwort möglich)



226 Antworten



**Limitation:** we got the feedback that many respondents did not pick option “partner” or “children” because they were not in a partnership or parenthood but would be in case they would get into a relationship or became parents

## Who could approach you with this topic?

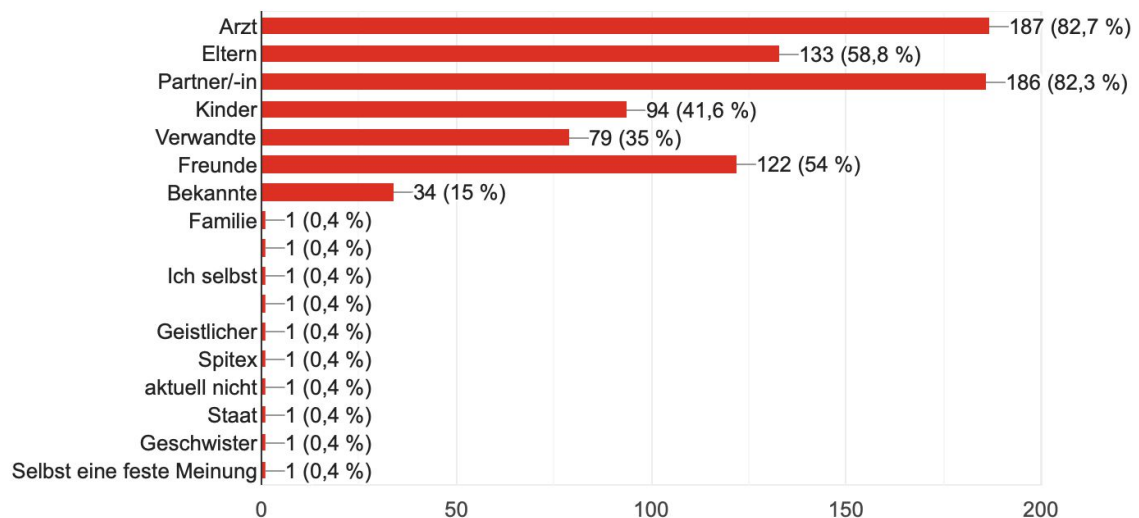
N=226

Nearly the same distribution. Doctor and partner could approach this topic (more than 80%, interestingly would more people allow the doctor to approach them with the topic, than approach the doctor themselves). Parents, friends, kids and relatives are also mentioned (relatives the least: 37%).

Wer könnte mit Ihnen Gesundheitsthemen (Patientenverfügung) besprechen? Wer dürfte mit diesem Thema auf Sie zukommen? (Mehrfachantwort möglich)



226 Antworten



**Limitation:** we got the feedback that many respondents did not pick option “partner” or “children” because they were not in a partnership or parenthood but would be in case they would get into a relationship or became parents

## Would you actively approach/educate your grandparents/parents with this topic?

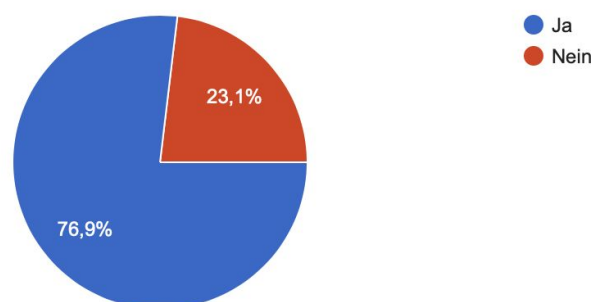
N=212

More than  $\frac{3}{4}$  of respondents would actively educate/approach their grandparents/parents with this topic.

Würden Sie Ihre Grosseltern/Eltern über dieses Thema aufklären/es aktiv ansprechen?



212 Antworten



**Limitation:** we got the feedback that many respondents did not pick option “yes” because their grandparents were not alive anymore. For further information see “subgroup young people”

## Interpretation general analysis

A majority of more than **70% of respondents know what an AD is**. However, **only 20% of respondents have an AD**. Showing that it's not a lack of knowledge in regards to know what is it, but there have to be other reasons why people do not have an AD while knowing what it is.

From all the people that have an AD, most reported that the process is not the easiest, but not the most difficult and hard to understand either. A majority of more than 60% stated that they would prefer to have an online option to fill out an AD. Interestingly, a majority of people that have an AD did not use a form, meaning they took the time to write it down themselves.

**Very important from the people that don't have an AD is the fact that an overwhelming majority of nearly 95% would fill out an AD** (under the current circumstances). The ones that (still) don't want an AD state that they did not think enough about this topic or don't want to deal with it.

