Supplemental Digital Content

Data and code availability

The data that support the findings of this study are not publicly available to preserve individuals' privacy under the European General Data Protection Regulation. Anonymized data and analysis code are, however, available from the authors upon reasonable request and with permission from Helse Bergen.

All data are located in controlled access data storage at the Helse Vest IKT until 31.12.2029.

Checklist for Reporting Of Survey Studies (CROSS)

(Sharma, A., et al., *A Consensus-Based Checklist for Reporting survey Studies (CROSS).* J Gen Intern Med, 2021. **36 (29)**: 79-87)

Section/topic	Item	Item description	Reported on page #
Title and abstract			
Title and abstract	1a	State the word "survey" along with a commonly used term in title or abstract to introduce the study's design.	1
	1b	Provide an informative summary in the abstract, covering background, objectives, methods, findings/results, interpretation/discussion, and conclusions.	2
Introduction			
Background	2	Provide a background about the rationale of study, what has been previously done, and why this survey is needed.	4 Add.file 1
Purpose/aim	3	Identify specific purposes, aims, goals, or objectives of the study.	4
Methods			
Study design	4	Specify the study design in the methods section with a commonly used term (e.g., cross-sectional or longitudinal).	4/12 Add.file 1
Data collection methods	5a	Describe the questionnaire (e.g., number of sections, number of questions, number and names of instruments used).	Add. file 2
	5b	Describe all questionnaire instruments that were used in the survey to measure particular concepts. Report target population, reported validity and reliability information, scoring/classification procedure, and reference links (if any).	4/5
	5c	Provide information on pretesting of the questionnaire, if performed (in the article or in an online supplement). Report the method of pretesting, number of times questionnaire was pre-tested, number and demographics of participants used for pretesting, and the level of similarity of demographics between pre-testing participants and sample population.	Add. file 1
	5d	Questionnaire if possible, should be fully provided (in the article, or as appendices or as an online supplement).	Add. file 2
Sample characteristics	6a	Describe the study population (i.e., background, locations, eligibility criteria for participant inclusion in survey, exclusion criteria).	
	6b	Describe the sampling techniques used (e.g., single stage or multistage sampling, simple random sampling, stratified sampling, cluster sampling, convenience sampling). Specify the locations of sample participants whenever clustered sampling was applied.	4

	6c	Provide information on sample size, along with details of sample size calculation.	6
	6d	Describe how representative the sample is of the study population (or target population if possible), particularly for population-based surveys.	Add.file 4
Survey administration	7a	Provide information on modes of questionnaire administration, including the type and number of contacts, the location where the survey was conducted (e.g., outpatient room or by use of online tools, such as SurveyMonkey).	5
	7b	Provide information of survey's time frame, such as periods of recruitment, exposure, and follow-up days.	4
	7c	Provide information on the entry process: –>For non-web-based surveys, provide approaches to minimize human error in data entry. –>For web-based surveys, provide approaches to prevent "multiple participation" of participants.	5
Study preparation	8	Describe any preparation process before conducting the survey (e.g., interviewers' training process, advertising the survey).	Add.file 1
Ethical considerations	9a	Provide information on ethical approval for the survey if obtained, including informed consent, institutional review board [IRB] approval, Helsinki declaration, and good clinical practice [GCP] declaration (as appropriate).	3
	9b	Provide information about survey anonymity and confidentiality and describe what mechanisms were used to protect unauthorized access.	3
Statistical analysis	10a	Describe statistical methods and analytical approach. Report the statistical software that was used for data analysis.	6 Add.file 3
	10b	Report any modification of variables used in the analysis, along with reference (if available).	Add.file 3
	10c	Report details about how missing data was handled. Include rate of missing items, missing data mechanism (i.e., missing completely at random [MCAR], missing at random [MAR] or missing not at random [MNAR]) and methods used to deal with missing data (e.g., multiple imputation).	6 Add.file 3
	10d	State how non-response error was addressed.	6 Add.file 3
	10e	For longitudinal surveys, state how loss to follow-up was addressed.	NA
	10f	Indicate whether any methods such as weighting of items or propensity scores have been used to adjust for non-representativeness of the sample.	NA
	10g	Describe any sensitivity analysis conducted.	Add.file 3 Add.file 4

Results			
Respondent characteristics	11a	Report numbers of individuals at each stage of the study. Consider using a flow diagram, if possible.	6/7
	11b	Provide reasons for non-participation at each stage, if possible.	7
	11c	Report response rate, present the definition of response rate or the formula used to calculate response rate.	6/7
	11d	Provide information to define how unique visitors are determined. Report number of unique visitors along with relevant proportions (e.g., view proportion, participation proportion, completion proportion).	7
Descriptive results	12	Provide characteristics of study participants, as well as information on potential confounders and assessed outcomes.	7
Main findings	13a	Give unadjusted estimates and, if applicable, confounder-adjusted estimates along with 95% confidence intervals and p-values.	8/10 Add.file 4
	13b	For multivariable analysis, provide information on the model building process, model fit statistics, and model assumptions (as appropriate).	Add.file 3 Add.file 4
	13c	Provide details about any sensitivity analysis performed. If there are considerable amount of missing data, report sensitivity analyses comparing the results of complete cases with that of the imputed dataset (if possible).	Add.file 4
Discussion			
Limitations	14	Discuss the limitations of the study, considering sources of potential biases and imprecisions, such as non-representativeness of sample, study design, important uncontrolled confounders.	13 Add.file 4
Interpretations	15	Give a cautious overall interpretation of results, based on potential biases and imprecisions and suggest areas for future research.	12/13/14
Generalizability	16	Discuss the external validity of the results.	13/14
Other sections			
Role of funding source	17	State whether any funding organization has had any roles in the survey's design, implementation, and analysis.	3
Conflict of interest	18	Declare any potential conflict of interest.	3
Acknowledgements	19	Provide names of organizations/persons that are acknowledged along with their contribution to the research.	3

GRIPP2 short form

(Staniszewska, S., et al., *GRIPP2 reporting checklists: tools to improve reporting of patient and public involvement in research.* BMJ, 2017. **358**: p. j3453)

Section and topic	**Item**	**Reported on page No**
1: Aim	Report the aim of PPI in the study	3 / Add.file 1
2: Methods	Provide a clear description of the methods used for PPI in the study	3/ 5 / Add.file 1
3: Study results	Outcomes—Report the results of PPI in the study, including both positive and negative outcomes	Add.file 1
4: Discussions and conclusions	Outcomes—Comment on the extent to which PPI influenced the study overall. Describe positive and negative effects	3 / Add.file 1
5: Reflections / critical perspective	Comment critically on the study, reflecting on the things that went well and those that did not, so others can learn from this experience	NA
PPI=patient and public involvement		

2. Questionnaire Development and Testing

For the purpose of this study, "old" was defined as age ≥ 67 years (retirement age in Norway) and "very old" was defined as age ≥ 80 years.

Item generation - mapping review (January – September 2019)

Publications addressing very old patients' treatment preferences were manually identified.

Additionally, we conducted the following literature search on proxy accuracy:

	Narrative	Search terms
P – Patient, **Problem or Population**	Surrogate statements	**proxy**, informant, **surrogate**, statement, prediction
I – Intervention	Family conference Structured discussion Advanced directives	
C – **Comparison, control or comparator**	Patients' preferences regarding treatment intensity and end-of-life care Subgroup: old, very old, incapacitated patients	**patient**, incapacitated, elderly, old, very old **preferences**, decision, intensive care, life-sustaining therapy, end-of-life
O – Outcome(s)	Accuracy Confidence Projections	accuracy, concordance

eTable 2.1: PICO process

Study selection:

Search results (June 9, 2019): PubMed 64, Embase 440, Cochrane 0, Cinahl 0

– duplicates (22)
– excluded screening title (11)
– conference abstracts (7)
– excluded screening abstract (49)
+ added cross-references (13)
– excluded after full text
    review articles (3)
    reporting same cohort (3)
    not reporting data on accuracy (3)

Included studies: 19

First author Year Country	N (pairs)	Age (subject/ proxy)	Setting	Study design	Domain of preferences	Accuracy	Other findings
Uhlmann 1998 USA [1]	90/ 105	74/69 74/42	Old outpatients ≥ 1 chronic disease	Multi centre Cross-sectional cohort (spouse / physician)	CPR / CPR + MV (hypothetical scenarios)	Mostly no better than chance alone In "current heath" scenario 82% (physicians)	Under-treatment error (physicians) Over-treatment error (spouses) High confidence
Seckler 1991 USA [2]	70	78/-	Old outpatients	Single centre Cross-sectional cohort (spouse / physician)	CPR (current health and severe cognitive impairment scenario)	No better than chance (physicians) Poor (self-designated proxy)	Under-treatment error (physicians) Over-treatment error (spouses) High confidence
Fagerlin (1) 1992 USA [3]	60	47/20	Healthy volunteers	Single centre Longitudinal cohort + intervention	Treatment intensity End-of-life decisions (hypothetical scenarios)	Modest No effect of intervention	Over-treatment error Strong evidence of assumed similarity
Fagerlin (2) 1992 USA [3]	361	73/62	Outpatients			Modest No effect of intervention	Over-treatment error Strong evidence of assumed similarity
Hare 1992 USA [4]	50	44/41	Outpatients	Cross-sectional cohort	Treatment intensity End-of-life decisions (hypothetical scenarios)	No better than chance	High confidence Over-treatment error
Layde 1995 USA [5]	1226	-/-	Seriously ill inpatients, est. 50% 6-month survival	Multi centre Cross-sectional cohort (SUPPORT)	CPR / DNR	Crude agreement 74%	Over-treatment error, improving towards the end of life No factors associated with concordance identified
Libbus 1995 USA [6]	30	58/52	Outpatients ≥ 1 chronic disease	Single centre Cross- sectional cohort	Treatment intensity End-of-life decisions (1 scenario, old patient PVS)	Crude agreement 60-77%	Over-treatment error Intermediate confidence Prior experience without effect
Matheis-Kraft 1997 USA [7]	60	79/-	Old women, inpatients and care facilities	Multi centre RCT	Treatment intensity End-of-life decisions (hypothetical scenarios)	No to poor agreement beyond chance, slightly better in study group, but not significant	Not reported
Mattimore 1997 USA [8]	2418	62/-	Est. 50% 6-month survival	Cross-sectional cohort	Permanent nursing home residency	Poor (both for surrogates and physicians)	Under-treatment error
Marbella 1998 USA [9]	717	64/-	Est. 50% 6-month survival	Multi centre Longitudinal cohort + intervention	Treatment intensity End-of-life decisions (hypothetical scenarios)	Modest to good, improving over time, but not by intervention	Agreement inversely correlated age
Sulmasy 1998 USA [10]	300	60/55	Est. 50% 2-years survival	Multi centre Cross-sectional cohort	Treatment intensity End-of-life decisions (hypothetical scenarios)	Poor to fair Association with various patient / proxy factors (ie. having discussed)	Over-treatment error, No corr. with age
Principe-Rodriguez 1999 Puerto Rico [11]	12	60/-	Inpatients, limited life expectancy	Single centre Cross- sectional cohort	CPR, organ support, End-of-life decisions	poor	Under-treatment error (not significant, small sample size)

Ditto 2001 USA [12]	401	73/63	Old outpatients	Multi Centre RCT	Treatment intensity End-of-life decisions (hypothetical scenarios)	High in current health scenario Moderate in all illness scenarios, no effect of interventions (2 types of AD +/- semi-structured discussion)	High mutual confidence Intervention improved perceived AD benefits and comfort Overtreatment-/ undertreatment ratio 2:1 -3:1
Briggs 2001 USA [13]	27	69/50	Inpatients, chronic single organ failure, limited life expectancy	Single centre Longitudinal cohort, intervention	Treatment intensity End-of-life decisions (hypothetical scenarios)	moderate	Moderate similarity High level of assumed similarity
Engelberg 2005 USA [14]	96	71/57	Hospice, mixed in-/outpatients, est. survival > 2 weeks	Multi centre Cross-sectional cohort	Preferences regarding dying and death	Variable agreement Good for 8/30 items Association with having discussed and higher income	Higher agreement on functional status and symptom burden No corr. with age
Volandes 2009 USA [15]	14	83/68	Geriatric outpatients, ≥ 65 years	Multi centre RCT (narrative +/- video)	CPR, organ support, End-of-life decisions In dementia scenario	33% increasing to 100% after intervention	
Song 2001 USA [16]	17	53/46	Outpatients, end-stage CKD, dialysis	Sigle centre RCT (ACP interview)	CPR, organ support, End-of-life decisions	Moderate congruence, improving to good after intervention	Over-treatment error
Bryant 2013 USA [17]	200	46/47	ED, ≥18 years, normal mental status, stable vitals	Single centre, cross-sectional cohort	Preferences regarding acute stroke treatment and clinical trial consent	Poor agreement, clinical treatment preference shows better agreement than consent to trial	High confidence
McDade-Montez 2013 USA [18]	197	32	Newlywed couples	Population sample Cross-sectional cohort	Treatment intensity End-of-life decisions (hypothetical scenarios)	Moderate agreement	High impact of personal preferences on proxy ratings (=assumed similarity)
Liu 2017 Taiwan [19]	1049 1901	60/48 60/50	Inpatients, advanced cancer	Single centre, 2 separate cross-sectional cohorts	CPR, organ support, End-of-life decisions	Poor to fair, significantly lower 10 years later	Over-treatment error

eTable 2.2: PICO search results. CPR=cardiopulmonary resuscitation, MV=mechanical ventilation, PVS=persistent vegetative state, RCT=randomized controlled trial, AD=advance directive, CKD=chronic kidney disease, ACP=advance care planning, ED=emergency department

Existing evidence - summarized findings:

- Very old patient's life sustaining treatment (LST) preferences:

Research regarding LST preferences conducted on patient populations with very limited life expectancy due to cancer or other chronic illness, show large variations across countries, cultures, populations, and individuals [20]. Little evidence exists regarding very old people with stable health who have limited life expectancy merely because they approach the final chapter of their lives. Two recent studies from France have explored this issue, showing that at least a moderate proportion (30-60%) of independent individuals above the age of 80 would refuse life-sustaining treatment interventions in case of acute life-threatening illness when being asked in a hypothetical situation [21]. A smaller, but still relevant proportion (14%) of very old patients who are asked about their preferences in the emergency room chose to refrain from ICU admission [22]. Whether this difference is due to a reference shift of values and expectations under the experience of acute illness, or a matter of chance due to small numbers, is unknown. Very little research has been conducted into the stability of patients' preferences regarding LST, and consequently estimates remain controversial [23, 24].

- Family members' accuracy to predict patients' LST preferences:

Numerous studies have aimed to quantify the accuracy of proxy statements regarding LST. Most studies were conducted in the USA 15-20 years ago, and showed poor to modest accuracy [25, 26]. Overtreatment errors (i.e. the proxy would choose LST, while the patient would refuse) and errors due to assumed similarity (i.e. the proxy is more likely to decide based on his / her own preferences rather than on true knowledge of the patient's preferences) appear to be frequent [3, 13, 18]. There is probably higher agreement when assessing observable, behavioural domains like functional status, or quality of life than in actual decision-making [27]. Some studies show high confidence in proxy decisions, both on the patients' and on the proxies' side, despite low proxy accuracy [1, 4, 12, 17]. Factors influencing proxy accuracy (i.e. age, timing, proxy-patient relationship, expected burden of treatment, likely outcome) and interventions to enhance proxy accuracy (i.e. advanced directives, family conferences, structured educational interviews) have been studied with conflicting results [9, 12, 25].

The validity of the existing evidence regarding very old patients' LST preferences and related proxy accuracy is limited by several factors:

- Most studies have used hypothetical scenarios to explore preferences regarding LST. In these studies, comprehension of the scenarios posed, and the consequences of the choices made are important and likely impact decision-making. Moreover, both patient preferences and proxy accuracy may change over time or with exposure to critical health-related events. We did not find any studies exploring the stability of proxy accuracy over time.

- None of the published scenarios address ICU admission in advanced age.

