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Deciding on behalf of others: a population survey on procedural preferences for surrogate decision-making

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ABSTRACT

Objectives To assess people's procedural preferences for making medical surrogate decisions, from the perspectives of both a potential surrogate and an incapacitated patient.
Design Computer-assisted telephone interviews. Respondents were randomly assigned either the role of an incapacitated patient or that of a potential surrogate for an incapacitated family member. They were asked to rate six approaches to making a surrogate decision: patient-designated surrogate, discussion among family members, majority vote of family members' individual judgements, legally assigned surrogate, population-based treatment indicator and delegating the decision to a physician.
Setting Germany and German-speaking and French-speaking parts of Switzerland.
Participants 2010 respondents were quota sampled from a panel (representative for the German and German-speaking and French-speaking Swiss populations, respectively, in terms of age, sex and regions).
Main outcome measures Endorsement of each approach (rated on a scale from 1 to 10). Degree to which preferences overlap between the perspective of potential surrogates and potential patients.
Results Respondents' endorsement of the six different approaches varied markedly (from Mdn=9.3 to Mdn=2.6). Yet the preferences of respondents taking the perspective of incapacitated patients corresponded closely with those of respondents taking the perspective of a potential surrogate (absolute differences ranging from 0.1 to 1.3). The preferred approaches were a patient-designated surrogate (Mdn=9.3) and all family members making a collective decision by means of group discussion (Mdn=9.3). The two least-preferred approaches were relying on a statistical prediction rule (Mdn=3.0) and delegating the decision to a physician (Mdn=2.6).
Conclusions Although respondents taking the perspective of an incapacitated patient preferred a patient-designated surrogate, few people have designated such a surrogate in practice. Policy-makers may thus consider implementing active choice, that is, identifying institutional settings in which many people can be reached (eg, when obtaining a driver's licence) and requesting them to complete advance directives and to designate a specific surrogate. Moreover, potential patients and surrogates alike highly valued shared surrogate decisions among family members. Policy-makers may consider acknowledging this possibility explicitly in future legislation, and caregivers

Strengths and limitations of this study

► Past research has focused on the accuracy of different approaches to making surrogate decisions for incapacitated patients, that is, on the proportion of surrogate decisions that are in line with hypothetical patients' real preferences.
► These analyses did not find evidence for substantial differences in accuracy between approaches.
► People's procedural preferences may therefore be an additional important criterion for evaluating surrogate decision-making approaches, but evidence from representative surveys is currently lacking.
► This is the first study to report representative evidence on potential patients' and surrogates' endorsements of six different approaches to surrogate decision-making.
► Future research should also assess procedural preferences for combinations of different approaches, which the current study did not do.

and physicians may consider promoting shared surrogate decisions in practice.

INTRODUCTION

Surrogate decisions in the medical context refer to decisions made on behalf of patients who are no longer able to express whether and how they want to be treated, nor specified their treatment preferences in any advance directives. Unfortunately, patients who may depend on a surrogate are no rare exception; for example, in the USA alone 15 000 patients live in a persistent vegetative state and another 100 000 are minimally conscious.[1] As only a fraction of the population has completed advance directives regarding their preferred medical treatment (about 10% in non-clinical populations),[2 3] for many of these patients a surrogate will have to make medical decisions on their behalf—be it a decision on standard procedures, or a momentous end-of-life

decision. Similarly, of the 47 million people worldwide who live with dementia (eg, Alzheimer's disease), rising to an estimated 131 million by 2050,[4] many will eventually lose their ability to make autonomous decisions and depend on a surrogate.

The legislation in some countries including several US states (as well as Switzerland and Germany, the setting of the present study)[5 6] explicitly permits a person to be designated as surrogate, making a 'substituted judgement' in case of necessity with the goal of approximating the patient's preferences as closely as possible. If no surrogate has been designated by the patient, a default surrogate may be assigned by law, using a nearest-relative hierarchy that starts with the spouse and progresses to one of the patient's adult children, a parent or an adult sibling. This hierarchy is implemented in the Swiss and other countries' legislations (but not in effect in Germany).[7–9] In the UK, the Mental Health Act stipulates the use of the same hierarchy for mentally incapacitated patients. Other approaches are not anchored in law but may nevertheless be adopted in practice. For example, the patient's family members may make a joint decision or delegate the decision to a physician. Further approaches, such as relying on a statistical prediction rule (ie, a 'population-based treatment indicator'), have been suggested in the literature[9] but not yet implemented in practice.