Respondents would discuss this topic with **doctors and partners mainly**, adding kids and friends (more than relatives). People would be happy to discuss this topic when approached from doctors, partners, kids and friends as well. This shows that partner and doctor are (still) the two main ways people want to discuss/be approached about this topic.

In regards to an intermediary approach this suggests that people still see the doctor as some sort of person of trust in this matter (even though most people don't see their doctor on a regular or even friendly basis {interpretation}). Regarding an intermediary approach within family, **a majority (more than 75%) would be willing to actively approach, educate their parents/grandparents about this topic raising awareness for people that are older and should have these thoughts in case of emergency** (all people should do this but risk groups even more).

## Subgroup analysis

After looking at the data of the whole population we divided participants into subgroups of interest in order to gain further explorative insights and detect trends of Covid-19 relevant group differences. We were looking at young people (age 45 or less), elderly people (age 56+), people with preexisting health conditions (existence any of Covid-19 risk factors) and elderly people with risk factors (age +56 & existence any of Covid-19 risk factors)

## 2. Subgroup Young People

Young people are well informed about AD, 89% know about AD and 79% would like to fill out an AD if circumstances are right, but only 14% actually have filled out an AD. This is in line with the general population showing that there is a gap between need and action of filling out an AD.

82% would actively approach their parents/grandparents about AD. Interestingly the 18% that would not talk about AD with their parents all have no AD themselves. They also seem to be mostly between 16-25 or 25-36 whereas young people willing to talk about AD with their parents seem to be a little older with most being 25-36 and 36-45. → Targeting “middle age” that already have family or have elderly parents (65 or older).

## 3. Subgroup Elderly (56+)

While 91% of this groups knows at least partly about the existence of an AD, only 36% have created one. Awareness and action is therefore higher than in the general population, nevertheless a significant gap between knowledge and action.

A finding of utmost importance is that of those who haven't filled out an AD, 100% would like to create one.

It is therefore important to further research the reason what keeps this group from filling out an AD even though there is a clear need (Bedürfnis). Factors that explain this gap are needed.

In summary, elderly people are very interested in getting an AD, but there seems to be factors that limit this population Group of acting on their needs.

Similar to the general population, people over 56 are overwhelmingly talking about AD with their physician and partners. Interestingly, 75% of the the elderly age group are willing to talk with their children about DA, 78 % are willing to be informed by their children. These Results didn't differ whether a person was willing to fill an AD or not or whether people already had an AD or not(no bias).

**These findings support our hypothesis, that the gap of need of an AD and actually filled AD could be solved by approaching this group through informed relatives, mainly children/grandchildren.**

## 4. Subgroup People at Risk

As expected most participants with a health risk know about AD (95% know at least partly what an AD is). Interestingly even though the higher likelihood of being in future need of hospitalization, only 23% of participants with a pre-existing covid-19 related risk factor have an AD. Interestingly this number changes only marginally when the factors old age and risk factor are combined (only 21% have an AD). This group is highly affected with a risk of

needing ICU treatment. In this group 85% of participants are willing to be informed by their children about AD and talk about it with them.

## 5. Short summary of findings

A majority of all respondents know what an AD is, but only a minority actually has an AD. But from all those that don't have one, a HUGE majority would take the time and actually fill out an AD! All respondents are mainly interested in discuss this topic with their partner and their doctor and would also be keen to get approached by those two groups in regard to this topic. More than 75% of all respondents are willing to educate/approach their grandparents/parents with this topic.

Young people are well-informed about AD, and would fill one out but have not done it. The young people that do not have an AD would also not talk about it with their parents. Young people (under 25 years) are more reluctant to discuss this topic with parents/grandparents than middle aged people.

In summary, elderly people are very interested in getting an AD, but there seems to be factors that limit this population group of acting on their needs.

Nearly all people in the risk group with chronic diseases know what an AD is or partially (95%). However, even though they are at high risk (especially now) only a minority has filled out an AD (even higher percentage than over all respondents). Interestingly, when older age and risk factors (chronic diseases) are combined, not more people filled out an AD even though chances of having to get ICU treatment are very high.

### **We surveyed over 200 people, this is what we found:**

- 1) Huge gap: people want AD but don't get them (even elderly or people at risk), and a majority knows about ADs
- 2) Old people are open to be approached by young (e.g. kids)
- 3) Young people are willing to inform their parents/grandparents and could therefore be intermediary

→ We are going to make the raw data available to judges in the attachments.