- Most studies have been conducted in the US, where uncertainty is dealt with in a different way than in Northern Europe. In the US, if a patient does not refuse treatment either personally or by a designated surrogate, the clinical default option is to provide treatment. This clinical default has affected the interpretation of the findings of several studies regarding proxy accuracy. For example, when dichotomizing Likert scales the "don't know" answers have been analysed together with the "do want treatment" answers in studies emanating from the US. Since it is not possible to predict individuals' preferences, where uncertainty exists regarding his / her own preference, these answers should have been reported and analysed separately [28].

- There are several ethical concerns with regard to the substituted judgement standard [29–31]. Even though statements by family members may have limited value as a "decision tool", ICU family conferences in process of decision-making may not be reduced to surrogate evidence alone.

Notwithstanding the normative value of ICU family conferences in a Norwegian context has not been elaborated yet.

• Large cultural and healthcare context differences (i.e. financing of health care provision, level of trust, medico-legal precautions, frequency of advanced directives, substituted judgment standards, place of death, ICU involvement at the time of death, frequency of LST limitations before ICU death) between the USA and Norway may limit the external validity of the existing evidence both regarding very old patients LST preferences and proxy accuracy.

Based on the findings of the literature review and discussions within the study group we constructed pairs of questionnaires addressing ICU admission preference in hypothetical events of acute critical illness in advanced age. eTable 2.3 summarizes the four predefined questionnaire development steps.

	Focus Group Interviews	**Pre-Test**	**Pilot-Test Respondent Group Sessions**	**Sensibility Test**
Timeframe	January 2020	February – March 2020	May – June 2021	August – September 2021
N (sample)	9 professionals 13 laymen	20 pairs (convenience)	20 pairs (non-probability)	20 pairs (non-probability)
Response rate		45%	70%	65%
Purpose / Questions addressed	Item generation Face validity Ethical issues	Feasibility Data dispersion Ethical issues	Comprehension Flow Salience Acceptability Administrative ease Time to complete	Completeness Appropriateness Suitability
Instrument version	1	1	2	3

e.Table 2.3: Questionnaire development - milestones

Face / Content validity (January 2020)*:*

The first draft of the questionnaires was evaluated by focus groups consisting of 9 health care professionals (4 senior ICU consultants, 2 junior anesthetists, 2 ICU nurse specialists, 1 research nurse, 2 geriatricians, 1 public health specialist) and 6 laymen (2 very old adults, 4 possible proxy decision makers, of those 2 with higher education, but no health care professionals).

Pre-testing: (February/March 2020):

We pre-tested a preliminary version of the questionnaire containing only one vignette and no questions regarding demographic or health-related information among 20 grandparent/parent pairs of medical students. Completed questionnaires were returned anonymously by mail. The response rate was 45% with eight complete pairs.

We assessed whether the case vignette was feasible, and produced responses with sufficient data dispersion to assess proxy accuracy and factors that might affect the choices made.

Very old adult's preference	N	Son's / daughter's prediction			
		Wants ICU admission	Does not want ICU admission	Wants the doctor to decide	Unsure about the very old participant's preference
Wants ICU admission	3	1	1	1	
Does not want ICU admission	1		1		
The doctor should decide	4	1		2	1
Unsure	0				

eTable2. 4: Pre-test results

We reduced and adjusted the "uncertain" and "the doctor should decide" response categories to "wishing to not engage in the decision" after the pre-test in order to more precisely match the Norwegian regulations, where patient preferences are an important information to the medical decision process, but the ultimate decisional authority remains with the treating physician(s). Additional space for free-text comments was provided, and the respondents were asked to elaborate the reason for their preference. Moreover, we abstracted confidence into the choices made as an independent item and asked the participant to indicate for each scenario how certain they feel about their answer regarding treatment preference on a five-point Likert-like scale.

The pre-test also revealed cases of assumed similarity, where the son/daughter apparently decided according to his/her own preferences, which were different from the preferences of their very old mother / father. None of the respondents commented on unpleasant feelings when confronted with questions regarding life-threatening illness, but several both very old persons and their adult children volunteered that they perceived the topic as relevant, important, and not sufficiently addressed yet.

An interesting observation from the pre-test was that respondents who opted for their physician to decide had less or no free text comments, compared to respondents who made a clear choice.

Pilot testing (May - June 2021): We assessed the penultimate versions of the questionnaires (one for the very old person, and one for the potential proxy) for face and content validity once again, and conducted a pilot study with regards to relevance, flow, arrangement and time to complete. The Regional Committee for Medical Research Ethics Western Norway, REK Vest, assessed this pilot project, and waived approval (Project ID 276403, date 25.05.2021). We recruited 18 pairs of very old people and their next-of-kin (the most likely proxy in case of an acute health related event) through user representatives, senior interest organizations, the volunteer service and the retired employee association at Haukeland University Hospital and through advertisements in public spaces and social media. We aimed for balance regarding gender, educational and cultural background. Potential participants were informed about the project by phone, and upon verbal consent, they received the questionnaire test package by mail. The package contained an information letter, the respective questionnaire (very old person / next-of-kin, version 2), and an evaluation sheet addressing understanding and processing of the questionnaire as well as an invitation to participate in a group interview. Fourteen very old and thirteen next-of-kin participants returned the completed questionnaires, and nine very old and four next-of-kin respondents participated in group interviews.

	Very old pilot participants	Next-of-kin pilot participants
N (total)	14	13 (5 spouses, 5 daughters, 2 sons, 1 friend)
N (male / female)	5 / 9	3 / 10
Age (median, SD, range) [yrs.]	84.5 / 4 / 80-94	63 / 14 / 52-88
Higher education	6	9
Born outside Norway	1 (Denmark)	1 (Sweden)

eTable 2.5: Demographics of the pilot population

All interview participants provided signed informed consent. They were asked to complete the questionnaire and the evaluation sheet before the interview. The participants could keep the questionnaire and the evaluation sheet as an aid memoire during the interview but were encouraged to not change their written answers. The evaluation forms did not contain any personal identifiable data and were collected after the interview.

The interviews took place at Haukeland University Hospital and followed a standardized template. They were not audiotaped. Two investigators met 3-6 participants. The group interviews were chaired by the principal investigator (GLS), assisted by a co-investigator (BÅS), who also wrote minutes. None of the interview participants expressed emotional distress or required comfort, and no further ethical concerns were revealed during pilot testing and group interviews.

Time to complete the questionnaire varied substantially, with a mean time of 60 minutes (SD 40 minutes, range 13-150 minutes). None of the pilot participants found the questionnaire too long, but several expressed, that the length was in keeping with the complexity and seriousness of the topic addressed. Most respondents did not identify any difficult questions (22/25) and no respondents were disturbed or upset by any of the questions or the topic in itself. Seven answers were missing, and six ambiguous answers were given. The missing and ambiguous answers were equally distributed among very old and nest-of-kin respondents and across the whole questionnaire. 20 of 25 returned questionnaires were answered completely and unambiguously. 21 of 25 respondents provided free-text comments, among them 15 were rated as informative and elaborate.

Statement	Response mean	Response range	Other observations
The information about intensive care was useful	4.0	3-5	
The number of scenarios was appropriate	2.7	1-4	Marked difference between respondents: respondents with a clear preference fed back on too many and too similar scenarios, while respondents with varying preference found them appropriate
There were too many similar scenarios	3.2	1-5	

eTable 2.6: Results of the pilot testing (5 point Likert-like scale, 1=strongly disagree, 5=strongly agree)

The content, wording and layout of the questionnaire and cover letter was revised according to the data from the evaluation sheets and a synthesis of the group interviews. The number of scenarios was reduced to three, and more detailed instructions were provided after each question.

Clinical sensibility testing (August – September 2021): The Regional Committee for Medical Research Ethics Western Norway, REK Vest, also waived approval for sensibility testing of the survey tool (Project ID 276403, date 25.05.2021).

We performed clinical sensibility testing of the penultimate versions of the questionnaires with an adaptation of the template published by Burns et al., 2008 [32] on a similar group of both very old and proxy volunteers (N=23).

Statement	Response median	Response range
Many questions are unsuitable or inappropriate	2.0	1-3
The questions address important aspects regarding intensive care of vey old people	4.2	3-5
Important questions regarding intensive care of very old people are missing	3.2*	1-4
The survey is suitable to elicit old people's values and wishes regarding intensive care	4.1	3-5

eTable 2.7: Results of the clinical sensibility testing (5 point Likert-like scale, 1=strongly disagree, 5=strongly agree)

* None of the respondents made any specific suggestion regarding further questions to be addressed.

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3. Questionnaire Formatting

Survey construction:

eTable 3.1 summarizes the structure of the questionnaires.

The questionnaire begins with a short summary of background information regarding intensive care in general and expected risks and benefits for very old patients in particular. The estimated quality of life regarding physical and cognitive function of ICU survivors aged ≥ 80 years is based on published data from Norway, Finland, the Netherlands and Canada [1–4], and a systematic review on cognitive impairment after intensive care [5].

In the following paragraphs, the participants are asked to make a treatment choice for each of three clinical scenarios. The very old person is asked only about his or her own preferences, while the proxy is asked to both indicate the likely wish of the very old person, and his or her own preferences. Three response options are provided: wishing admission to intensive care, not wishing admission to intensive care, and wishing to not engage in the decision.

	Questionnaire for the very old person (potential patient)		Questionnaire for the next-of-kin (potential proxy)	
Cover (p.1) / instructions / contact information (p.2) Background information (p.3)				
	Paragraph no.	Questions	Paragraph no.	Questions
Scenario 1–3	1-3	3 x 3	1-3	3 x 6
Family involvement in medical decision-making	4	5	4	3
Experiences with intensive care and advanced care planning	5	5	5	6
Demographics	6	7	8	7
Health	7	5	6	5
Frailty / EuroQuol 5D-5L	8	6	7	6
Re-contact permission	9	1	9	1
Comments	10	1	10	1
Pages / questions (total)	15 / 39		18 / 47	

eTable 3.1: questionnaire structure

The vignettes for the scenarios were randomly chosen from 20 hypothetical patient histories of acute life-threatening illness causing a higher degree of acute organ failure (equaling > 2 SOFA points) [6].

All scenarios are constructed in a similar manner, containing three paragraphs, following the same template:

1. The vignette, consisting of 2-3 sentences summarizing the current diagnosis and acute organ failure. The type and frequency of diagnoses is representative for ICU admission diagnosis in very old patients in Norway and Europe (eTable 3.2). For each questionnaire, there are three vignettes – two framed as a history of a male patient, and one framed as a female patient or vice versa. The vignettes are presented in a random order.
2. Three to four sentences describing dichotomous therapeutic options as either intensive care with sedation requirements and some kind of invasive organ support or ward care with conservative treatment and the possibility for symptom alleviation.
3. Three sentences regarding the consequences of the choices. In 50% of the questionnaires, the expected outcome is framed as mortality, and in the remaining 50%, it is framed as survival. To avoid confusion the same framing is used for all three vignettes in each questionnaire. The survival outcome estimates are based on short- and long-term outcome data from the VIP-2 study dataset (eTable 3.2), and they are identical for all vignettes (approx. 80% ICU survival and < 50% long term survival).

	VIP-2 (May 2018-May 2019)				**NIR (May 2018-May 2019)**			
ICU admission diagnosis	N (%)	Survival (%)			N (%)	Survival (%)		
		ICU	30 d	6 m		ICU	30 d	1 y
Overall	3921 (100)	73	75	40	3069 (100)	86	67	47
ARF	941 (24)	75	76	34	951 (31)	84		
Sepsis	392 (14)	68	70	33	338 (11)	86		
Shock	540 (14)	72	71	34	737 (24)	88		
Acute surgery	541 (14)	80	82	45	614 (23)	86		
Trauma	233 (6)	69	70	30	215 (7)	85		
Neuro	190 (5)	68	68	30	153 (5)	87		

eTable 3.2: Main ICU admission diagnosis and survival of very old ICU patients in Europe (VIP-2 data set, personal communication, Hans Flaatten, April 2021) and in Norway (Norwegian Intensive Care Registry, personal communication, Reidar Kvåle, April 2021)

The questionnaires also includes observed variables that may influence treatment preferences and proxy accuracy including: demographics, education, religion, previous experience with and / or communication about serious illness, comorbidity, polypharmacy, frailty (Clinical Frailty Scale, version 2, [7]), quality of life (EuroQol-5D-5L, registration ID: 30864, [8]) and projection (i.e. the proxy's own treatment preferences, [9, 10]).

Additionally, space for the following free-text comments is provided:

- Elaborating the treatment choices made after each scenario
- Expectations regarding family members contribution into the decisional process
- General comments

To enable for a longitudinal follow-up survey aiming at assessing preference and proxy accuracy stability over time, the respondents are asked to provide their name and address at the end of the questionnaire. They are advised that providing name and address for follow-up is voluntary, about their right to withdraw at any time and that taking part in a longitudinal cohort will affect data handling, i.e. data will be stored pseudonymously instead of anonymously.

The longitudinal follow-up will be a separate study with revised questionnaires and revised protocol according to the findings of the cross-sectional study.

The layout of the questionnaire was created in compliance with the guidelines for visual design of paper questionnaires by Statistics Norway [11].

All questionnaires had a unique participant / dyad identifier. The English translation of the provided examples is not validated.

References:

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4. Statistical analyses

We report basic descriptive statistics for the survey participants – counts, percentages, means and standard deviations – both for the overall cohort and stratified by ICU admission preference.

To estimate the participants' preferences regarding life-sustaining treatment, we report the marginal proportion of responses in each category ('wants ICU admission', 'does not want ICU admission', 'does not want to engage in the decision'), along with 95% confidence intervals (CIs). To take into account the dependence between the responses for the three scenarios (e.g., the answer to scenario 1 and 2 for a single patient is more likely to be the same than if the two answers came from two *different* patients), all proportions were calculated using Generalized Estimating Equation (GEE) models with an 'exchangeable' correlation structure.

Sample size calculations done before data collection showed that with responses from 200 respondents, we could estimate the preference proportions with an absolute margin of error less than 7%, based on 95% confidence intervals, which we deemed sufficient. For example, if 50% of the respondents wanted ICU admission, the corresponding 95% confidence interval would be approx. 43%–57%.

To investigate factors associated with the participants' ICU admission preference, we fitted mixed-effects logistic models with 'wanting ICU admission' as the outcome. Explanatory variables included the experimental framing effects (vignette gender and mortality/survival) and demographic and health-related characteristics of the very old respondents. Vignette (there were twenty possible vignettes) was included as a random intercept. All variables included in the model were pre-specified before data collection, except CPS (Comorbidity Polypharmacy Score), as a measure of comorbidity, and health care professional background. These two variables were included post-hoc because we thought they might *potentially* be important predictors of the patient preferences.

Sample size calculations for the logistic models showed that we would only have statistical power to detect large effects. For example, the effect of a binary predictor with a prevalence of 50% (e.g., the survival vs. mortality framing predictor) had to correspond to an odds ratio (OR) of at least 2.33 (outcome 50% vs. 70%) for the power to be 80% or greater (with 200 participants). For continuous predictors, an OR of 1.5 for the event rate at one standard deviation above the mean compared to the event rate at the mean, would be sufficient.

The above calculations were based on simple logistic regression, i.e., assuming that only *one* preference (from one patient scenario) was expressed for each respondent. Initially, we were hoping to use mixed-effects models to include all *three* scenarios for each respondent in the same model, thereby increasing the statistical power, i.e., making it possible to detect lower odds ratios. We would take into account the dependence between the three scenarios responses from the same respondent by having a random intercept for 'respondent' (in addition to a random intercept for 'scenarios') in the model.

However, this model gave confusing coefficient estimates. (Basically, the OR estimates were unrealistically large, e.g., an estimated OR > 26 for the effect of male respondent gender. The reason was that all male respondents were predicted to have a very small 'respondent' random intercept, which would be compensated by the large OR.) We believe this problem would be reduced or eliminated if we would had a few more scenarios for each respondent, as this would be make it easier to estimate the 'respondent' effects.