People who engage in advance care planning, as well as relatives of an incapacitated patient, may therefore be confronted with the question of which approach is best for making a surrogate decision. The different approaches can be evaluated on at least two criteria: accuracy and procedural preference. Accuracy refers to the proportion of surrogate decisions that are in line with incapacitated patients' true preferences. As the latter by definition cannot be assessed once a patient is incapacitated, the accuracy of surrogate decisions is typically estimated using hypothetical scenarios. A systematic review of studies using such scenarios revealed accuracy levels of 69% for patient-designated surrogates and 68% for legally assigned surrogates.[10] More recently, Frey et al[11] found similar levels of accuracy in the context of actual families (n=64), namely 68% for patient-designated surrogates and 70% for surrogates selected according to the nearest-relative hierarchy. In addition, Frey et al assessed the accuracy of different surrogate decisions rendered jointly by family members: Decisions made after open discussion among family members had an accuracy level of 70%, those made after casting individual votes and applying a majority rule had an accuracy level of 71%. Finally, another study found that a preliminary population-based treatment indicator accurately predicted preferences in 78.5% of cases, whereas individual surrogates achieved an accuracy level of 78.4% (note that the authors of this study raised the possibility that the observed accuracy levels may be inflated as a result of the relatively 'easy' scenarios used).[9] In sum, the predictive accuracies of the various approaches to surrogate decision-making tested to date clearly exceed chance level (which would be 50%, as the scenarios typically require a binary decision) but do not appear to differ appreciably among each other.[9 11]

The second criterion on which surrogate decisions can be evaluated—procedural preference—refers to potential patients' and surrogates' preferences for how a surrogate decision is made—and in particular, by whom. For example, incapacitated patients may wish to delegate their autonomy to the person they feel closest to and trust most. Also potential surrogates may care about how a decision is made; as there will always be some uncertainty, surrogates may struggle with whether they are making the right decision, ponder its acceptance among other family members and possibly anticipate postdecisional regret. They may therefore prefer to make a shared surrogate decision with other family members. As in the canonical definition of 'shared decision-making' between a physician and a patient,[12 13] sharing could ease the emotional distress potentially experienced by the person who has to make a momentous decision (ie, an individual surrogate). Moreover, shared decisions about important matters lead to an increase in perceived procedural justice, as opposed to those made by an individual alone.[14]

In line with these concerns, having 'support and others to talk to' and 'working towards consensus' have been identified as key factors that help surrogates to make these difficult decisions.[15] In one study, 18% of actual patient-designated surrogates indicated that they planned to seek input from others in the surrogate's network.[16] Moreover, first evidence from families indicates that both potential patients and surrogates prefer shared decision-making approaches to delegating the decision to a surrogate assigned by a legal hierarchy (even though this person is often the same person the patient would have designated) or to a physician, or to applying a statistical prediction rule.[11] Finally, a recent study investigated whether a 'patient preference predictor' (PPP, ie, a statistical prediction rule that predicts which treatment a patient would want, based on the treatment that patients in similar circumstances would prefer) was perceived as a valuable and acceptable tool to assist shared decision-making.[17] When the PPP was framed as an intervention that would reduce stress on their 'durable power of attorney' (typically a family member), 48% of respondents wished the PPP prediction to be considered; when it was presented as an intervention that would increase the chances of being treated consistently with their own preferences, 55% of respondents wished it to be considered. The latter assumption (ie, that a PPP increases predictive accuracy) is not yet supported by empirical evidence, however, and because the framing of the questions in the study may have implied so, this level of agreement could be inflated. Nevertheless, it indicates that a sizeable proportion of people may appreciate the use of some form of a technical decision aid, such as a statistical prediction rule.

If the different approaches were to substantially differ in terms of their accuracy, those differences might, of course, influence procedural preferences. However, given that the differences between the currently available approaches to making surrogate decisions are negligible,[9–11] it is all the more important to have a solid empirical assessment of people's procedural preferences. To date, representative assessments of those preferences are lacking. As such, it also remains unknown to what extent potential patients' and surrogates' preferences overlap or conflict with each other.

