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# BMJ Open

## Protocol for EXICODE: The EXIstential health COhort Denmark – a registry and survey study on adult Danes.

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4 **Protocol for EXICODE: The EXIstential health COhort DENmark – a**  
5 **registry and survey study on adult Danes.**  
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## ABSTRACT

### Introduction

EXICODE is established to examine how existential and spiritual needs, practices and orientations in a secular culture is linked to health outcomes, illness trajectory, and overall cost of care in patients. Existential and spiritual wellbeing has previously been shown to have positive effects on health. While people turn to existential and spiritual orientations and practices during aging, struggle with illness, and approaching death, patients with severe illness like e.g. cancer experience existential and spiritual needs which are often unmet in secular societies leading to spiritual pain, unnecessary suffering, worse quality of life and higher medical costs of care.

### Methods and analysis

EXICODE is designed as a national cohort comprising a ten percent random sample of the adult Danish population with individual level registry and survey data. Specific patient subgroups are oversampled to ensure diseased respondents. The questionnaire used in the survey consists of a collection of validated instruments on existential and spiritual constructs suited for secular culture as well as some ad hoc questions compiled in the comprehensive EXICODE Questionnaire.

### Ethics and dissemination

The project is registered for legal and GDPR concerns by the University of Southern Denmark, journal number: 10.367, for ethical concerns by the University of Southern Denmark Research Ethics Committee (institutional review board), journal number: 20/39546. The project follows The Danish Code of Conduct for Research Integrity and is carried out in accordance with the Helsinki Declaration. Results will be disseminated widely through publications in peer-reviewed scientific journals, international conferences, patient societies as well as mass and social media.

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## STRENGTHS AND LIMITATIONS OF THIS STUDY

- The study takes advantage of the comprehensive, valid, and detailed clinical and demographic information available in the Danish national registries that are based on administrative information established independently of the research questions.
- The study is limited by the well-known risk for selection bias with the possibility for leaving out the most distressed, ill, or low socio-economic-status patients as well as low digital literacy participants as the survey is administered digitally.
- Access to registry data on non-responders will give the possibility to discuss results in light of non-responder characteristics.
- The combination of the questionnaire consisting of validated instruments on existential and spiritual constructs and the detailed clinical and sociodemographic registry data which can be linked at an individual level entails the possibility for a unique, large, and high-quality cohort.

## INTRODUCTION

Patients in hospitals in secular cultures such as Denmark experience existential and spiritual needs.[1] Some patients in general practice also have such needs and many would like their doctor to inquire about them, while many general practitioners rarely do.[2, 3] There are various reasons for this, one is a knowledge gap as to what effects existential and spiritual needs, engagement practices and orientations have in the Danish secular culture and the implications of these for health care and cost of care.[1] Consequently, there is a lack in the provision of spiritual care since the necessary knowledge to guide and back up societal and clinical policies on spiritual care is lacking.[4] EXICODE is established with the aim of examining these relations in order to provide solid evidence upon which to build clinical interventions, eHealth solutions and patient, relatives, and health care professional support measures, which can aid in providing existential and spiritual care.

### Terminology

Since the field of faith and health is limited by a heterogenous use of terms, a clarification is in order.[5] In the manuscript the term 'existential and spiritual' (in Danish: *eksistentiel og "åndelig"*, not "*spirituel*") will be used to nominate existential aspects of meaning, unless more specific terminology is provided. Such aspects may be both; (1) religious, e.g. related to specific religious connotation, community, theology, relation to God/higher power etc., (2) spiritual, e.g. often a more universal and subjective experience of the transcendent or salient/sacred features in the environment, with or without specific theology etc., or (3) secular, e.g. related to personal values, meaning in life, relation to nature or other persons.[6, 7] The term 'spiritual care' refers to caring for existential and spiritual needs.[8]

EXICODE refers to EXIstential health COhort DENmark, but the name bears more meaning than such. The project is also named thus as we are attempting to put the difficult to grasp constructs of existential and spiritual needs, orientations, and practices on some sort of "code" – that we may address these issues and their impact on secular society quantitatively. This is done with the utmost respect that such concepts will for some people always remain larger than what may be embedded in even the most comprehensive survey.