While we do think the model that includes three scenarios for each respondent is technically *valid* (e.g., low *P*-values do indicate real effects), we believe the coefficient estimates would be confusing for the reader, so in our main analysis, we only report the results for the *first* scenario. (This was scenario chosen because the response to the first scenario would in theory not be influenced by the responses to the subsequent scenarios, while the response on the second and third scenarios might influenced by the respondent's initial response.) However, we also report the results for similar models for the second and third scenario, and for all three scenarios.

There were some missing data. To increase precision and reduce bias in estimates caused by missing data, we used multiple imputation for the main analysis (scenario 1). In the imputation model, the outcome variable and explanatory variables from the regression model were included along with the variables 'education' (four levels) and 'admitted to hospital within the previous 12 months' ('yes' vs. 'no'), which we thought would be able to predict the values of these variables or the probability of a variable having missing values.

The data were imputed using the mice function from the R 'mice' package, with 50 imputations, 30 iterations and otherwise default options. Depending on the variables imputed, this uses predictive mean matching (for continuous variables), logistic regression ('yes'/'no' variables), or polytomous regression (categorical variables). We report the results both from a complete-case analysis and from the multiple imputation analysis.

To assess the next of kins' ability to predict their family member's preference, we report the overall percentage agreement between the next of kins' proxy preference and the old patient's actual preference (*proxy accuracy*). We also report this stratified by the next of kins' proxy response. Similarly, we also report percentage agreement between the next of kins' proxy preference and their *own* preference (*assumed similarity*), and between the next of kins' own preference and the old patient's actual preference (*true similarity*). Estimates and CIs are as before based on GEE models.

To examine variables associated with 'correct prediction', we looked at the first scenrio and only at responses where the old respondent *had* a preference ('wants ICU admission' or 'does not want ICU admission'), the reasoning being that it is only reasonable to try to predict the preference if the respondent actually *has* a preference. The model fitted was a mixed-effects logistic regression model with vignette as random intercept.

All statistical models were fitted using R version 4.2.3. We used the R packages 'mice' version 3.16.0 (for multiple imputation), 'lme4' version 1.1-34 and 'glmmTMB' version 1.1.8 (for mixed-effects logistic models), and 'geepack' version 1.3.9 (for GEE models). Other analyses were performed using IBM SPSS Statistics for Windows version 29.0 or Microsoft Excel.

5. Additional data and analyses

A) Representativeness

	Study cohort	Reference population
Gender	52% (f); 48% (m)	≥ 80 yrs. (2023)*: 59% (f); 41% (m)
Marital status	Single: 6% Married / registered partner: 50% Widowed: 39% Separated/ divorced: 5%	≥ 80 yrs. (2023)* Single: 4% Married: 40% Widowed: 45% Separated / divorced: 10%
Religion	Christian: 78% Other religion: 1% No religion: 21%	membership / total population (2023)* Christian: 71% Other religion: 6% No religion: 23%
Educational level	Primary school: 20% Secondary school: 15% Vocational training / - college: 25% University: 39%	≥ 67 yrs. (2021)* Primary school: 24.8% Secondary school: 47.6% Vocational school: 2.5 % University: 25.2%
Healthcare professionals	17% (female 90%)	55-66 yrs. (2021)*: 18% (female 85%)
Comorbidities	Reported conditions: Diabetes 12% Cancer 25%	Prevalence ≥ 80 yrs. (2019)* Diabetes 11% Cancer (cumulative risk + survival): 30%
EQ VAS	72.0 ± 18.1 SD	67.7 ± 22.0 (n = 170)†

eTable 5.1: Representativeness of the study cohort compared to the target population
*Statistics Norway, www.ssb.no, accessed 30.03.2023
†Andersen FH, Flaatten H, Klepstad P, et al (2015):
Long-term survival and quality of life after intensive care for patients 80 years of age or older. Ann Intensive Care 5:53. https://doi.org/10.1186/s13613-015-0053-0 (n= 179, ≥ 80 yrs., Western Norway)

B) Factors affecting the odds of the very old respondents opting for ICU admission

	First scenario complete case analysis			First scenario with multiple imputation			Second scenario complete case analysis			Third scenario complete case analysis			All scenarios complete case analysis		
	OR	**95% CI**	***P*-value**	**OR**	**95% CI**	***P*-value**	**OR**	**95% CI**	***P*-value**	**OR**	**95% CI**	***P*-value**	**OR**	**95% CI**	***P*-value**
Experimental: Vignette framing															
Outcome															
Mortality	–	–		–	–		–	–		–	–		–	–	
Survival	1.76	0.82, 3.81	0.15	1.42	0.75, 2.71	0.28	1.93	0.88, 4.22	0.1	1.59	0.74, 3.43	0.24	4.82□	0.92, 25.4	0.06
Vignette gender															
Female	–	–		–	–		–	–		–	–		–	–	
Male	0.66	0.31, 1.43	0.30	1.06	0.55, 2.02	0.86	1.17	0.54, 2.53	0.69	1.43	0.64, 3.22	0.38	0.8	0.39, 1.64	0.55
Observed: Very old respondents' characteristics															
Age (years)															
	0.96	0.86, 1.06	0.41	0.94	0.86, 1.03	0.20	0.89	0.79, 0.99	0.04*	0.86	0.76, 0.96	0.008*	0.79	0.63, 0.99	0.04*
Respondent gender															
Female	–	–		–	–		–	–		–	–		–	–	
Male	2.29	0.96, 5.5	0.06	2.27	1.08, 4.78	0.03*	4.74	1.9, 11.8	<0.001*	4.51	1.76, 11.6	0.002*	26.3□	3.32, 209	0.002*
Marital status – living together with someone															
No	–	–		–	–		–	–		–	–		–	–	
Yes	0.79	0.33, 1.89	0.59	0.98	0.47, 2.02	0.95	1.38	0.6, 3.18	0.45	1.02	0.43, 2.44	0.96	1.16	0.2, 6.82	0.87
Being religious															
No	–	–		–	–		–	–		–	–		–	–	
Yes	2.39	0.89, 6.39	0.08	2.13	0.87, 5.20	0.10	2.56	0.96, 6.85	0.06	2.63	0.98, 7.04	0.06	9.71□	1.26, 75.1	0.03*
Health care professional background															
No	–	–		–	–		–	–		–	–		–	–	
Yes	0.69	0.21, 2.26	0.54	0.72	0.27, 1.95	0.52	1.04	0.31, 3.48	0.95	1.76	0.8, 3.86	0.96	0.88	0.09, 8.74	0.91
Comorbidity-polypharmacy score															
	1.01	0.9, 1.13	0.89	1.01	0.92, 1.11	0.79	1.08	0.96, 1.21	0.22	1.03	0.92, 1.16	0.63	1.13	0.88, 1.45	0.35
Clinical frailty scale															
	1.13	0.75, 1.71	0.56	1.17	0.82, 1.67	0.39	0.78	0.51, 1.21	0.27	1.39	0.9, 2.13	0.13	1.2	0.51, 2.82	0.68
Health realted quality of life (EuroQol-5D VAS)															
	1.00	0.97, 1.03	0.88	1.00	0.97, 1.02	0.72	0.99	0.96, 1.02	0.62	1.03	1.0, 1.07	0.07	1.02	0.96, 1.09	0.47
ICU experience – as patient or relative															
No	–	–		–	–		–	–		–	–		–	–	
Yes	2.71	1.23, 5.98	0.01*	2.15	1.08, 4.27	0.03*	1.76	0.80, 3.88	0.16	1.76	0.8, 3.86	0.16	8.39□	1.39, 50.8	0.02*

eTable 5.2: Mixed-effects logistic regression model for the two vignette-framing effects and very old respondents' characteristics on the odds of wanting ICU admission ('yes' vs. 'no'/'don't know')for the three scenarios separately, and across all scenarios. Missing values are handled by complete case analysis or multiple imputation.
CI = Confidence Interval, * significance level $p < 0.05$.
□ See supplemental material 4 for an explanation of the unrealistic high effects of age, gender, religion and ICU experience when including all three scenario answers in the analysis.

C) Additional data on respondent dyads' agreement

5.1. Response counts - cross tabulations

a. Very old respondent – next-of-kin proxy statement (proxy accuracy)

	The next-of-kin respondents' proxy statement			Total
The very old respondents' actual preference	*Opting for ICU admission*	*Opting against ICU admission*	*Not wishing to decide*	
Opting for ICU admission	110 (52%)	30 (23%)	14 (23%)	154
Opting against ICU admission	64 (30%)	79 60%)	26 (43%)	169
Not wishing to decide	39 (18%)	24 (18%)	21 (34%)	84
Total	213 (100%)	133 (100%)	61 (100%)	407

eTable 5.3: Next-of-kins' proxy statement vs. very old respondents' preference, ● = agreement, ● = the next of kin opts for higher treatment intensity, ● = the next of kin opts for lower treatment intensity

b. Next-of-kin proxy statement - next-of-kin own preference (assumed similarity)

	The next-of-kin respondents' proxy statement			Total
The next-of-kin respondents' own preference	*Opting for ICU admission*	*Opting against ICU admission*	*Not wishing to decide*	
Opting for ICU admission	188 (82%)	6 (4%)	20 (30%)	214
Opting against ICU admission	23 (10%)	132 (87%)	12 (18%)	167
Not wishing to decide	18 (8%)	14 (9%)	34 (52%)	66
Total	**229 (100%)**	**152 (100%)**	**66 (100%)**	**447**

eTable 5.4: Next of kin proxy statement vs. next of kins' own preference, ● = agreement

c. Conversation between the very old respondent and the next of kin on the topic in question prior to survey participation

"Have you had a conversation regarding treatment preferences in an event of critical illness, permanent dependency and / or the end of life?"		The next-of-kin's responses		
		No	Yes	Sum
The very old patients' responses	No	**56**	26	82
	Yes	17	**28**	45
Sum		73	54	127

eTable 5.5: Respondent dyads agreement on, whether they have had had a conversation regarding treatment preferences in an event of critical illness, permanent dependency and / or the end of life

5.2. Agreement with 95% CIs, stratified by respondent preferences

a. Very old respondent – next-of-kin proxy statement (proxy accuracy)

	% agreement			
	Estimate	95% CI		
The very old respondents' actual preference				
Opting for ICU admission	71%	60%	to	80%
Opting against ICU admission	45%	36%	to	55%
Not wishing to decide	21%	12%	to	36%
The next-of-kin respondents' proxy statement				
Opting for ICU admission	48%	39%	to	57%
Opting against ICU admission	60%	48%	to	70%
Not wishing to decide	25%	14%	to	40%

eTable 5.6: percentage agreement between very old respondents ICU admission preference and next-of-kins' proxy statement, stratified by the very old respondents' actual ICU admission preference and the next of kins' proxy statement. CI: Confidence Interval

b. Next-of-kin proxy statement - next-of-kin own preference (assumed similarity)

	% agreement			
	Estimate	95% CI		
The very old respondents' actual preference				
Opting for ICU admission	80%	70%	to	87%
Opting against ICU admission	78%	70%	to	84%
Not wishing to decide	85%	73%	to	92%
The next-of-kin respondents' proxy statement				
Opting for ICU admission	81%	72%	to	87%
Opting against ICU admission	84%	75%	to	91%
Not wishing to decide	47%	32%	to	62%
The next-of-kin respondents' own preference				
Opting for ICU admission	85%	77%	to	91%
Opting against ICU admission	78%	68%	to	85%
Not wishing to decide	51%	35%	to	66%

eTable 5.7: percentage agreement between the next of kins' own ICU admission preference and the next-of-kins' proxy statement, stratified by the very old respondents' actual ICU admission preference, the next of kins' proxy statement, and the next of kins' own ICU admission preference. CI: Confidence Interval

5.3. Factors affecting proxy accuracy

Variables		OR	95% CI	*P*-value
Very old respondent's ICU admission preferences				
	Yes	-	-	
	No	**0.14**	**0.04, 0.45**	**0.001***
Very old respondents' age		**0.81**	**0.67, 0.98**	**0.03***
Next-of-kin respondent's age		**1.03**	**0.94, 1.12**	**0.54**
Very old respondent's gender				
	Female	**-**	**-**	
	Male	**0.39**	**0.10, 1.59**	**0.19**
Next-of-kin respondent's gender				
	Female	**-**	**-**	
	Male	**0.54**	**0.12, 2.47**	**0.42**
Next of kin respondent's religion				
	Not religious	**-**	**-**	
	Religious	**1.06**	**0.26, 4.36**	**0.93**
Next-of-kin respondent's ICU experience				
	No	**-**	**-**	
	Yes	**2.40**	**0.63, 9.10**	**0.20**
"Have you [the next-of-kin-respondent] had a conversation with your very old family member regarding his / her treatment preferences in an event of severe illness, permanent dependency or at the end of life?				
	No	**-**	**-**	
	Yes	**0.96**	**0.27, 3.42**	**0.95**
Relationship within the respondent dyad				
	Married, registered partner	**-**	**-**	
	Parent - child	**3.34**	**0.23, 47.6**	**0.37**
	Other	**1.53**	**0.06, 41.0**	**0.80**
"How certain are you [the next-of-kin-respondent] that you state your very old family member's ICU admission preference correctly?"				**0.003***
	Very certain	**-**	**-**	
	Somewhat certain	**0.53**	**0.16, 1.74**	**0.29**
	Neither certain nor uncertain	**0.04**	**0.02, 0.25**	**< 0.001***
	Somewhat uncertain	**0.03**	**0.00, 0.26**	**0.002***
	Very uncertain	**0.00**	**0.00, –**	**1**

eTable 5.8: Mixed-effects logistic regression model for respondents' characteristics on the odds of predicting correct. CI: Confidence Interval, * significance level $p < 0.05$.

Comments:

It is challenging to create a regression model for factors affecting proxy accuracy. Fictional example:

- 90% of the very old respondents want to be admitted to ICU
- 70% of the next-of-kin respo0ndents think the very old respondent want to be admitted, but there is *no* real association with the very old respondent's actual preference

If we estimate the probability of agreement between proxy statements and the very old respondents' true preferences based on various explanatory variables, all variables associated with the probability of wanting admission will *seem* to be associated with the probability of *agreement*.

For example, if men are more likely than women predict 'opting for ICU admission', it will look like gender is a predictor of agreement. So, gender might look like a predictor of agreement even if men and women are equally good at predicting their very old family member's preference. And this spurious association will hold *even* if we were to pair the very old respondent's questionnaire with a *random* (i.e., not their own) proxy statement.

One solution could be to stratify by the very old respondents' responses resulting in small numbers (too few observations to conduct regression analyses). Alternatively, we can include, as done above, their responses as a covariate in the model (but this has stricter assumptions, namely that effect of the predictors is the same for all the very old respondents' answers).

Since we found a large effect of the next-of-kins' certainty in their proxy statement on the odds of predicting correct, we attempted to present this result in a simpler way. We calculated the agreement stratified by certainty and by the very old respondents' preference / the next of kins' proxy statement:

	Next-of-kin's certainty about the very old respondent's ICU admission preference	*n*	Agreement between next-of-kin's proxy statement and the very old respondent's true ICU admission preference Estimate**	95% CI		
Very old respondents' actual preference*						
Opting <u>for</u> ICU admission	Very certain	51	89%	71%	to	96%
	Somewhat certain	75	76%	61%	to	86%
	Neither certain nor uncertain	22	42%	22%	to	66%
	Somewhat uncertain	5	22%	3%	to	73%
	Very uncertain	3	0%	0%	to	0%
Opting <u>against</u> ICU admission	Very certain	42	48%	30%	to	67%
	Somewhat certain	100	45%	33%	to	57%
	Neither certain nor uncertain	20	41%	26%	to	59%
	Somewhat uncertain	14	26%	8%	to	58%
	Very uncertain	0	–	–	to	–
Next of kin's respndents' proxy statement*						
Opting <u>for</u> ICU admission	Very certain	62	70%	54%	to	82%
	Somewhat certain	93	56%	44%	to	68%
	Neither certain nor uncertain	18	49%	27%	to	72%
	Somewhat uncertain	6	25%	3%	to	78%
	Very uncertain	0	–	–	to	–
Opting <u>against</u> ICU admission	Very certain	29	85%	57%	to	96%
	Somewhat certain	62	78%	62%	to	88%
	Neither certain nor uncertain	15	54%	28%	to	77%
	Somewhat uncertain	7	50%	17%	to	83%
	Very uncertain	0	–	–		–

eTable 5.9: Proxy accuracy and next-of-kin respondent's certainty stratified by the very old respondents' ICU admission preferences and by the next-of-kin respondents' proxy statements. *n*: number of responses**; CI: confidence interval.