Relatedly, it remains unknown to what extent preferences vary as a function of sociodemographic and other relevant characteristics (eg, age, whether a person has prepared a living will or designated a surrogate). Answers to these questions will help to advise people on how best to make surrogate decisions, and as they may have implications for legislation they could thus inform future policy-making.

METHODS
Representative survey
We conducted computer-assisted telephone interviews with people aged at least 14 years who lived in Germany (n=1007) or Switzerland (German-speaking and French-speaking parts; n=1003). Respondents were recruited in September 2012 from a panel maintained by an international market research company (Gesellschaft für Konsumforschung) and interviewed in the context of a typical omnibus survey (Telebus); the sizes of the quota-driven samples were chosen such that they are representative for age, sex and regions of the respective populations. The French version of the questionnaire was professionally translated by the survey company, which also conducted the interviews, compensated respondents and provided us with respondents' sociodemographic information.

In the survey, respondents were randomly assigned either the role of an incapacitated patient or the role of an incapacitated patient's close relative. The interviewers read the instructions for the two perspectives as follows (English translation).

> Please imagine that you have [a member of your family has] advanced Alzheimer's disease or are [is] in a coma after an accident. That is, you are [this family member is] no longer capable of making decisions regarding life-sustaining medical treatments. If you [your family member] had not completed a living will with clear instructions, who should make the decisions that may determine your [the family member's] life and death? I am now going to list six different possibilities. Please tell me how strongly you agree or disagree with each of them. If you [your family member] were incapacitated, how strongly would you want a treatment decision to be made by…

Respondents then indicated their preferences on a scale from 1 (strong disagreement) to 10 (strong agreement) for each of the following six possibilities (presented in randomised order for each respondent): A decision should be made (1) by an individual person whom you have (the family member has) previously designated as surrogate; (2) by an individual person determined according to a legal hierarchy (starting with the spouse, followed by an adult child, a parent or an adult sibling); (3) by family members making a collective decision through discussion with the aim of finding a consensus; (4) by family members making a collective decision by casting individual votes and implementing the majority choice; (5) by a physician and (6) in accordance with the decision that the majority of patients in a similar situation would have made. Finally, respondents were asked whether they had completed a living will, designated a potential surrogate and registered as an organ donor. In Germany and Switzerland, active consent is required to become an organ donor (eg, by completing a form downloaded from the internet).

Patient and public involvement
No patients were involved in setting the research question or the outcome measures, nor were they involved in developing plans for design or implementation of the study. No patients were asked to advise on interpretation or writing up of results. There are no plans to disseminate the results of the research to study participants.

STATISTICAL ANALYSES
All of the analyses were conducted using R.[18] The full dataset is available at http://osf.io/5aa4b. We report respondents' sociodemographic characteristics (sex, age, household size, employment status, education, income and city size) separately for the two samples. Moreover, we report these data both after poststratification (ie, after applying sample weights; table 1) as well as before poststratification (ie, the unweighted raw values; online supplementary table S1). The poststratification weights were computed separately for the two samples and were used to fine tune the representativeness of the quota-driven samples for the respective populations. We incorporated them for reporting the sociodemographic characteristics (using the R-package survey[19]) as well as in all beta regression analyses described below. Because income levels, educational levels and city sizes differed between the two countries, we created separate sets of bins for each country such that the corresponding bins contained comparable numbers of respondents for both countries.

We report three sets of analyses regarding respondents' procedural preferences. First, in figure 1, we present the empirical distributions of the unweighted ratings together with the densities of the weighted data (using kernel density estimation[20]). These distributions are plotted separately for the different approaches, the

Table 1 Sociodemographic characteristics of the two samples after poststratification