### Spirituality and health in secular culture

Links between religiosity, spirituality, and health have been well established over the last decades.[9] Generally, it has been shown that spiritual well-being, understood in terms of meaningfulness, hope, trust and coherence with a higher power, is a positive predictor for better physical, mental and social health including reduced morbidity, increased longevity, faster recovery, and a happier life.[9] Spiritual needs or struggles may emerge from patients' existential or spiritual convictions during a health crisis (or life crisis in healthy individuals).[10] Also, people turn to existential and spiritual orientations and practices the more they age, struggle with illness,

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4 or approach death.[11-13] Some of these needs and struggles may be related to health impairment,  
5 wellbeing, depressive intention to escape from illness, etc.[14-19] A phenomenologically specific  
6 experience that may give rise to substantial spiritual needs, as it accompanies serious illness, is the  
7 near-death experience (NDE). Experienced in all cultures and throughout all times, an NDE can be  
8 a lifechanging event which may require professional support.[20]  
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13 Being diagnosed with cancer represent such a health crisis. North American studies with cancer  
14 patients suggest that between 66-83% of patients want their physicians to inquire about religiosity  
15 or spiritual issues,[2, 21] and 21% of cancer patients in a Danish study reported one or more  
16 "spiritual / religious concerns".[22] Conversely, spirituality has been found to be a positive  
17 resource in cancer coping, to be positively associated with quality of life, and to improve symptom  
18 tolerance in aging cancer populations.[23-30] Studies, also from Denmark, have even found  
19 spirituality to be associated with increased longevity and reduced risk of cancer.[31-34] These  
20 findings have been replicated in various cultural settings.[35] It is noteworthy, that even in more  
21 secular European societies, spirituality was a relevant resource to cope with chronic and serious  
22 illness.[36-47]  
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29 There is a large amount of research into various cardiac arrest survivor outcomes, i.e. [48-53]  
30 However, there is limited knowledge about existential and spiritual needs related to surviving a  
31 cardiac arrest.[54] Research highlights the importance of attention to these needs.[54-57] Many  
32 studies suggest that survivors have increased anxiety, depression and other psychological needs,  
33 and a comprehensive Danish study has shown increased risk of suicide after cardiac arrest with  
34 successful resuscitation.[58, 59] Many patients with cardiovascular disease experience high levels  
35 of unfulfilled existential and spiritual needs, associated with poorer existential, mental, and  
36 physical well-being.[60]  
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42 Likewise, Chronic Obstructive Pulmonary Disease (COPD) patients, who suffer from dyspnoea as  
43 the major symptom, may have unmet spiritual needs. The risk of suffocation entails physical and  
44 psychological distress – distress that has been found to lead to existential and spiritual distress and  
45 prompt spiritual needs. Thus, a review regarding palliative and end-of-life care for patients with  
46 severe COPD, identified spiritual care as one of the most neglected but important areas of care for  
47 COPD.[61, 62] A Danish study found similar spiritual needs in Danish COPD patients. It is  
48 noteworthy that existential or spiritual resources help COPD patients cope with life and consider  
49 life as valuable and beautiful, despite severe disease.[63] Nevertheless, COPD patients across  
50 various cultural settings have few to talk to about spiritual issues, which may partly be due to  
51 stigma and a sense of self-blame.[64-66]  
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57 It is worth noting that the pathophysiologic processes behind suffering from cancer, cardiac arrest  
58 or having COPD are very different, resulting in different situations for the patient. Cancer  
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4 diagnoses have very heterogenous expressions, cardiac arrest is often a sudden event  
5 characterized among other things by the potential of (full) recovery (however, seldom recovery  
6 from the underlying cause), while COPD is a slowly progressing disease with no possibilities of  
7 being cured, and with focus on coping, relief of symptoms, and halting of disease progression  
8 (which may also be the case for some cancer patients). Likewise, existential and spiritual needs and  
9 practices may also be very different across age groups.  
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### 14 **Implications for secular Denmark**

15 Secular societies are among other things characterized by a strong separation of church and state.  
16 This is also the case in Denmark where religion plays a minor role in public discourse and church  
17 attendance is unusually low.[67-71] There are multiple reasons for this secularism of the Danish  
18 culture. Consequently, Danes consider “faith and religion” to be the largest taboo just after  
19 “mental illness”. [72] This attitude is reflected in the health care system with regards to the spiritual  
20 care administered. Health professionals are generally convinced existential and spiritual resources  
21 have a positive impact on patients’ health and handling of disease,[73, 74] just as they agree  
22 spiritual care should be performed.[75, 76] However, patients are largely not receiving such  
23 spiritual care.[2, 4, 21, 75-79] It is reasonable to expect that this is similar in other secular cultures  
24 as well. Studies from relatively more religious regions in North America, show that palliative  
25 patients who experience low levels of existential and spiritual support have lower quality of life,  
26 encounter more complications, and higher overall medical care costs.[80-82] Thus, a focus on  
27 alleviating existential and spiritual pain may embed a large financial potential for health economy  
28 in secular cultures as well. Supporting researchers, clinicians, and policymakers in providing  
29 existential and spiritual care for the patients and relatives in need of such, may also have large  
30 impact on public health. The imaginable approaches and interventions are numerous, some  
31 already on their way. While in secular societies such as Denmark, the physical, psychological, and  
32 social aspects of health have for decades been utilized and exploited, with the proper evidence,  
33 perhaps it is time to invite existential and spiritual resources of patients and relatives to contribute  
34 to their health.  
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### 45 **Objectives**