* Based only on scenarios where the patient expressed an opinion (admit / not admit).
** Each respondent had a response for 1–3 scenarios, and the estimate and CI listed is based on a GEE model that takes into account the dependence between multiple responses for the same respondent. This is the reason that the percentage agreement estimate is not necessarily a multiple of 1/*n*.

INTENSIVE CARE OF THE VERY OLD: WHAT DO THEY WISH FOR THEMSELVES?

UNIVERSITETET I BERGEN

HELSE BERGEN
Haukeland universitetssjukehus

Dear participant,

Thank you for your interest in this study. It aims at bringing forward knowledge about very old peoples' thoughts, attitudes and preferences regarding intensive care in the event of acute life-threatening illness. We also would like to know more about which role family members of very old patients have in situations when difficult medical decisions need to be made. Vi hope that better understanding in this field will improve very old patients' hospital stay when they are admitted with acute illness, so they to a larger degree receive the treatments they prefer and will benefit from.

On the next page you will find more information about intensive care in general and its implications for very old patients in particular.

The questionnaire consists of ten parts. It starts with three fictional patient histories. After each history you are asked to imagine that you are this patient and answer, whether you would prefer to be admitted to intensive care given you would be this patient with your background and your current health. All these patient histories have the common feature, that we have limited knowledge regarding the benefit of intensive care for very old patients. This implies, that the doctors will not be able to give strong advice, which treatment to choose, and different doctors may have different recommendations.

In part 4 of the questionnaire we ask whether you have a next-of-kin whom you regard the right person to receive information and advise the medical team regarding your preferences in an event of acute critical illness. We ask also about your thoughts regarding family involvement, when medical decisions need to be made. Part 5 addresses your experience with acute severe illness, and whether you have given advance directives or communicated your preferences to somebody already. In parts 6 to 8 we request some general information about you, like age, gender and education, as well as information regarding your health, fitness and quality of life. In part 9 there is space for your comments. Finally (part 10) you are asked to provide contact details, so we can send you a similar questionnaire in 1-2 years.

You don't need to answer questions you find unpleasant or not appropriate. If you feel in need for help or comfort when thinking about serious illness, you may call 55 97 68 50.
A health secretary will answer your call and establish contact with the principal investigator of this project Dr. Leonie Schwarz. Or you can write a few words and ask us to make contact by e-mail: gabriele.leonie.schwarz@helse-bergen.no.

Background information for the project:

- Intensive care means getting admitted to a hospital unit where advanced life-saving treatment is given. A lot of medical technical equipment is used for this purpose, like breathing machines, pumps and other devices. Many patients in an intensive care unit have to be put to sleep (artificial coma).
- Intensive care is demanding both physically, emotionally and mentally. Very old patients who survive intensive care often lose a lot of weight, and are subsequently weak. The majority is also confused for a while under or after intensive care. Usually patients are in need of rehabilitation and training for a longer period of time after discharge.
- The alternative to intensive care is treatment and care on a regular hospital ward. The therapies given there are less invasive, and the patient can be awake. Also here, good pain control and comfort care can be provided. Usually it is easier to visit the patient on a regular ward, and the patient is allowed more privacy and more personal items than on the intensive care ward.
- Even though intensive care is provided with an intention to save life, it is not certain that the chances of survival *with a good outcome* are better with intensive care compared to regular ward care in many acute conditions that may affect the oldest patients.
- Less than half of all patients who received intensive care at an age of 80 years or more in Norway are alive after one year. Many of them experience persistently reduced physical and mental function, and need more assistance in their every-day life than before. Notwithstanding, most very old survivors of intensive care report on satisfying quality of life.
- In an event of acute, life threatening illness it is often impossible for the patient to participate in shared decision-making, while decisions regularly need to be made under time constraints and at high stakes. In these cases usually the patient's next-of-kin is asked to inform about the patients presumed treatment preferences.
- We know little about very old people's treatment preferences in an event of acute life-threatening illness, and how they wish decisions regarding invasive medical treatments should be made, when they are not capable to consent themselves.
- Furthermore, we do not know enough regarding the family members' role in these difficult decision processes, and we therefore aim to shed light into the whole interaction between patient, family members and health care professionals, when the choice is either to provide or to refrain from intensive care.

Patient history 1:

A man in his 80s underwent a small operation for a kidney stone attack. During the following day he became acutely unwell, and a serious bloodstream infection was diagnosed with impaired function of several vital organs. The patient immediately received intravenous antibiotics (given right into a blood vessel). However, both kidney function and lung function deteriorated, and he became confused.

The treating physicians discuss now whether to transfer the patient to the intensive care unit for organ support with a breathing machine and kidney replacement with a dialysis machine. In order to provide this treatment she will require to be put into drug-induced coma for some days. Alternatively, she can stay on the regular hospital ward, and continue current treatment. There she can also receive medications to alleviate pain, breathlessness and other burdensome symptoms if needed.

Approximately four of five patients in this situation survive intensive care, and a few might also survive without intensive care. Less than a half of all intensive care survivors are alive after 6-12 month. Both physical and mental function is permanently reduced among many survivors.

1.1 Imagine now that you are this patient. What would you wish for yourself?
Check the ONE answer that suits you best:

- ❑ I would wish to be admitted to intensive care
- ❑ I would not wish to be admitted to intensive care
- ❑ I would wish to not engage in the decision

1.2 How certain are you about your choice? Check only ONE box:

- ❑ Very certain
- ❑ Somewhat certain
- ❑ Neither certain nor uncertain
- ❑ Somewhat uncertain
- ❑ Very uncertain

1.3 Can you elaborate why you would have this preference?

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Patient history 2:

A woman in her 80s fell from a ladder and was admitted to hospital with fractures in the shoulder blade and in several ribs on the left side. One week into the course she is found increasingly fatigued and confused. Pneumonia was diagnosed and she is treated with intravenous antibiotics (given right into a blood vessel). Notwithstanding, she develops severe blood stream infection and failing function in several vital organs.

The treating physicians discuss now whether to transfer the patient to the intensive care unit for organ support with a breathing machine and kidney replacement with a dialysis machine. In order to provide this treatment she will require to be put into drug-induced coma for some days. Alternatively, she can stay on the regular hospital ward, and continue current treatment. There she can also receive medications to alleviate pain, breathlessness and other burdensome symptoms if needed.

Approximately four of five patients in this situation survive intensive care, and a few might also survive without intensive care. Less than a half of all intensive care survivors are alive after 6-12 month. Both physical and mental function is permanently reduced among many survivors.

2.1 Imagine now that you are this patient. What would you wish for yourself?
Check the ONE answer that suits you best:

- ❑ I would wish to be admitted to intensive care
- ❑ I would not wish to be admitted to intensive care
- ❑ I would wish to not engage in the decision

2.2 How certain are you about your choice? Check only ONE box:

- ❑ Very certain
- ❑ Somewhat certain
- ❑ Neither certain nor uncertain
- ❑ Somewhat uncertain
- ❑ Very uncertain

2.3 Can you elaborate why you would have this preference?

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Patient history 3:

A woman in her 80s was operated for a whole in her stomach resulting from a gastric ulcer. Stomach content had leaked into the abdominal cavity and caused a serious bloodstream infection. Therefore, she received intravenous antibiotics (given right into a blood vessel). As a consequence of this infection she has now reduced consciousness, and failing function in several other vital organs.

The treating physicians discuss now whether to transfer the patient to the intensive care unit for organ support with a breathing machine and kidney replacement with a dialysis machine. In order to provide this treatment she will require to be put into drug-induced coma for some days. Alternatively, she can stay on the regular hospital ward, and continue current treatment. There she can also receive medications to alleviate pain, breathlessness and other burdensome symptoms if needed.

Approximately four of five patients in this situation survive intensive care, and a few might also survive without intensive care. Less than a half of all intensive care survivors are alive after 6-12 month. Both physical and mental function is permanently reduced among many survivors.

3.1 Imagine now that you are this patient. What would you wish for yourself?
Check the ONE answer that suits you best:

- ❑ I would wish to be admitted to intensive care
- ❑ I would not wish to be admitted to intensive care
- ❑ I would wish to not engage in the decision

3.2 How certain are you about your choice? Check only ONE box:

- ❑ Very certain
- ❑ Somewhat certain
- ❑ Neither certain nor uncertain
- ❑ Somewhat uncertain
- ❑ Very uncertain

3.3 Can you elaborate why you would have this preference?

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4. Many patients can't communicate their treatment preferences in an event of acute life-threatening illness. This part of the questionnaire asks how you think health care professionals and the patient's next-of-kin should cooperate in a situation like this.

4.1 Do you have a next of kin (close family member or friend) who you regard the right person to receive information about your condition and to inform about your treatment preferences, should you fall seriously ill? Check only ONE box:

- ❑ Yes
- ❑ No

If you answered this question with <u>no</u>: Please move to part 5.

If you answered this question with <u>yes</u>:

We ask you kindly to give the envelope marked "Questionnaire: Next-of-kin participant" to this person. If there are several persons you regard equally important in this setting, we ask you to choose the first in the order below (question 4.2).

It is will improve the quality of the survey, that you and your next-of-kin complete the questionnaires independently. Therefore, we ask you to not talk about the content of the survey before having posted your responses.

4.2 Which relationship does this next-of-kin have to you? Check only ONE box:

- ❑ Spouse
- ❑ Registered partner
- ❑ Child
- ❑ Partner (not living at the same address)
- ❑ Grandchild
- ❑ Other relative
- ❑ Friend

4.3 Would you wish that the doctors discuss the treatment options with your next-of-kin in this situation? Check only ONE box:

- ❑ Yes
- ❑ No
- ❑ Don't know

4.4 How certain are you that your next-of-kin could give the right answer to the question, which treatment you would prefer? Check only ONE box:

- ❑ Very certain
- ❑ Somewhat certain
- ❑ Neither certain nor uncertain
- ❑ Somewhat uncertain
- ❑ Very uncertain

4.5 Can you elaborate in which way you wish your next-of-kin should contribute to the decision making process in this situation?

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5. This part of the questionnaire asks about your experience with acute severe illness and about your thoughts regarding this issue.

All patients who are acutely admitted to a hospital, are first taken care of at the *emergency department*. From there they are transferred to a hospital department (ward) for further treatment.

Only very sick patients who are in need for continuous monitoring and / or mechanical organ support, for example with a breathing machine, are admitted to an *intensive care unit.*

5.1 Have you been admitted to an intensive care unit before? Check only ONE box:

- ❑ Yes
- ❑ No

5.2 Have you experienced to visit an intensive care unit as a next-of-kin?
Check only ONE box:

- ❑ Yes
- ❑ No

An *advance directive* is a document where you state which kind of treatment you wish to receive / not to receive, if you can't express your preferences in an event of serious illness.

A *power of attorney* is a document where you authorize one or several persons to protect your interests and make decisions on your behalf, when you are not able to do so yourself.

5.3 Do you have signed an advance directive or a power of attorney?
Check only ONE box:

- ❑ Yes
- ❑ No

5.4 Have you had a conversation with your next of kin regarding your treatment preferences in case of severe illness, permanent dependency or at the end of life?
Check only ONE box:

- ❑ Yes
- ❑ No

5.5 Have you had a conversation with your general practitioner regarding your treatment
Check only ONE box:

- ❑ Yes
- ❑ No

6. Now we will ask you to answer some questions about yourself.

Check the ONE most appropriate box:

6.1 Age:

…… years

6.2 Where are you born?

- ❑ Norway
- ❑ Another country

6.3 If you are not born in Norway, which country are you born in? .....

6.4 Gender:

- ❑ Female
- ❑ Male
- ❑ Other / do not wish to answer

6.5 Marital status:

- ❑ Single
- ❑ Married / registered partner 7 partner living at the same address
- ❑ Widowed / remaining partner (registered, same address)
- ❑ Separated / divorced

6.6 Religion:

- ❑ Christian
- ❑ Other religion
- ❑ No religion

6.7 Highest level of education?

- ❑ Primary school
- ❑ Secondary school
- ❑ Vocational training
- ❑ College / University

6.8 What was your latest occupation before retirement? ……

7. This part of the questionnaire deals with your health.

7.1 Do you, or did you suffer from any of the following conditions?
Check ALL boxes that apply to you:

- ❑ None of the conditions under

- ❑ Asthma / COPD
- ❑ Autoimmune disease
- ❑ Dementia
- ❑ Diabetes
- ❑ Atherosclerosis (narrowing of blood vessels)
- ❑ Stroke
- ❑ Heart attack / myocardial infarction
- ❑ Heart failure
- ❑ Chronic pain
- ❑ Cancer
- ❑ Weakness / paralysis after stroke
- ❑ Liver disease
- ❑ Gastric ulcer
- ❑ Kidney failure
- ❑ Mental illness
- ❑ Permanent loss of function after trauma

7.2 How many different medications do you take daily?
If you do not take any medications regularly, write “0”
If you are not sure, write the approximate number.

..... (Write a number)

7.3 Have you been admitted to hospital during the last 12 month?
Check only ONE box:

- ❑ Yes
- ❑ No

8. This part of the questionnaire deals with your physical fitness and health related quality of life.

How fit do you feel?
Check the ONE box next to the picture and text which best describes you:

❑  [validated Norwegian translation of the Clinical Frailty Scale, version 2]

❑  [validated Norwegian translation of the Clinical Frailty Scale, version 2]

❑  [validated Norwegian translation of the Clinical Frailty Scale, version 2]

❑  [validated Norwegian translation of the Clinical Frailty Scale, version 2]

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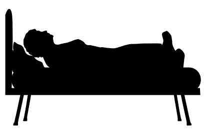
❑  [validated Norwegian translation of the Clinical Frailty Scale, version 2]

❑  [validated Norwegian translation of the Clinical Frailty Scale, version 2]

❑  [validated Norwegian translation of the Clinical Frailty Scale, version 2]

[EuroQuol 5D™, self, validated Norwegian form, page 1]

[EuroQuol 5D™, self, validated Norwegian form, page 2]

9. Do you have any thoughts regarding this survey which you would like to share with us?

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10. May we send a similar questionnaire to you in about 1-2 years?

If so, we ask you to fill in your name and address under. Your contact information will be stored separately, so the answers you gave in this questionnaire will not be directly identifiable. Even if you provide your contact information now, you can still at any time and without giving any reason withdraw from the study.

Name: .....

Address: .....

THANK YOU SO MUCH FOR TAKING THE TIME TO COMPLETE THIS QUESTIONNAIRE!

INTENSIVBEHANDLING AV ELDRE: HVA ØNSKER DE SELV?

UNIVERSITETET I BERGEN

HELSE BERGEN
Haukeland universitetssjukehus

D008-E

Kjære studiedeltaker

Takk for din interesse for denne spørreundersøkelsen. Den har til formål å bringe frem kunnskap om eldre menneskers tanker, holdninger og ønsker når det gjelder intensivbehandling ved akutt livstruende sykdom. Vi ønsker dessuten å belyse hvilken rolle pårørende til eldre mennesker har når vanskelige medisinske beslutninger må tas. Vi håper at økt kunnskap om dette vil bidra til at eldre mennesker i større grad kan få den behandlingen de ønsker, og som de har nytte av, når de blir innlagt på sykehus med akutt sykdom.

På neste side finner du mer informasjon om intensivbehandling generelt og om hva dette innebærer spesielt for eldre.

Spørreskjemaet består av ti deler. Det begynner med tre tenkte pasienthistorier. Etter hver historie ber vi deg om å forestille deg at du er denne pasienten, og om å svare på om du ville ønsket intensivbehandling, gitt at du med din bakgrunn og din helse var denne pasienten. Alle disse pasienthistoriene har til felles at vi har mangelfull kunnskap om nytten av slik behandling hos de aller eldste. Det betyr at legene ikke med sikkerhet vil kunne si hva som er det rette valget, og at forskjellige leger kan ha ulike anbefalinger.