Variable	Levels (Germany/Switzerland)	Germany	Switzerland
Sample size		n=1007	n=1003
Perspective: surrogate		n=505 (50%)	n=501 (50%)
Female		n=517 (51%)	n=507 (51%)
Age (years)		M=48 (SD=18.4)	M=43.6 (SD=15.6)
Household size		M=2.5 (SD=1.6)	M=2.8 (SD=1.7)
Employed		n=574 (57%)	n=694 (69%)
Education			
0	Compulsory education	n=568 (60%)	n=580 (58%)
1	Upper secondary education	n=245 (26%)	n=115 (12%)
2	College	n=129 (14%)	n=308 (31%)
Income			
0	<€1500/<SFr7000	n=234 (31%)	n=316 (32%)
1	<€2500/<SFr9000	n=223 (30%)	n=165 (17%)
2	<€4000/<SFr12 000	n=189 (25%)	n=163 (17%)
3	>€4000/>SFr12 000	n=102 (14%)	n=132 (13%)
City size			
0	<5000/<2000	n=157 (16%)	n=130 (13%)
1	<20 000/<10 000	n=270 (27%)	n=134 (13%)
2	<100 000/<200 000	n=278 (28%)	n=347 (35%)
3	<500 000/>200 000	n=147 (15%)	n=391 (39%)
4	>500 000/NA	n=155 (15%)	
Living will		n=265 (26%)	n=134 (13%)
Designated a surrogate		n=449 (45%)	n=260 (26%)
Organ donor		n=215 (21%)	n=235 (23%)

'Compulsory education' comprises all educational levels below Abitur (Germany) and Matura (Switzerland). 'Upper secondary education' indicates completion of Abitur/Matura. 'College' comprises all educational levels equivalent to a university degree or higher.
NA, not applicable.

two perspectives and the two samples. To model the distributions, we ran a separate Bayesian beta regression[21] for each combination of approach, perspective and sample (ie, for each subpanel in figure 1) with an intercept only[i]. The beta distribution is ideal for modelling scales with a lower and an upper bound, which often exhibit uncorrectable skew and heteroscedasticity.[22] In figure 1, we depict the medians of each modelled beta distribution (ie, the means of their posterior distributions as point estimates), together with their uncertainty intervals (the 95% highest density intervals (HDIs) of the posterior distributions).

Second, to compare the agreement between the two perspectives, we ran a Bayesian beta regression for each approach (using the same method as described above), with an intercept and a dummy variable 'perspective' (reference level: patient) as the sole predictor variable[ii]. We use these coefficients to report the differences between the medians of the beta distributions as a function of perspective, pooled across the two samples. These analyses are reported in the main text of the results section.

Third, we also present an exploratory regression analysis for each of the approaches using the same method as for the previous models, where preference strength is predicted by a set of sociodemographic variables and other relevant variables; in particular, whether a person has completed a living will, designated a surrogate and registered as an organ donor. 'Age' and 'household size' were treated as continuous predictors and were mean centred. 'Education', 'income' and 'city size' were treated as ordinal predictors and implemented using sum contrasts. All other predictors were treated as binary predictors with the indicated effect levels (see table 2). These analyses are reported in the main text of the results section as well as in table 2.

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[i]The models used a log link-function and weakly informative default priors: N (0, 10) for the intercept and Cauchy (0, 5) for the auxiliary link function phi. Weakly informative priors provide some statistical regularisation and thus guard against overfitting the data.