I del 4 av spørreskjemaet spør vi om du har en pårørende som du tenker ville vært den rette til å motta informasjon om din tilstand og til å opplyse behandlerne om dine ønsker i tilfelle akutt sykdom, og om du kunne levere et tilsvarende spørreskjema til vedkommende. Vi spør også om dine tanker rundt pårørendes rolle når medisinske beslutninger skal tas. Del 5 handler om dine erfaringer med akutt alvorlig sykdom og om hvorvidt du allerede har lagt planer eller snakket med noen om dette. I del 6 til 8 spør vi deg om noen generelle opplysninger, som alder, kjønn og yrke, om noen helseopplysninger og om din livskvalitet. I del 9 er det plass til dine kommentarer. Til slutt (del 10) ber vi deg om dine kontaktopplysninger, slik at vi kan sende deg et lignende spørreskjema om 1–2 år.

Du behøver ikke å svare på spørsmål som du synes er ubehagelige eller som ikke passer for deg. Dersom du trenger råd eller trøst når du tenker på alvorlig sykdom, kan du ringe 55 97 68 50. En helsesekretær vil ta imot beskjed og formidle kontakt med prosjektleder Dr. Leonie Schwarz. Eller du kan skrive noen ord og be om kontakt på e-post: gabriele.leonie.schwarz@helse-bergen.no.

Bakgrunn for prosjektet:

- Intensivbehandling innebærer at man blir innlagt på en avdeling der avansert livreddende behandling blir gitt. Det blir brukt mye medisinsk teknisk utstyr, som pustemaskiner, pumper, og andre apparater. Mange pasienter på en intensiv-avdeling må bli lagt i kunstig koma.
- Intensivbehandling er krevende for kroppen, følelseslivet og tankevirksomheten. Eldre pasienter som overlever slik behandling, taper ofte mye vekt, og de er svake i tiden etterpå. De fleste er også forvirret i en periode under og etter oppholdet. Det er vanlig at man trenger hjelp og opptrening over lengre tid etter et intensivopphold.
- Alternativet til intensivbehandling er behandling på vanlig sykehusavdeling (sengepost). Behandlingen der er mindre inngripende, og pasienten kan være våken. Også her er det mulig å gi god smertelindring. Det er som regel lettere å få besøk, og pasienten kan ha litt mer privatliv og flere personlige eiendeler enn på en intensivavdeling.
- Selv om intensivbehandling blir gitt med formålet om å redde liv, så er det ikke sikkert at sjansen for å overleve *med et godt resultat* er større på intensivavdelingen enn på sengepost ved mange akutte tilstander som rammer de eldste pasientene.
- Mindre enn halvparten av pasientene over 80 år som har fått intensivbehandling i Norge, er i live etter ett år. Mange har vedvarende nedsatt funksjon, både fysisk og psykisk, og trenger mer hjelp i hverdagen enn før. Samtidig oppgir de fleste overlevende å ha god livskvalitet.
- Ved akutt, livstruende sykdom er det ofte ikke mulig for pasienten å medvirke i beslutningsprosessen. Samtidig må beslutningen ofte tas under tidspress og kan ha store konsekvenser. I slike tilfeller blir vanligvis nærmeste pårørende bedt om å gi opplysninger om pasientens sannsynlige behandlingsønsker.
- Vi vet lite om hva eldre mennesker vil foretrekke av behandling ved akutt livstruende sykdom og om hvordan de ønsker at beslutninger om inngripende medisinsk behandling skal tas dersom de ikke kan samtykke selv.
- Vi vet heller ikke nok om pårørendes rolle i slike vanskelige beslutningsprosesser, og vi ønsker derfor å belyse hele samhandlingen mellom pasient, pårørende og helsepersonell når valget står mellom å tilby eller avstå fra intensivbehandling.

Pasienthistorie 1:

En mann i 80-årene fikk utført en liten operasjon for nyrestensanfall. I løpet av det neste døgnet blir han akutt dårlig, og det blir påvist blodforgiftning med svikt i flere livsviktige organer. Pasienten får antibiotika og væske intravenøst (inn i en blodåre) med en gang, men likevel blir både nyrefunksjonen og lungefunksjonen verre, og han blir forvirret.

Legene drøfter nå om pasienten skal bli overflyttet til intensivavdelingen for å få behandling med pustemaskin og nyreerstattende behandling med dialysemaskin. Det vil medføre at han må legges i kunstig koma i noen dager. Alternativet er at han blir værende på vanlig sengeavdeling og fortsetter med behandlingen han har fått til nå. Ved behov kan han også få medisin som lindrer smerter, tung pust og andre plagsomme symptomer.

Omtrent fire av fem pasienter i denne situasjonen overlever intensivbehandlingen, og noen overlever også uten intensivbehandling. Av alle som får intensivbehandling, er mindre enn halvparten i live etter 6–12 måneder. Både fysisk og psykisk funksjon er varig redusert hos mange av dem som overlever.

1.1 Tenk deg nå at du er denne pasienten. Hva ville du ønsket for deg selv?
Kryss av i den ENE boksen for den påstanden som passer best for deg:

- ❑ Jeg ville ønsket innleggelse på intensivavdelingen
- ❑ Jeg ville ikke ønsket innleggelse på intensivavdelingen
- ❑ Jeg ville ikke ønsket å ta stilling til dette

1.2 Hvor sikker er du på at du ville ønsket det slik? Kryss av i EN boks:

- ❑ Helt sikker
- ❑ Nokså sikker
- ❑ Hverken sikker eller usikker
- ❑ Nokså usikker
- ❑ Helt usikker

1.3 Kan du utdype hvorfor du ville ønsket det slik?

……..

……..

……..

Pasienthistorie 2:

En kvinne i 80-årene falt fra en stige og ble innlagt på sykehus med brudd i skulderblad og i flere ribbein på venstre side. Etter en uke blir hun tiltagende sliten og forvirret. Det blir påvist lungebetennelse, og hun får behandling med antibiotika intravenøst (rett inn i en blodåre). Til tross for denne behandlingen utvikler hun blodforgiftning med sviktende funksjon i flere livsviktige organer.

Legene drøfter nå om pasienten skal bli overflyttet til intensivavdelingen for å få behandling med pustemaskin og nyreerstattende behandling med dialysemaskin. Det vil medføre at hun må legges i kunstig koma i noen dager. Alternativet er at hun blir værende på vanlig sengeavdeling og fortsetter med behandlingen hun har fått til nå. Ved behov kan hun også få medisin som lindrer smerter, tung pust og andre plagsomme symptomer.

Omtrent fire av fem pasienter i denne situasjonen overlever intensivbehandlingen, og noen overlever også uten intensivbehandling. Av alle som får intensivbehandling, er mindre enn halvparten i live etter 6–12 måneder. Både fysisk og psykisk funksjon er varig redusert hos mange av dem som overlever.

2.1 Tenk deg nå at du er denne pasienten. Hva ville du ønsket for deg selv?
Kryss av i den ENE boksen for den påstanden som passer best for deg:

- ❑ Jeg ville ønsket innleggelse på intensivavdelingen
- ❑ Jeg ville ikke ønsket innleggelse på intensivavdelingen
- ❑ Jeg ville ikke ønsket å ta stilling til dette

2.2 Hvor sikker er du på at du ville ønsket det slik? Kryss av i EN boks:

- ❑ Helt sikker
- ❑ Nokså sikker
- ❑ Hverken sikker eller usikker
- ❑ Nokså usikker
- ❑ Helt usikker

2.3 Kan du utdype hvorfor du ville ønsket det slik?

……..

……..

……..

Pasienthistorie 3:

En kvinne i 80-årene ble operert for et hull på magesekken på grunn av magesår. Mageinnhold har lekket ut i bukhulen og ført til blodforgiftning. Hun ble derfor behandlet med antibiotika intravenøst (rett inn i en blodåre). Som følge av blodforgiftningen har hun nedsatt bevissthet og sviktende funksjon i flere andre livsviktige organer.

Legene drøfter nå om pasienten skal bli overflyttet til intensivavdelingen for å få behandling med pustemaskin og nyreerstattende behandling med dialysemaskin. Det vil medføre at hun må legges i kunstig koma i noen dager. Alternativet er at hun blir værende på vanlig sengeavdeling og fortsetter med behandlingen hun har fått til nå. Ved behov kan hun også få medisin som lindrer smerter, tung pust og andre plagsomme symptomer.

Omtrent fire av fem pasienter i denne situasjonen overlever intensivbehandlingen, og noen overlever også uten intensivbehandling. Av alle som får intensivbehandling, er mindre enn halvparten i live etter 6–12 måneder. Både fysisk og psykisk funksjon er varig redusert hos mange av dem som overlever.

3.1 Tenk deg nå at du er denne pasienten. Hva ville du ønsket for deg selv?
Kryss av i den ENE boksen for den påstanden som passer best for deg:

- ❑ Jeg ville ønsket innleggelse på intensivavdelingen
- ❑ Jeg ville ikke ønsket innleggelse på intensivavdelingen
- ❑ Jeg ville ikke ønsket å ta stilling til dette

3.2 Hvor sikker er du på at du ville ønsket det slik? Kryss av i EN boks:

- ❑ Helt sikker
- ❑ Nokså sikker
- ❑ Hverken sikker eller usikker
- ❑ Nokså usikker
- ❑ Helt usikker

3.3 Kan du utdype hvorfor du ville ønsket det slik?

……..

……..

……..

4. Mange pasienter kan ikke gjøre rede for sine behandlingsønsker ved akutt livstruende sykdom. Denne delen av spørreskjemaet handler om hvordan du tenker helsevesenet og pårørende bør samarbeide i en slik situasjon.

4.1 Har du en pårørende (familiemedlem eller venn) som du tenker er den rette personen til å motta informasjon om din tilstand og til å gi opplysninger om dine behandlingsønsker hvis du skulle bli alvorlig syk? Kryss av i EN boks:

- ❑ Ja
- ❑ Nei

Hvis du har svart nei på dette spørsmålet: Du kan gå rett videre til del 5.

Hvis du har svart ja på dette spørsmålet:

Vi ber deg om å gi konvolutten merket «Til studiedeltaker: Pårørende» til denne personen. Hvis du har flere pårørende som du mener er likestilte i en slik situasjon, ber vi deg om å velge den første i rekkefølgen under (spørsmål 4.2).

Det er en fordel for kvaliteten av studien at du og din pårørende fyller ut spørreskjemaene hver for dere. Vi ber om at dere ikke snakker sammen om innholdet av spørreundersøkelsen før dere har sendt inn svarene.

4.2 Hvilken tilknytning har vedkommende til deg? Kryss av i EN boks:

- ❑ Ektefelle
- ❑ Samboer
- ❑ Barn
- ❑ Kjæreste/partner som du ikke bor sammen med
- ❑ Barnebarn
- ❑ Annen slektning
- ❑ Venn

4.3 Ville du ønsket at legene drøfter behandlingsmulighetene med din(e) nærmeste pårørende i en slik situasjon? Kryss av i EN boks:

- ❑ Ja
- ❑ Nei
- ❑ Vet ikke

4.4 Hvor sikker er du på at din(e) nærmeste pårørende kan svare rett på hva du ville ønsket for deg selv i en slik situasjon? Kryss av i EN boks:

- ❑ Helt sikker
- ❑ Nokså sikker
- ❑ Hverken sikker eller usikker
- ❑ Nokså usikker
- ❑ Helt usikker

4.5 Kan du utdype hvordan du ønsker at din nærmeste pårørende skal bidra til å ta beslutninger i en slik situasjon?

……..

……..

……..

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……..

5. Denne delen av spørreskjemaet handler om din erfaring med akutt alvorlig sykdom og dine tanker rundt dette.

Alle pasienter som blir innlagt på sykehus med behov for øyeblikkelig hjelp, kommer først til *akuttmottaket*. Derfra blir de flyttet til en avdeling (sengepost) for videre behandling.

Bare pasienter som er så syke at de trenger kontinuerlig overvåkning og/eller organstøttende behandling med apparater, for eksempel med en pustemaskin, blir innlagt på en *intensivavdeling.*

5.1 Har du selv vært innlagt på en intensivavdeling før? Kryss av i EN boks:

- ❑ Ja
- ❑ Nei

5.2 Har du erfaring med å være pårørende på en intensivavdeling? Kryss av i EN boks:

- ❑ Ja
- ❑ Nei

Et *livstestament* er et dokument hvor du skriver hva du ønsker / ikke ønsker av behandling hvis du senere blir alvorlig syk og ikke lenger kan uttrykke egne ønsker.

En *fremtidsfullmakt* er en fullmakt du gir én eller flere personer til å ivareta dine interesser når du ikke lenger er i stand til det selv.

5.3 Har du et livstestament eller en fremtidsfullmakt? Kryss av i EN boks:

- ❑ Ja
- ❑ Nei

5.4 Har du snakket med din(e) nærmeste pårørende om dine ønsker for behandling ved alvorlig sykdom, ved langvarig pleie eller ved livets slutt? Kryss av i EN boks:

- ❑ Ja
- ❑ Nei

5.5 Har du snakket med din fastlege om dine ønsker for behandling ved alvorlig sykdom, ved langvarig pleie eller ved livets slutt? Kryss av i EN boks:

- ❑ Ja
- ❑ Nei

6. Nå ber vi deg om å besvare noen spørsmål om deg selv.

Kryss av i den ENE boksen som passer best for deg:

6.1 Alder:

…… år

6.2 Hvor er du født?

- ❑ Norge
- ❑ Annet land

6.3 Hvis du ikke er født i Norge, hvilket land er du født i? .....

6.4 Kjønn:

- ❑ Kvinne
- ❑ Mann
- ❑ Annet / ønsker ikke å svare

6.5 Sivilstand:

- ❑ Enslig
- ❑ Gift / registrert partner / samboer
- ❑ Enke/enkemann
- ❑ Separert/skilt

6.6 Livssyn:

- ❑ Kristent livssyn
- ❑ Annet religiøst livssyn
- ❑ Ikke-religiøst livssyn

6.7 Hva er den høyeste utdanningen du har tatt?

- ❑ Grunnskole
- ❑ Gymnas/videregående
- ❑ Yrkesskole/fagbrev
- ❑ Høyskole/universitet

6.8 Hva var ditt siste yrke før du ble pensjonist? ……

7. Denne delen av spørreskjemaet handler om din helse.

7.1 Har du, eller har du hatt, én eller flere av disse sykdommene?
Kryss av i ALLE bokser som passer for deg:

- ❑ Ingen av de nedenstående sykdommene

- ❑ Astma/KOLS
- ❑ Autoimmun sykdom
- ❑ Demens
- ❑ Diabetes
- ❑ Forkalkning i pulsårer
- ❑ Hjerneslag/drypp
- ❑ Hjerteinfarkt
- ❑ Hjertesvikt
- ❑ Kronisk smerte
- ❑ Kreft
- ❑ Lammelse etter slag
- ❑ Leversykdom
- ❑ Magesår
- ❑ Nyresvikt
- ❑ Psykisk sykdom
- ❑ Varig mén etter traume/skade

7.2 Hvor mange forskjellige medikamenter tar du daglig?
Hvis du ikke bruker medikamenter daglig, skriv 0.
Hvis du er usikker, skriv cirka antall.

..... (skriv antall)

7.3 Har du vært innlagt på sykehus i løpet av de siste 12 månedene?
Kryss av i EN boks:

- ❑ Ja
- ❑ Nei

8. Denne delen av spørreskjemaet handler om din fysiske form og helserelatert livskvalitet.

Hvor sprek føler du deg?
Sett kryss i den ENE boksen ved siden av bildet og teksten som best beskriver deg:

❑ 

Veldig sprek
Personer som er robuste, aktive, energiske og motiverte. De pleier å trene og er blant de sprekeste i sin aldersgruppe.

❑ 

Sprek
Personer som ikke har aktive sykdomssymptomer, men er mindre spreke enn personer i kategori 1. Ofte trener de eller er veldig aktive av og til, for eksempel sesongpreget.

❑ 

Klarer seg bra
Personer der medisinske problemer er velkontrollerte, selv om de kan ha symptomer av og til, men som ikke er regelmessig aktive bortsett fra vanlige gåturer.

❑ 

Lever med svært mild skrøpelighet
Denne kategorien ble tidligere kalt «sårbar», og markerer en tidlig overgang fra å være helt selvstendig. Selv om de ikke er avhengig av daglig hjelp fra andre, vil symptomer begrense deres aktiviteter. De klager ofte over at de er «langsomme» og/eller blir slitne/trøtte ila dagen.

❑ 

Lever med mild skrøpelighet
Disse er mer tydelig langsomme, og trenger hjelp til komplekse aktiviteter i dagliglivet (økonomi, transport, tungt husarbeid). Vanligvis vil mild skrøpelighet i økende grad føre til problemer med å handle eller gå utenfor hjemmet alene, lage mat, ordne medisiner, og evnen til lett husarbeid begynner å bli begrenset.

❑ 

Lever med moderat skrøpelighet
Personer som må ha hjelp til alle aktiviteter utendørs og med å stelle hjemmet. Innendørs har de ofte problemer med trapper, trenger hjelp til bading/dusj og kan trenge litt hjelp til å kle på seg (veiledning, med tilsyn).

❑ 

Lever med alvorlig skrøpelighet
Personer som er helt avhengige av hjelp til personlig stell uansett årsak (fysisk eller kognitiv). Likevel fremstår de som stabile og uten høy risiko for å dø (innen anslagsvis 6 måneder).

❑ 

Lever med svært alvorlig skrøpelighet
Personer som er helt avhengige av hjelp i dagliglivet og nærmer seg livets slutt. Vanligvis vil de ikke komme seg igjen selv etter mild sykdom.

❑ 

Terminalt syk
Nærmer seg livets slutt. I denne kategorien inngår personer med en forventet levetid på <6 måneder uten at de lever med alvorlig skrøpelighet. (Mange terminalt syke pasienter kan være fysisk aktive inntil de er svært nær døden).

Under hver overskrift ber vi deg krysse av den ENE boksen som best beskriver helsen din I DAG.

GANGE

- Jeg har ingen problemer med å gå omkring ❑
- Jeg har litt problemer med å gå omkring ❑
- Jeg har middels store problemer med å gå omkring ❑
- Jeg har store problemer med å gå omkring ❑
- Jeg er ute av stand til å gå omkring ❑

PERSONLIG STELL

- Jeg har ingen problemer med å vaske meg eller kle meg ❑
- Jeg har litt problemer med å vaske meg eller kle meg ❑
- Jeg har middels store problemer med å vaske meg eller kle meg ❑
- Jeg har store problemer med å vaske meg eller kle meg ❑
- Jeg er ute av stand til å vaske meg eller kle meg ❑

VANLIGE GJØREMÅL *(f.eks. arbeid, studier, husarbeid, familie- eller fritidsaktiviteter)*

- Jeg har ingen problemer med å utføre mine vanlige gjøremål ❑
- Jeg har litt problemer med å utføre mine vanlige gjøremål ❑
- Jeg har middels store problemer med å utføre mine vanlige gjøremål ❑
- Jeg har store problemer med å utføre mine vanlige gjøremål ❑
- Jeg er ute av stand til å utføre mine vanlige gjøremål ❑

SMERTER / UBEHAG

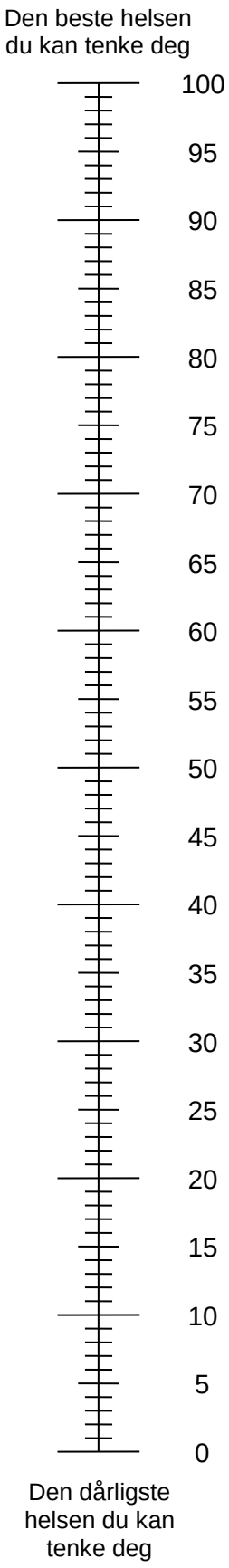
- Jeg har verken smerter eller ubehag ❑
- Jeg har litt smerter eller ubehag ❑
- Jeg har middels sterke smerter eller ubehag ❑
- Jeg har sterke smerter eller ubehag ❑
- Jeg har svært sterke smerter eller ubehag ❑

ANGST / DEPRESJON

- Jeg er verken engstelig eller deprimert ❑
- Jeg er litt engstelig eller deprimert ❑
- Jeg er middels engstelig eller deprimert ❑
- Jeg er svært engstelig eller deprimert ❑
- Jeg er ekstremt engstelig eller deprimert ❑

- Vi vil gjerne vite hvor god eller dårlig helsen din er I DAG.
- Denne skalaen er nummerert fra 0 til 100.
- 100 betyr den beste helsen du kan tenke deg.
  0 betyr den dårligste helsen du kan tenke deg.
- Sett en X på skalaen for å angi hvordan helsen din er I DAG.
- Skriv deretter tallet du merket av på skalaen inn i boksen nedenfor.

HELSEN DIN I DAG = ☐



D008-E

9. Har du tanker angående denne spørreundersøkelsen som du ønsker å dele med oss?

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10. Kan vi sende deg en tilsvarende spørreundersøkelse om 1–2 år?

I så fall ber vi deg om å oppgi ditt navn og din adresse. Din kontaktinformasjon vil bli lagret adskilt, slik at svarene du har gitt i spørreskjemaet, ikke vil være direkte identifiserbare. Om du oppgir din kontaktinformasjon nå, så kan du likevel når som helst og uten begrunnelse trekke deg fra studien.

Navn: .....

Adresse: .....

TUSEN TAKK FOR AT DU TOK DEG TID TIL Å BESVARE VÅRE SPØRSMÅL!

INTENSIVE CARE OF THE VERY OLD: WHAT DO THEY WISH FOR THEMSELVES?

UNIVERSITETET I BERGEN

HELSE BERGEN
Haukeland universitetssjukehus

Dear participant,

Thank you for your interest in this study. It aims at bringing forward knowledge about very old peoples' thoughts, attitudes and preferences regarding intensive care in the event of acute life-threatening illness. We also would like to know more about which role family members of very old patients have in situations when difficult medical decisions need to be made. Vi hope that better understanding in this field will improve very old patients' hospital stay when they are admitted with acute illness, so they to a larger degree receive the treatments they prefer and will benefit from.

On the next page you will find more information about intensive care in general and its implications for very old patients in particular.

The questionnaire consists of ten parts. It starts with three fictional patient histories. After each history you are asked to first imagine that your very old relative is this patient and to answer, whether he or she would prefer intensive care, given he or she would be this patient with his or her background and current health. Afterwards we ask you to imagine, that you yourself are this patient, and answer the same question once again. All these patient histories have the common feature, that we have limited knowledge regarding the benefit of intensive care for very old patients. This implies, that the doctors will not be able to give strong advice, which treatment to choose, and different doctors may have different recommendations.

In part 4 of the questionnaire we ask about your thoughts regarding family involvement, when medical decisions need to be made. Part 5 addresses your, and your very old relatives experience with acute severe illness, and whether your very old relative has given advance directives or communicated his or her preferences to you already. In parts 6 and 7 we request some information regarding your very old relative's health, fitness and quality of life. Furthermore, we ask for some general information about you yourself (part 8). In part 9 there is space for your comments. Finally (part 10) you are asked to provide contact details, so we can send you a similar questionnaire in 1-2 years.

You don't need to answer questions you find unpleasant or not appropriate. If you feel in need for help or comfort when thinking about serious illness, you may call 55 97 68 50.
A health secretary will answer your call and establish contact with the principal investigator of this project Dr. Leonie Schwarz. Or you can write a few words and ask us to make contact by e-mail: gabriele.leonie.schwarz@helse-bergen.no.

Background information for the project:

- Intensive care means getting admitted to a hospital unit where advanced life-saving treatment is given. A lot of medical technical equipment is used for this purpose, like breathing machines, pumps and other devices. Many patients in an intensive care unit have to be put to sleep (artificial coma).
- Intensive care is demanding both physically, emotionally and mentally. Elderly patients who survive intensive care often lose a lot of weight, and are weak for a longer period of time afterwards. The majority is also confused for a while under or after intensive care. Usually patients are in need of rehabilitation and training for a longer period of time afterwards.
- The alternative to intensive care is treatment and care on a regular hospital ward. The therapies given there are less invasive, and the patient can be awake. Also here good pain control and comfort care can be provided. Usually it is easier to visit the patient on a regular ward, and the patient is allowed more privacy and more personal items than on the intensive care ward.
- Even though intensive care is provided with an intention to save life, it is not certain that the chances of survival *with a good outcome* are better with intensive care compared to regular ward care in many acute conditions that may affect the oldest patients.
- Less than half of all patients who received intensive care at an age of 80 years or more in Norway are alive after one year. Many of them experience persistently reduced physical and mental function, and need more assistance in their every-day life than before. Notwithstanding, most very old survivors report satisfying quality of life.
- In an event of acute, life threatening illness it is often impossible for the patient to participate in shared decision-making, while decisions regularly need to be made under time constraints and at high stakes. In these cases usually the patient's next-of-kin is asked to inform about the patients presumed treatment preferences.
- We know little about very old people's treatment preferences in an event of acute life-threatening illness, and how they wish decisions regarding invasive medical treatments should be made, when they are not capable to consent themselves.
- Furthermore, we do not know enough regarding the family members' role in these difficult decision processes, and we therefore aim to shed light into the whole interaction between patient, family members and health care professionals, when the choice is either to provide or to refrain from intensive care.

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- Intensive care means getting admitted to a hospital unit where advanced life-saving treatment is given. A lot of medical technical equipment is used for this purpose, like breathing machines, pumps and other devices. Many patients in an intensive care unit have to be put to sleep (artificial coma).
- Intensive care is demanding both physically, emotionally and mentally. Very old patients who survive intensive care often lose a lot of weight, and are subsequently weak. The majority is also confused for a while under or after intensive care. Usually patients are in need of rehabilitation and training for a longer period of time after discharge.
- The alternative to intensive care is treatment and care on a regular hospital ward. The therapies given there are less invasive, and the patient can be awake. Also here, good pain control and comfort care can be provided. Usually it is easier to visit the patient on a regular ward, and the patient is allowed more privacy and more personal items than on the intensive care ward.
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- Furthermore, we do not know enough regarding the family members' role in these difficult decision processes, and we therefore aim to shed light into the whole interaction between patient, family members and health care professionals, when the choice is either to provide or to refrain from intensive care.

Patient history 1:

A man in his 80s underwent a small operation for a kidney stone attack. During the following day he became acutely unwell, and a serious bloodstream infection was diagnosed with impaired function of several vital organs. The patient immediately received intravenous antibiotics (given right into a blood vessel). However, both kidney function and lung function deteriorated, and he became confused.

The treating physicians discuss now whether to transfer the patient to the intensive care unit for organ support with a breathing machine and kidney replacement with a dialysis machine. In order to provide this treatment she will require to be put into drug-induced coma for some days. Alternatively, she can stay on the regular hospital ward, and continue current treatment. There she can also receive medications to alleviate pain, breathlessness and other burdensome symptoms if needed.

Approximately four of five patients in this situation survive intensive care, and a few might also survive without intensive care. Less than a half of all intensive care survivors are alive after 6-12 month. Both physical and mental function is permanently reduced among many survivors.

1.1 Imagine now that <u>your very old relative</u> is this patient.
What do you think, he or she would wish for him- or herself?
Check the ONE most appropriate answer:

- ❑ He / She would wish to be admitted to intensive care
- ❑ He / She would <u>not</u> wish to be admitted to intensive care
- ❑ He /She would wish to not engage in the decision

1.2 How certain are you that he / she would make that choice? Check only ONE box:

- ❑ Very certain
- ❑ Somewhat certain
- ❑ Neither certain nor uncertain
- ❑ Somewhat uncertain
- ❑ Very uncertain

1.3 Can you elaborate why you think, <u>your very old relative</u> would have this preference?

……..

……..

……..

1.4 Imagine now that <u>you yourself</u> are this patient. What would you wish for <u>yourself</u>?
Check the ONE answer that suits you best:

- ❑ I would wish to be admitted to intensive care
- ❑ I would <u>not</u> wish to be admitted to intensive care
- ❑ I would wish to not engage in the decision

1.5 How certain are you about your choice for <u>yourself</u>? Check only ONE box:

- ❑ Very certain
- ❑ Somewhat certain
- ❑ Neither certain nor uncertain
- ❑ Somewhat uncertain
- ❑ Very uncertain

1.6 Can you elaborate why you would have this preference for <u>yourself</u>?

……..

……..

……..

Patient history 2:

A woman in her 80s fell from a ladder and was admitted to hospital with fractures in the shoulder blade and in several ribs on the left side. One week into the course she is found increasingly fatigued and confused. Pneumonia was diagnosed and she is treated with intravenous antibiotics (given right into a blood vessel). Notwithstanding, she develops severe blood stream infection and failing function in several vital organs.

The treating physicians discuss now whether to transfer the patient to the intensive care unit for organ support with a breathing machine and kidney replacement with a dialysis machine. In order to provide this treatment she will require to be put into drug-induced coma for some days. Alternatively, she can stay on the regular hospital ward, and continue current treatment. There she can also receive medications to alleviate pain, breathlessness and other burdensome symptoms if needed.

Approximately four of five patients in this situation survive intensive care, and a few might also survive without intensive care. Less than a half of all intensive care survivors are alive after 6-12 month. Both physical and mental function is permanently reduced among many survivors.

2.1 Imagine now that <u>your very old relative</u> is this patient.
What do you think, he or she would wish for him- or herself?
Check the ONE most appropriate answer:

- ❑ He / She would wish to be admitted to intensive care
- ❑ He / She would <u>not</u> wish to be admitted to intensive care
- ❑ He /She would wish to not engage in the decision

2.2 How certain are you that he / she would make that choice? Check only ONE box:

- ❑ Very certain
- ❑ Somewhat certain
- ❑ Neither certain nor uncertain
- ❑ Somewhat uncertain
- ❑ Very uncertain

2.3 Can you elaborate why you think, <u>your very old relative</u> would have this preference?

……..

……..

……..

2.4 Imagine now that <u>you yourself</u> are this patient. What would you wish for <u>yourself</u>?
Check the ONE answer that suits you best:

- ❑ I would wish to be admitted to intensive care
- ❑ I would <u>not</u> wish to be admitted to intensive care
- ❑ I would wish to not engage in the decision

2.5 How certain are you about your choice for <u>yourself</u>? Check only ONE box:

- ❑ Very certain
- ❑ Somewhat certain
- ❑ Neither certain nor uncertain
- ❑ Somewhat uncertain
- ❑ Very uncertain

2.6 Can you elaborate why you would have this preference for <u>yourself</u>?

……..

……..

……..

Patient history 3:

A woman in her 80s was operated for a whole in her stomach resulting from a gastric ulcer. Stomach content had leaked into the abdominal cavity and caused a serious bloodstream infection. Therefore, she received intravenous antibiotics (given right into a blood vessel). As a consequence of this infection she has now reduced consciousness, and failing function in several other vital organs.

The treating physicians discuss now whether to transfer the patient to the intensive care unit for organ support with a breathing machine and kidney replacement with a dialysis machine. In order to provide this treatment she will require to be put into drug-induced coma for some days. Alternatively, she can stay on the regular hospital ward, and continue current treatment. There she can also receive medications to alleviate pain, breathlessness and other burdensome symptoms if needed.