[ii]For the coefficients of this predictor, we used the default prior of N (0, 2.5).
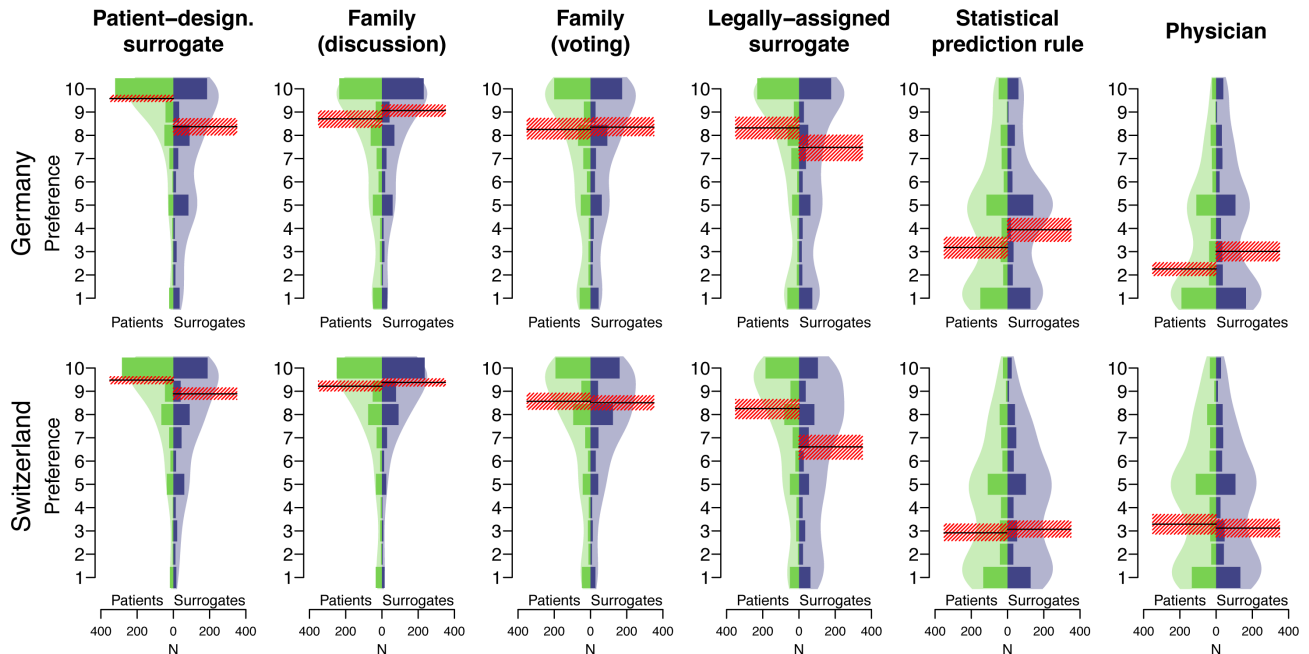
Figure 1 Preferences for the six approaches to surrogate decision-making, separately for the 'patient' perspective (left side of each panel) and the 'surrogate' perspective (right side of each panel). The upper panels show data for Germany; the lower panels, Switzerland. The histograms (ie, horizontal bars) show the raw data, whereas the shaded areas show kernel densities obtained from poststratification of the survey data. Horizontal lines depict the medians of the modelled beta distributions, with the red-shaded areas representing 95% highest density intervals.

To illustrate, the coefficient of −0.79 (first column, second row) indicates how much less (on the scale from 1 to 10) respondents of the surrogate perspective endorsed the approach of a 'patient-designated surrogate', in comparison to the respondents of the patient perspective.

RESULTS
Characteristics of study population
Table 1 lists respondents' sociodemographic characteristics (note that these are weighted values after poststratification, in contrast to the empirical values reported next). Across both samples, 1043 females and 967 males participated in the study, with a mean age of 47.7 years (range 14–89 years, SD=15.9 years). Of all respondents, 348 (17%) lived in single households, 706 (35%) in 2 person households and 956 (48%) in households of 3 or more persons. Four hundred and fifteen (21%) of respondents had completed a living will, 723 (36%) had designated a surrogate and 462 (23%) had registered as organ donors.

Procedural preferences
Endorsements varied substantially across the six approaches to making surrogate decisions (figure 1). However, the preferences of respondents taking the perspective of an incapacitated patient ('patients') and those taking the perspective of an incapacitated patient's family member ('surrogates') were, for the most part, aligned—with only two noteworthy exceptions: When pooled across German and Swiss respondents, the approach most preferred by 'patients' was to rely on a patient-designated surrogate (Mdn=9.7, HDI=9.6 to 9.8),

whereas 'surrogates' rated this option second (Mdn=8.9, HDI=8.7 to 9.1). The approach second-most preferred by 'patients' (only slightly behind a patient-designated surrogate) was to involve all family members in the decision by means of a group discussion aimed at finding consensus (Mdn=9.3, HDI=9.1 to 9.4). For 'surrogates', this was the preferred approach (Mdn=9.4, HDI=9.2 to 9.5). 'Patients' and 'surrogates' had similar and slightly lower endorsements of involving all family members by means of majority voting (Mdn=8.7, HDI=8.5 to 9.0; and Mdn=8.6, HDI=8.4 to 8.9, respectively). Whereas for 'patients' assigning a surrogate according to the nearest-relative hierarchy (Mdn=8.6, HDI=8.3 to 8.9) was endorsed to about the same degree as majority voting, for 'surrogates' endorsements of such a legally assigned surrogate were somewhat lower (Mdn=7.3, HDI=6.8 to 7.7). The second least-preferred approach by both 'patients' and 'surrogates' was to rely on a statistical prediction rule (Mdn=2.8, HDI=2.5 to 3.1; and Mdn=3.3, HDI=3.0 to 3.6, respectively). The least-preferred approach by both 'patients' and 'surrogates' was to delegate the decision to a physician (Mdn=2.4, HDI=2.2 to 2.7; and Mdn=2.8, HDI=2.5 to 3.1, respectively).

Predictors of procedural preferences
The exploratory regression analyses revealed that several predictors had a substantial impact on respondents' preferences. We only report effects with HDIs excluding 0 (see table 2 for all coefficients), grouped into five sets of results. First, 'surrogates' gave substantially lower ratings for individual surrogate approaches (ie, a patient-designated

Table 2 Bayesian beta regression results

	Pat. design surrogate	Family (discussion)	Family (voting)	Leg. assigned surrogate	Stat. prediction rule	Physician
Intercept	**9.45 (9.14 to 9.74)**	**9.41 (9.04 to 9.71)**	**8.69 (8.04 to 9.28)**	**7.92 (7 to 8.75)**	**3.06 (2.34 to 3.81)**	**3.05 (2.32 to 3.84)**
Perspective (sur.)	**−0.79 (−1.26 to −0.34)**	0.1 (−0.22 to 0.38)	−0.14 (−0.77 to 0.49)	**−1.1 (−2.02 to −0.15)**	0.65 (−0.2 to 1.54)	0.36 (−0.45 to 1.23)
Sex (female)	**0.28 (0.07 to 0.47)**	0.14 (−0.15 to 0.43)	0.31 (−0.27 to 0.83)	0.41 (−0.41 to 1.16)	0.23 (−0.52 to 1.01)	0.59 (−0.29 to 1.53)
Age	0 (−0.3 to 0.3)	0 (−0.37 to 0.3)	0.02 (−0.63 to 0.6)	0.03 (−0.89 to 0.85)	0.02 (−0.69 to 0.79)	0.04 (−0.68 to 0.86)
Education	0.01 (−0.3 to 0.35)	−0.05 (−0.48 to 0.31)	−0.06 (−0.77 to 0.63)	−0.25 (−1.31 to 0.69)	−0.57 (−1.19 to 0.09)	−0.37 (−1.07 to 0.41)
Employed (y)	0.09 (−0.14 to 0.32)	−0.12 (−0.44 to 0.16)	−0.15 (−0.7 to 0.37)	−0.55 (−1.3 to 0.26)	**−0.67 (−1.1 to −0.18)**	−0.25 (−0.85 to 0.32)
Income	0.08 (−0.2 to 0.37)	0.02 (−0.34 to 0.35)	−0.05 (−0.76 to 0.56)	0.06 (−0.88 to 0.92)	0.05 (−0.72 to 0.86)	0.08 (−0.74 to 0.88)
Household size	−0.04 (−0.36 to 0.28)	0.03 (−0.31 to 0.35)	0.04 (−0.61 to 0.64)	0.28 (−0.6 to 1.12)	0.21 (−0.54 to 1.03)	−0.06 (−0.81 to 0.74)
City size	0.05 (−0.24 to 0.36)	−0.07 (−0.45 to 0.32)	−0.05 (−0.74 to 0.6)	0.2 (−0.67 to 1.11)	0.02 (−0.76 to 0.82)	0.22 (−0.68 to 1.07)
Country (Germany)	−0.14 (−0.48 to 0.16)	−0.35 (−0.75 to 0.06)	−0.22 (−0.82 to 0.4)	0.05 (−0.76 to 0.9)	0.03 (−0.61 to 0.82)	**−0.84 (−1.31 to −0.33)**
Living will (y)	−0.02 (−0.44 to 0.37)	−0.42 (−1.04 to 0.14)	−0.69 (−1.67 to 0.2)	−0.07 (−1.28 to 98)	−0.65 (−1.37 to 0.16)	−0.59 (−1.33 to 0.29)
Design. sur. (y)	0.21 (−0.08 to 0.46)	0.18 (−0.15 to 0.48)	0.41 (−0.24 to 0.96)	**1.34 (0.69 to 1.91)**	0.78 (−0.19 to 1.86)	−0.33 (−1.08 to 0.48)
Organ donor (y)	0.12 (−0.19 to 0.41)	0.03 (−0.38 to 0.4)	−0.08 (−0.87 to 0.58)	−0.57 (−1.66 to 0.46)	−0.27 (−1.05 to 0.54)	0.23 (−0.75 to 1.16)