Approximately four of five patients in this situation survive intensive care, and a few might also survive without intensive care. Less than a half of all intensive care survivors are alive after 6-12 month. Both physical and mental function is permanently reduced among many survivors.

3.1 Imagine now that <u>your very old relative</u> is this patient.
What do you think, he or she would wish for him- or herself?
Check the ONE most appropriate answer:

- ❑ He / She would wish to be admitted to intensive care
- ❑ He / She would <u>not</u> wish to be admitted to intensive care
- ❑ He /She would wish to not engage in the decision

3.2 How certain are you that he / she would make that choice? Check only ONE box:

- ❑ Very certain
- ❑ Somewhat certain
- ❑ Neither certain nor uncertain
- ❑ Somewhat uncertain
- ❑ Very uncertain

3.3 Can you elaborate why you think, <u>your very old relative</u> would have this preference?

……..

……..

……..

3.4 Imagine now that <u>you yourself</u> are this patient. What would you wish for <u>yourself</u>?
Check the ONE answer that suits you best:

- ❑ I would wish to be admitted to intensive care
- ❑ I would <u>not</u> wish to be admitted to intensive care
- ❑ I would wish to not engage in the decision

3.5 How certain are you about your choice for <u>yourself</u>? Check only ONE box:

- ❑ Very certain
- ❑ Somewhat certain
- ❑ Neither certain nor uncertain
- ❑ Somewhat uncertain
- ❑ Very uncertain

3.6 Can you elaborate why you would have this preference for <u>yourself</u>?

……..

……..

……..

4. Many patients can't communicate their treatment preferences in an event of acute life-threatening illness. This part of the questionnaire asks how you think health care professionals and the patient's next-of-kin should cooperate in a situation like this.

4.1 Would you wish that the doctors discuss the treatment options for <u>your very old relative</u> with you in this situation? Check only ONE box:

- ❑ Yes
- ❑ No
- ❑ Don't know

4.2 How certain are you that you could give the right answer to the question, which treatment <u>your very old relative</u> would prefer in this situation?
Check only ONE box:

- ❑ Very certain
- ❑ Somewhat certain
- ❑ Neither certain nor uncertain
- ❑ Somewhat uncertain
- ❑ Very uncertain

4.3 Can you elaborate in which way you as a next-of-kin should contribute to the decision making process in this situation?

……..

……..

……..

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……..

5. This part of the questionnaire asks about your and / or your very old relative's experiences with acute severe illness and whether your very old relative has shared his / her thoughts with you.

All patients who are acutely admitted to a hospital, are first taken care of at the *emergency department*. From there they are transferred to a hospital department (ward) for further treatment.

Only very sick patients who are in need for continuous monitoring and / or mechanical organ support, for example with a breathing machine, are admitted to an *intensive care unit.*

5.1 Have you yourself been admitted to an intensive care unit before?
Check only ONE box:

- ❑ Yes
- ❑ No

5.2 Has your very old relative been admitted to an intensive care unit before?
Check only ONE box:

- ❑ Yes
- ❑ No
- ❑ Don't know

5.3 Have you yourself experienced to visit an intensive care unit as a next-of-kin?
Check only ONE box:

- ❑ Yes
- ❑ No

5.4 Has your very old relative experienced to visit an intensive care unit as a next-of-kin? Check only ONE box:

- ❑ Yes
- ❑ No
- ❑ Don't know

An *advance directive* is a document where you state which kind of treatment you wish to receive / not to receive, if you can't express your preferences in an event of serious illness.

A *power of attorney* is a document where you authorize one or several persons to protect your interests and make decisions on your behalf, when you are not able to do so yourself.

5.5 Has <u>your very old relative</u> signed an advance directive or a power of attorney?
Check only ONE box:

- ❑ Yes
- ❑ No
- ❑ Don't know

5.6 Has <u>your very old relative</u> had a conversation with you regarding his / her treatment preferences in case of severe illness, permanent dependency or at the end of life?
Check only ONE box:

- ❑ Yes
- ❑ No

6. This part of the questionnaire deals with the health of your very old relative.

6.1 Does he / she, or did he / she suffer from any of the following conditions?
Check ALL boxes that apply to you:

- ❑ None of the conditions under

- ❑ Asthma / COPD
- ❑ Autoimmune disease
- ❑ Dementia
- ❑ Diabetes
- ❑ Atherosclerosis (narrowing of blood vessels)
- ❑ Stroke
- ❑ Heart attack / myocardial infarction
- ❑ Heart failure
- ❑ Chronic pain
- ❑ Cancer
- ❑ Weakness / paralysis after stroke
- ❑ Liver disease
- ❑ Gastric ulcer
- ❑ Kidney failure
- ❑ Mental illness
- ❑ Permanent loss of function after trauma

6.2 How many different medications does he / she take daily?
If you do not take any medications regularly, write "0"
If you are not sure, write the approximate number.

..... (Write a number)

6.3 Has he / she been admitted to hospital during the last 12 month?
Check only ONE box:

- ❑ Yes
- ❑ No

7. This part of the questionnaire deals with the physical fitness and health related quality of life <u>of your very old relative</u>.

How fit is your <u>very old relative</u>?
Check the ONE box next to the picture and text which best describes you:

❑  [validated Norwegian translation of the Clinical Frailty Scale, version 2]

❑  [validated Norwegian translation of the Clinical Frailty Scale, version 2]

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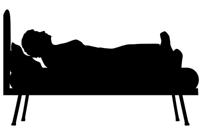
❑  [validated Norwegian translation of the Clinical Frailty Scale, version 2]

❑  [validated Norwegian translation of the Clinical Frailty Scale, version 2]

[EuroQuol 5D™, proxy, validated Norwegian form, page 1]

[EuroQuol 5D™, proxy, validated Norwegian form, page 2]

8. Finally, we will ask you to answer some questions about yourself.

Check the ONE most appropriate box:

6.1 Age:

…… years

6.2 Where are you born?

- ❑ Norway
- ❑ Another country

6.3 If you are not born in Norway, which country are you born in? .....

6.4 Gender:

- ❑ Female
- ❑ Male
- ❑ Other / do not wish to answer

6.5 Marital status:

- ❑ Single
- ❑ Married / registered partner 7 partner living at the same address
- ❑ Widowed / remaining partner (registered, same address)
- ❑ Separated / divorced

6.6 Religion:

- ❑ Christian
- ❑ Other religion
- ❑ No religion

6.7 Highest level of education?

- ❑ Primary school
- ❑ Secondary school
- ❑ Vocational training
- ❑ College / University

8.1 What is / was your occupation? ……

9. Do you have any thoughts regarding this survey which you would like to share with us?

.....

.....

.....

.....

.....

.....

.....

.....

.....

.....

10. May we send a similar questionnaire to you in about 1-2 years?

If so, we ask you to fill in your name and address under. Your contact information will be stored separately, so the answers you gave in this questionnaire will not be directly identifiable. Even if you provide your contact information now, you can still at any time and without giving any reason withdraw from the study.

Name: .....

Address: .....

THANK YOU SO MUCH FOR TAKING THE TIME TO COMPLETE THIS QUESTIONNAIRE!

INTENSIVBEHANDLING AV ELDRE: HVA ØNSKER DE SELV?

UNIVERSITETET I BERGEN

HELSE BERGEN
Haukeland universitetssjukehus

D008-P

Kjære studiedeltaker

Takk for din interesse for denne spørreundersøkelsen. Den har til formål å bringe frem kunnskap om eldre menneskers tanker, holdninger og ønsker når det gjelder intensivbehandling ved akutt livstruende sykdom. Vi ønsker dessuten å belyse hvilken rolle pårørende til eldre mennesker har når vanskelige medisinske beslutninger må tas. Vi håper at økt kunnskap om dette vil bidra til at eldre mennesker i større grad kan få den behandlingen de ønsker, og som de har nytte av, når de blir innlagt på sykehus med akutt sykdom.

På neste side finner du mer informasjon om intensivbehandling generelt og om hva dette innebærer spesielt for eldre.

Spørreskjemaet består av ti deler. Det begynner med tre tenkte pasienthistorier. Etter hver historie ber vi deg om å forestille deg først at den du er pårørende til, er denne pasienten, og om å svare på om vedkommende ville ønsket intensiv-behandling, gitt at han eller hun med sin bakgrunn og sin helse var denne pasienten. Etterpå ber vi deg om å forestille deg at du selv er denne pasienten, og besvare det samme spørsmålet en gang til. Alle disse pasienthistoriene har til felles at vi har mangelfull kunnskap om nytten av slik behandling hos de aller eldste. Det betyr at legene ikke med sikkerhet vil kunne si hva som er det rette valget, og at forskjellige leger kan ha ulike anbefalinger.

I del 4 av spørreskjemaet spør vi om dine tanker rundt pårørendes rolle når medisinske beslutninger skal tas. Del 5 handler om deres erfaringer med akutt alvorlig sykdom og om den du er pårørende til, allerede har lagt planer eller snakket med deg om dette temaet. I del 6 og 7 spør vi om helsen og livskvaliteten til den du er pårørende til. Vi ber deg dessuten om noen generelle opplysninger om deg selv (del 8). I del 9 er det plass til dine kommentarer. Til slutt (del 10) ber vi deg om dine kontaktopplysninger, slik at vi kan sende deg et lignende spørreskjema om 1–2 år.

Du behøver ikke å svare på spørsmål som du synes er ubehagelige eller som ikke passer for deg. Dersom du trenger råd eller trøst når du tenker på alvorlig sykdom, kan du ringe 55 97 68 50. En helsesekretær vil ta imot beskjed og formidle kontakt med prosjektleder Dr. Leonie Schwarz. Eller du kan skrive noen ord og be om kontakt på e-post: gabriele.leonie.schwarz@helse-bergen.no.

Bakgrunn for prosjektet:

- Intensivbehandling innebærer at man blir innlagt på en avdeling der avansert livreddende behandling blir gitt. Det blir brukt mye medisinsk teknisk utstyr, som pustemaskiner, pumper, og andre apparater. Mange pasienter på en intensiv-avdeling må bli lagt i kunstig koma.
- Intensivbehandling er krevende for kroppen, følelseslivet og tankevirksomheten. Eldre pasienter som overlever slik behandling, taper ofte mye vekt, og de er svake i tiden etterpå. De fleste er også forvirret i en periode under og etter oppholdet. Det er vanlig at man trenger hjelp og opptrening over lengre tid etter et intensivopphold.
- Alternativet til intensivbehandling er behandling på vanlig sykehusavdeling (sengepost). Behandlingen der er mindre inngripende, og pasienten kan være våken. Også her er det mulig å gi god smertelindring. Det er som regel lettere å få besøk, og pasienten kan ha litt mer privatliv og flere personlige eiendeler enn på en intensivavdeling.
- Selv om intensivbehandling blir gitt med formålet om å redde liv, så er det ikke sikkert at sjansen for å overleve *med et godt resultat* er større på intensivavdelingen enn på sengepost ved mange akutte tilstander som rammer de eldste pasientene.
- Mindre enn halvparten av pasientene over 80 år som har fått intensivbehandling i Norge, er i live etter ett år. Mange har vedvarende nedsatt funksjon, både fysisk og psykisk, og trenger mer hjelp i hverdagen enn før. Samtidig oppgir de fleste overlevende å ha god livskvalitet.
- Ved akutt, livstruende sykdom er det ofte ikke mulig for pasienten å medvirke i beslutningsprosessen. Samtidig må beslutningen ofte tas under tidspress og kan ha store konsekvenser. I slike tilfeller blir vanligvis nærmeste pårørende bedt om å gi opplysninger om pasientens sannsynlige behandlingsønsker.
- Vi vet lite om hva eldre mennesker vil foretrekke av behandling ved akutt livstruende sykdom og om hvordan de ønsker at beslutninger om inngripende medisinsk behandling skal tas dersom de ikke kan samtykke selv.
- Vi vet heller ikke nok om pårørendes rolle i slike vanskelige beslutningsprosesser, og vi ønsker derfor å belyse hele samhandlingen mellom pasient, pårørende og helsepersonell når valget står mellom å tilby eller avstå fra intensivbehandling.

Pasienthistorie 1:

En mann i 80-årene fikk utført en liten operasjon for nyrestensanfall. I løpet av det neste døgnet blir han akutt dårlig, og det blir påvist blodforgiftning med svikt i flere livsviktige organer. Pasienten får antibiotika og væske intravenøst (inn i en blodåre) med en gang, men likevel blir både nyrefunksjonen og lungefunksjonen verre, og han blir forvirret.

Legene drøfter nå om pasienten skal bli overflyttet til intensivavdelingen for å få behandling med pustemaskin og nyreerstattende behandling med dialysemaskin. Det vil medføre at han må legges i kunstig koma i noen dager. Alternativet er at han blir værende på vanlig sengeavdeling og fortsetter med behandlingen han har fått til nå. Ved behov kan han også få medisin som lindrer smerter, tung pust og andre plagsomme symptomer.

Omtrent fire av fem pasienter i denne situasjonen overlever intensivbehandlingen, og noen overlever også uten intensivbehandling. Av alle som får intensivbehandling, er mindre enn halvparten i live etter 6–12 måneder. Både fysisk og psykisk funksjon er varig redusert hos mange av dem som overlever.

1.1 Tenk deg nå at den du er pårørende til, er denne pasienten.
Hva mener du hun/han ville ha ønsket?
Kryss av i den ENE boksen for den påstanden som passer best for henne/ham:

- ❑ Hun/han ville ønsket innleggelse på intensivavdelingen
- ❑ Hun/han ville ikke ønsket innleggelse på intensivavdelingen
- ❑ Hun/han ville ikke ønsket å ta stilling til dette

1.2 Hvor sikker er du på at hun/han ville ønsket det slik? Kryss av i EN boks:

- ❑ Helt sikker
- ❑ Nokså sikker
- ❑ Hverken sikker eller usikker
- ❑ Nokså usikker
- ❑ Helt usikker

1.3 Kan du utdype hvorfor du tenker den du er pårørende til, ville ønsket det slik?

……..

……..

……..

1.4 Tenk deg nå at du selv er denne pasienten. Hva ville du ønsket for deg selv?
Kryss av i den ENE boksen for den påstanden som passer best for deg:

- ❑ Jeg ville ønsket innleggelse på intensivavdelingen
- ❑ Jeg ville ikke ønsket innleggelse på intensivavdelingen
- ❑ Jeg ville ikke ønske å ta stilling til dette

1.5 Hvor sikker er du på at du ville ønsket det slik? Kryss av i EN boks:

- ❑ Helt sikker
- ❑ Nokså sikker
- ❑ Hverken sikker eller usikker
- ❑ Nokså usikker
- ❑ Helt usikker

1.6 Kan du utdype hvorfor du ville ønsket det slik for deg selv?

……..

……..

……..

Pasienthistorie 2:

En kvinne i 80-årene falt fra en stige og ble innlagt på sykehus med brudd i skulderblad og i flere ribbein på venstre side. Etter en uke blir hun tiltagende sliten og forvirret. Det blir påvist lungebetennelse, og hun får behandling med antibiotika intravenøst (rett inn i en blodåre). Til tross for denne behandlingen utvikler hun blodforgiftning med sviktende funksjon i flere livsviktige organer.

Legene drøfter nå om pasienten skal bli overflyttet til intensivavdelingen for å få behandling med pustemaskin og nyreerstattende behandling med dialysemaskin. Det vil medføre at hun må legges i kunstig koma i noen dager. Alternativet er at hun blir værende på vanlig sengeavdeling og fortsetter med behandlingen hun har fått til nå. Ved behov kan hun også få medisin som lindrer smerter, tung pust og andre plagsomme symptomer.

Omtrent fire av fem pasienter i denne situasjonen overlever intensivbehandlingen, og noen overlever også uten intensivbehandling. Av alle som får intensivbehandling, er mindre enn halvparten i live etter 6–12 måneder. Både fysisk og psykisk funksjon er varig redusert hos mange av dem som overlever.