Intercepts reflect the mean ratings in the reference levels (see below) on the response scale of 1–10. 'Age' and 'household size' were treated as continuous predictors and were mean centred. 'Education', 'income' and 'city size' were treated as ordinal predictors and implemented with sum contrasts, such that the models' intercepts show the grand mean across all levels of the ordinal predictors (ie, for 'education' with three levels, the contrast weights −1, 0, 1 were used, for 'income' with four levels, the contrast weights −3, −1, 1, 3 were used and for 'city size' with five levels, the contrast weights −2, −1, 0, 1, 2 were used). All other predictors were treated as binary predictors with the indicated effect levels; coefficients denote changes from the intercept when a predictor's value is changed from 0 to 1 (ie, for the binary predictors, a change from the reference category to the effect category, indicated in parentheses after the predictor variable's name). Values in brackets are 95% HDIs. Coefficients with HDIs excluding 0 are printed in bold. The coding of the variables is specified in table 1.

surrogate or a legally assigned surrogate) than did 'patients' (Mdn=−0.8, HDI=−1.3 to −0.3 for a patient-designated surrogate; and Mdn=−1.1, HDI=−2.0 to −0.2 for a legally assigned surrogate). These findings corroborate the comparisons reported in the previous section. Second, respondents who had themselves designated a surrogate expressed a higher endorsement of relying on a legally assigned surrogate (Mdn=1.3, HDI=0.7 to 1.9), but—somewhat surprisingly—not of a patient-designated surrogate. The latter result may be a ceiling effect: ratings for the patient-designated surrogate were already high, leaving little room for increase. Third, the German (relative to the Swiss) respondents were generally less in agreement with relying on a physician (Mdn=−0.8, HDI=−1.3 to −0.3). Fourth, employed respondents were less in agreement with using a statistical prediction rule (Mdn=−0.7, HDI=−1.1 to −0.2). Fifth, female respondents expressed higher endorsement of relying on a patient-designated surrogate (Mdn=0.3, HDI=0.1 to 0.5).

DISCUSSION

Principal findings

First, the preferences of potential patients and surrogates were closely aligned, but varied strongly across the six approaches to making surrogate decisions. The preferred approaches were a patient-designated surrogate (though less so for potential surrogates than for potential patients) and all family members rendering a collective decision after group discussion. The two least-preferred approaches—for both potential patients and potential surrogates—were using a statistical prediction rule or delegating the decision to a physician. Second, 36% of the respondents reported that they had already designated a surrogate. Given that respondents had a strong preference for this approach, this rate seems low.

Comparison with past research

Past research has not systematically investigated people's procedural preferences for making surrogate decisions but has focused on the predictive accuracy of those approaches. The results of one study assessing procedural preferences[11] largely converge with the current findings. However, that study did not use representative samples of respondents. Furthermore, respondents were required to rank order the approaches according to their preferences as opposed to rating them individually (as in the current survey). Therefore, in contrast to the present study, respondents could express neither indifference nor small differences in preferences between approaches. In sum, the present survey is the first to comprehensively assess people's procedural preferences for making surrogate decisions from the perspective of both potential patients and potential surrogates and representatively for two European countries (Germany and Switzerland).