2.1 Tenk deg nå at den du er pårørende til, er denne pasienten.
Hva mener du hun/han ville ha ønsket?
Kryss av i den ENE boksen for den påstanden som passer best for henne/ham:

- ❑ Hun/han ville ønsket innleggelse på intensivavdelingen
- ❑ Hun/han ville ikke ønsket innleggelse på intensivavdelingen
- ❑ Hun/han ville ikke ønsket å ta stilling til dette

2.2 Hvor sikker er du på at hun/han ville ønsket det slik? Kryss av i EN boks:

- ❑ Helt sikker
- ❑ Nokså sikker
- ❑ Hverken sikker eller usikker
- ❑ Nokså usikker
- ❑ Helt usikker

2.3 Kan du utdype hvorfor du tenker den du er pårørende til, ville ønsket det slik?

……..

……..

……..

2.4 Tenk deg nå at du selv er denne pasienten. Hva ville du ønsket for deg selv?
Kryss av i den ENE boksen for den påstanden som passer best for deg:

- ❑ Jeg ville ønsket innleggelse på intensivavdelingen
- ❑ Jeg ville ikke ønsket innleggelse på intensivavdelingen
- ❑ Jeg ville ikke ønske å ta stilling til dette

2.5 Hvor sikker er du på at du ville ønsket det slik? Kryss av i EN boks:

- ❑ Helt sikker
- ❑ Nokså sikker
- ❑ Hverken sikker eller usikker
- ❑ Nokså usikker
- ❑ Helt usikker

2.6 Kan du utdype hvorfor du ville ønsket det slik for deg selv?

……..

……..

……..

Pasienthistorie 3:

En kvinne i 80-årene ble operert for et hull på magesekken på grunn av magesår. Mageinnhold har lekket ut i bukhulen og ført til blodforgiftning. Hun ble derfor behandlet med antibiotika intravenøst (rett inn i en blodåre). Som følge av blodforgiftningen har hun nedsatt bevissthet og sviktende funksjon i flere andre livsviktige organer.

Legene drøfter nå om pasienten skal bli overflyttet til intensivavdelingen for å få behandling med pustemaskin og nyreerstattende behandling med dialysemaskin. Det vil medføre at hun må legges i kunstig koma i noen dager. Alternativet er at hun blir værende på vanlig sengeavdeling og fortsetter med behandlingen hun har fått til nå. Ved behov kan hun også få medisin som lindrer smerter, tung pust og andre plagsomme symptomer.

Omtrent fire av fem pasienter i denne situasjonen overlever intensivbehandlingen, og noen overlever også uten intensivbehandling. Av alle som får intensivbehandling, er mindre enn halvparten i live etter 6–12 måneder. Både fysisk og psykisk funksjon er varig redusert hos mange av dem som overlever.

3.1 Tenk deg nå at den du er pårørende til, er denne pasienten.
Hva mener du hun/han ville ha ønsket?
Kryss av i den ENE boksen for den påstanden som passer best for henne/ham:

- ❑ Hun/han ville ønsket innleggelse på intensivavdelingen
- ❑ Hun/han ville ikke ønsket innleggelse på intensivavdelingen
- ❑ Hun/han ville ikke ønsket å ta stilling til dette

3.2 Hvor sikker er du på at hun/han ville ønsket det slik? Kryss av i EN boks:

- ❑ Helt sikker
- ❑ Nokså sikker
- ❑ Hverken sikker eller usikker
- ❑ Nokså usikker
- ❑ Helt usikker

3.3 Kan du utdype hvorfor du tenker den du er pårørende til, ville ønsket det slik?

……..

……..

……..

3.4 Tenk deg nå at du selv er denne pasienten. Hva ville du ønsket for deg selv?
Kryss av i den ENE boksen for den påstanden som passer best for deg:

- ❑ Jeg ville ønsket innleggelse på intensivavdelingen
- ❑ Jeg ville ikke ønsket innleggelse på intensivavdelingen
- ❑ Jeg ville ikke ønske å ta stilling til dette

3.5 Hvor sikker er du på at du ville ønsket det slik? Kryss av i EN boks:

- ❑ Helt sikker
- ❑ Nokså sikker
- ❑ Hverken sikker eller usikker
- ❑ Nokså usikker
- ❑ Helt usikker

3.6 Kan du utdype hvorfor du ville ønsket det slik for deg selv?

……..

……..

……..

4. Mange pasienter kan ikke gjøre rede for sine behandlingsønsker ved akutt livstruende sykdom. Denne delen av spørreskjemaet handler om hvordan du tenker helsevesenet og pårørende bør samarbeide i en slik situasjon.

4.1 Ville du ønsket at legene drøfter behandlingsmulighetene for den du er pårørende til, med deg i en slik situasjon? Kryss av i EN boks:

- ❑ Ja
- ❑ Nei
- ❑ Vet ikke

4.2 Hvor sikker er du på at du kan svare rett på hva den du er pårørende til, ville ønsket for seg selv i en slik situasjon? Kryss av i EN boks:

- ❑ Helt sikker
- ❑ Nokså sikker
- ❑ Hverken sikker eller usikker
- ❑ Nokså usikker
- ❑ Helt usikker

4.3. Kan du utdype hvordan du som pårørende ønsker å bidra til å ta beslutninger i en slik situasjon?

……..

……..

……..

……..

……..

……..

……..

……..

……..

……..

5. Denne delen av spørreskjemaet handler om erfaring du og/eller den du er pårørende til, har med akutt alvorlig sykdom og om den du er pårørende til, har gitt utrykk for sine tanker rundt dette.

Alle pasienter som blir innlagt på sykehus med behov for øyeblikkelig hjelp, kommer først til *akuttmottaket*. Derfra blir de flyttet til en avdeling (sengepost) for videre behandling.

Bare pasienter som er så syke at de trenger kontinuerlig overvåkning og / eller organstøttende behandling med apparater, for eksempel med en pustemaskin, blir innlagt på en *intensivavdeling.*

5.1 Har du selv vært innlagt på en intensivavdeling før?
Kryss av i EN boks:

- ❑ Ja
- ❑ Nei

5.2 Har den du er pårørende til, vært innlagt på en intensivavdeling før?
Kryss av i EN boks:

- ❑ Ja
- ❑ Nei
- ❑ Vet ikke

5.3 Har du selv erfaring med å være pårørende på en intensivavdeling?
Kryss av i EN boks:

- ❑ Ja
- ❑ Nei

5.4 Har den du er pårørende til, erfaring med å være pårørende på en intensivavdeling?
Kryss av i EN boks:

- ❑ Ja
- ❑ Nei
- ❑ Vet ikke

Et *livstestament* er et dokument hvor du skriver hva du ønsker / ikke ønsker av behandling hvis du senere blir alvorlig syk og ikke lenger kan uttrykke egne ønsker.

En *fremtidsfullmakt* er en fullmakt du gir én eller flere personer til å ivareta dine interesser når du ikke lenger er i stand til det selv.

5.5 Har den du er pårørende til, et livstestament eller en fremtidsfullmakt?
Kryss av i EN boks:

- ❑ Ja
- ❑ Nei
- ❑ Vet ikke

5.6 Har den du er pårørende til, snakket med deg om sine ønsker for behandling ved alvorlig sykdom, ved langvarig pleie eller ved livets slutt?
Kryss av i EN boks:

- ❑ Ja
- ❑ Nei

6. Denne delen av spørreskjemaet handler om helsen til den du er pårørende til.

6.1 Har hun/han, eller har hun/han hatt, én eller flere av disse sykdommene?
Kryss av i ALLE bokser som passer for henne/ham:

- ❑ Ingen av de nedenstående sykdommene

- ❑ Astma/KOLS
- ❑ Autoimmun sykdom
- ❑ Demens
- ❑ Diabetes
- ❑ Forkalkning i pulsårer
- ❑ Hjerneslag/drypp
- ❑ Hjerteinfarkt
- ❑ Hjertesvikt
- ❑ Kronisk smerte
- ❑ Kreft
- ❑ Lammelse etter slag
- ❑ Leversykdom
- ❑ Magesår
- ❑ Nyresvikt
- ❑ Psykisk sykdom
- ❑ Varig mén etter traume/skade

6.2 Hvor mange forskjellige medikamenter tar hun/han daglig?
Hvis hun/han ikke bruker medikamenter daglig, skriv 0.
Hvis du er usikker, skriv cirka antall.

..... (skriv antall)

6.3 Har den du er pårørende til, vært innlagt på sykehus i løpet av de siste 12 månedene? Kryss av i EN boks:

- ❑ Ja
- ❑ Nei
- ❑ Vet ikke

7. Denne delen av spørreskjemaet handler om fysisk form og helse-relatert livskvalitet til den du er pårørende til.

Hvor sprek er den du er pårørende til?
Sett kryss i den ENE boksen ved siden av bildet og teksten som best beskriver henne/ham:

❑ 

Veldig sprek
Personer som er robuste, aktive, energiske og motiverte. De pleier å trene og er blant de sprekeste i sin aldersgruppe.

❑ 

Sprek
Personer som ikke har aktive sykdomssymptomer, men er mindre spreke enn personer i kategori 1. Ofte trener de eller er veldig aktive av og til, for eksempel sesongpreget.

❑ 

Klarer seg bra
Personer der medisinske problemer er velkontrollerte, selv om de kan ha symptomer av og til, men som ikke er regelmessig aktive bortsett fra vanlige gåturer.

❑ 

Lever med svært mild skrøpelighet
Denne kategorien ble tidligere kalt «sårbar», og markerer en tidlig overgang fra å være helt selvstendig. Selv om de ikke er avhengig av daglig hjelp fra andre, vil symptomer begrense deres aktiviteter. De klager ofte over at de er «langsomme» og/eller blir slitne/trøtte ila dagen.

❑ 

Lever med mild skrøpelighet
Disse er mer tydelig langsomme, og trenger hjelp til komplekse aktiviteter i dagliglivet (økonomi, transport, tungt husarbeid). Vanligvis vil mild skrøpelighet i økende grad føre til problemer med å handle eller gå utenfor hjemmet alene, lage mat, ordne medisiner, og evnen til lett husarbeid begynner å bli begrenset.

❑ 

Lever med moderat skrøpelighet
Personer som må ha hjelp til alle aktiviteter utendørs og med å stelle hjemmet. Innendørs har de ofte problemer med trapper, trenger hjelp til bading/dusj og kan trenge litt hjelp til å kle på seg (veiledning, med tilsyn).

❑ 

Lever med alvorlig skrøpelighet
Personer som er helt avhengige av hjelp til personlig stell uansett årsak (fysisk eller kognitiv). Likevel fremstår de som stabile og uten høy risiko for å dø (innen anslagsvis 6 måneder).

❑ 

Lever med svært alvorlig skrøpelighet
Personer som er helt avhengige av hjelp i dagliglivet og nærmer seg livets slutt. Vanligvis vil de ikke komme seg igjen selv etter mild sykdom.

❑ 

Terminalt syk
Nærmer seg livets slutt. I denne kategorien inngår personer med en forventet levetid på <6 måneder uten at de lever med alvorlig skrøpelighet. (Mange terminalt syke pasienter kan være fysisk aktive inntil de er svært nær døden).

Under hver overskrift ber vi deg krysse av den ENE boksen som du mener best beskriver helsen til den du er pårørende til, I DAG.

GANGE

- Ingen problemer med å gå omkring ❑
- Litt problemer med å gå omkring ❑
- Middels store problemer med å gå omkring ❑
- Store problemer med å gå omkring ❑
- Ute av stand til å gå omkring ❑

PERSONLIG STELL

- Ingen problemer med å vaske seg eller kle seg ❑
- Litt problemer med å vaske seg eller kle seg ❑
- Middels store problemer med å vaske seg eller kle seg ❑
- Store problemer med å vaske seg eller kle seg ❑
- Ute av stand til å vaske seg eller kle seg ❑

VANLIGE GJØREMÅL *(f.eks. arbeid, studier, husarbeid, familie- eller fritidsaktiviteter)*

- Ingen problemer med å utføre sine vanlige gjøremål ❑
- Litt problemer med å utføre sine vanlige gjøremål ❑
- Middels store problemer med å utføre sine vanlige gjøremål ❑
- Store problemer med å utføre sine vanlige gjøremål ❑
- Ute av stand til å utføre sine vanlige gjøremål ❑

SMERTER / UBEHAG

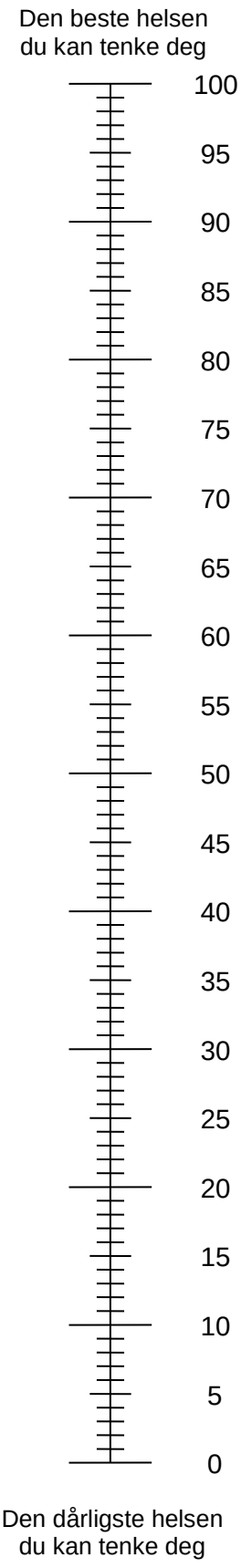
- Verken smerter eller ubehag ❑
- Litt smerter eller ubehag ❑
- Middels sterke smerter eller ubehag ❑
- Sterke smerter eller ubehag ❑
- Svært sterke smerter eller ubehag ❑

ANGST / DEPRESJON

- Verken engstelig eller deprimert ❑
- Litt engstelig eller deprimert ❑
- Middels engstelig eller deprimert ❑
- Svært engstelig eller deprimert ❑
- Ekstremt engstelig eller deprimert ❑

- Vi vil gjerne vite hvor god eller dårlig du mener helsen til den du er pårørende til, er I DAG.
- Denne skalaen er nummerert fra 0 til 100.
- 100 betyr den beste helsen du kan tenke deg.
  0 betyr den dårligste helsen du kan tenke deg.
- Sett en X på skalaen for å angi hvordan du mener helsen til den du er pårørende til, er I DAG.
- Skriv deretter tallet du merket av på skalaen inn i boksen nedenfor.

PASIENTENS HELSE I DAG ☐



8. Til slutt ber vi deg om å besvare noen spørsmål om deg selv.

Kryss av i den ENE boksen som passer best for deg:

8.1 Alder:

…… år

8.2 Hvor er du født?

- ❑ Norge
- ❑ Annet land

8.3 Hvis du ikke er født i Norge, hvilket land er du født i? .....

8.4 Kjønn:

- ❑ Kvinne
- ❑ Mann
- ❑ Annet / ønsker ikke å svare

8.5 Sivilstand:

- ❑ Enslig
- ❑ Gift / registrert partner / samboer
- ❑ Enke/enkemann
- ❑ Separert/skilt

8.6 Livssyn:

- ❑ Kristent livssyn
- ❑ Annet religiøst livssyn
- ❑ Ikke-religiøst livssyn

8.7 Hva er den høyeste utdanningen du har tatt?

- ❑ Grunnskole
- ❑ Gymnas/videregående
- ❑ Yrkesskole/fagbrev
- ❑ Høyskole/universitet

8.8 Hva er/var yrket ditt? ……

9. Har du tanker angående denne spørreundersøkelsen som du ønsker å dele med oss?

.....

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.....

10. Kan vi sende deg en tilsvarende spørreundersøkelse om 1–2 år?

I så fall ber vi deg om å oppgi ditt navn og din adresse. Din kontaktinformasjon vil bli lagret adskilt, slik at svarene du har gitt i spørreskjemaet, ikke vil være direkte identifiserbare. Om du oppgir din kontaktinformasjon nå, så kan du likevel når som helst og uten begrunnelse trekke deg fra studien.

Navn: .....

Adresse: .....

TUSEN TAKK FOR AT DU TOK DEG TID TIL Å BESVARE VÅRE SPØRSMÅL!