Strengths and limitations

This study drew on two large (quota-driven) samples representative for age, sex and regions for the German and (German-speaking and French-speaking) Swiss populations, respectively. Moreover, we used poststratification weights to approximate the underlying population characteristics even more precisely. Thus, our samples of two European countries provide a solid empirical foundation for assessing people's preferences on different approaches to making surrogate decisions. However, it remains open to what extent these preferences generalise to other countries or cultures that may differ in terms of relevant dimensions, such as individualism versus collectivism.[23]

As in previous research on surrogate decision-making, we did not interview actual patients or surrogates, because the preferences of incapacitated patients—in terms of both what and how to decide—cannot be assessed by definition. However, as people of any age group can unexpectedly become incapacitated (eg, after an accident) or become a surrogate, the respondents surveyed in this study constitute the relevant reference class of people. The preferences we report should therefore be representative of those that would emerge in real situations in Germany and Switzerland.

Our survey focused on six approaches to making surrogate decisions that are either already implemented in practice or discussed in the literature. To obtain broadly generalisable results, the investigated approaches had to be described in a general, concise form. In some real-life settings, additional information regarding the different approaches might be available (eg, in the case of delegating a decision to a physician: for how long has the physician been treating the patient?). Moreover, in practice some of these approaches may be combined. For example, a patient's family members could deliberate together to find a consensus and additionally consider the recommendation of a 'patient preference predictor' (PPP; knowing what most other people in the patient's situation would prefer may be a welcome input to the family's discussion). Future research should thus investigate how the combination of different approaches impacts potential patients' and surrogates' procedural preferences, as well as the accuracy of the resulting surrogate decisions. Aggregating predictions may increase their accuracy[24]—given that the errors of different methods are not redundant—as has, for example, been demonstrated for medical diagnostics.[25 26]

Implications for clinicians and policy-makers

In line with previous research reporting that only a minority of people have completed advance directives,[2 3] we found that only 21% of respondents had a living will and only 36% had designated a surrogate. In clinical practice, incapacitated patients' preferences on what and how to decide on their behalf thus remain unknown in many cases. Caregivers, physicians and family members then face the difficult situation of having to make surrogate decisions. Previous research has indicated that there

are no large differences in accuracy between different approaches to making surrogate decisions—at least, not between the approaches currently implemented in practice or investigated in scientific studies. Of course, this does not exclude the possibility that future research may prove successful in developing population-based treatment indicators[9] that increase predictive accuracy. Yet our results indicate that people have clear preferences regarding which of those approaches to implement in practice, from the perspective of both potential patients and potential surrogates.

A first implication of our findings follows from people's strong preference for relying on a patient-designated surrogate. As only a minority of people have actually designated a surrogate, policy-makers may consider implementing active choice,[27 28] that is, requiring citizens to fill in a living will or to designate one or multiple surrogates, in institutional settings where a large proportion of the population can be reached—for example, when obtaining a driver's licence or registering for health insurance.

A second and complementary implication is to systematically promote the involvement of all family members in surrogate decisions; this was the approach preferred by potential surrogates and the second choice of potential patients (only slightly behind their first choice, namely, a patient-designated surrogate). In line with theories on procedural preferences in group decision-making, a collective decision permits the burden of such a grave decision to be shared[15 16] and also seems to be perceived as fair, with everyone having the chance to contribute to the final decision.[14] Collective approaches should thus be promoted in practice as well as recognised in the legislation, which currently only provides for individualistic approaches (ie, an individual patient-designated surrogate or legally assigned surrogate). For example, should an incapacitated patient not have completed an advance directive, and should time permit, physicians may advise family members to deliberate and make a joint decision.

A third implication follows from the low endorsement of using statistical prediction rules or delegating the decision to a physician. Apparently, most potential patients and surrogates value keeping the decision within the family. Of course, if future research finds that a particular approach (eg, the use of a statistical prediction rule or of a different form of decision aid) can substantially increase accuracy, its acceptance might change.

Unanswered questions and future research
As outlined above, future research should address two questions. First, to what extent do these findings generalise to other countries and cultures? Second, can a combination of different approaches increase their predictive accuracy, and how will it influence procedural preferences?

CONCLUSION
Endorsements of different possible approaches to making surrogate decisions vary strongly; in other words, it clearly matters to people how surrogate decisions are made in practice. To ease this decision process, physicians and caregivers could inform potential surrogates (as well as patients threatened with incapacitation) of the different options and their strengths and weaknesses. Finally, legislation should honour people's preferences on how to make these potentially very difficult decisions by explicitly acknowledging the possibility of shared surrogate decision-making.

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