46 This paper reports the protocol for EXICODE – the EXistential health COhort DENmark. The  
47 overall aim of the cohort is to examine in the secular Danish setting existential and spiritual  
48 constructs and establish evidence on the links between existential and spiritual constructs of  
49 interest with clinical, economic, and demographic variables.  
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## 53 **METHODS AND ANALYSIS**

### 54 **Study design**

55 EXICODE is designed as a national cohort based on registry and survey data.  
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### 59 **Registries**



The Danish national health registries collect detailed administrative data on all Danish citizens, including sociodemographic data and data on health care utilization, hospitalization, medications used etc.[83] All Danish citizens are registered in the Danish Civil Registration System (CRS) with a unique identification number enabling accurate linkage between registries at an individual level.

### Participant selection and recruitment

All participants are identified through the CRS. Participants are a random selection of ten percent of the adult (age >18yrs) Danish population. Furthermore, to ensure diseased participation, three subsamples are invited: (1) cancer patients diagnosed with either of the ten most frequent cancer diagnosis groups in Denmark during 2020 (based on NORDCAN classification [84]), (2) out-of-hospital cardiac arrest survivors (OHCAS) registered in 2016 through 2019, and (3) COPD patients hospitalized for COPD in 2020 (table 1). Since timeliness of disease event is considered important with regards to the outcomes investigated, the latest available registry data was sought. These diverse diagnosis categories are intended to contribute to nuanced understandings in the relation of health and existential needs as they span different age groups, disease progressions and severities and hope for a cure.

Table 1. Yearly incidence of the ten most frequent cancer diagnoses, out-of-hospital cardiac arrest, and chronic obstructive pulmonary disease (hospitalized) in Denmark.

	ICD-10	Men	Women	Total
<b>Cancer (NORDCAN 2016)</b>				
Colorectal	DC18-21	2904	2400	5304
Breast	DC50	46	4714	4760
Lung (incl. trachea)	DC33-34	2335	2367	4702
Prostate	DC61	4519	N/A	4519
Kidney, bladder, and other urinary tract	DC65-68, DD09.0-1, DD30.1-9, DD41.1-9	2254	891	3145
Malignant melanoma of the skin	DC43	1220	1388	2608
Esophagus, stomach, pancreas	DC15, DC16, DC25	1267	801	2068
Gynaecological	DC54, DC56.9, DC57.0-4	N/A	1862	1862
Brain and central nervous system	DC70-72, DC75.1-3, DD32-33, DD42-43	647	775	1422
Lip, oral, pharyngeal	DC00-14\DC10.1	711	298	1009
<b>Total</b>				31399
<b>Cardiac arrest (Danish Cardiac Arrest Registry 2016)</b>				

Out-of-hospital cardiac arrest (OHCA) (30d survival: 10.40%)	DI46*	2230	1251	3481
<b>Chronic Obstructive Pulmonary Disease (Lash et. al 2011)</b>				
Mucopurulent bronchitis, chronic bronchitis, emphysema, or COPD as primary diagnosis <b>OR</b> Pneumonia, respiratory insufficiency as primary with (J41-44) as secondary diagnosis	J41-44* <b>OR</b> Primary: J96+J13-18 + Secondary: J41-44	~5980	~7020	~13.000

All participants are invited digitally via 'e-Boks' (a secure national online e-post service that most Danes utilize; a small portion of older Danes do not use e-Boks) through their CRS-number to participate and fill out a digital survey. e-Boks will automatically retain letters erroneously sent to CRS-numbers of deceased individuals. The invitation letter includes information about how the individual was identified (thus, there are four slightly different letters), the study, information and legal notice on data management, consent to participate as well as a personal link to the questionnaire. e-Boks digital letters and the survey will be realized by Ramboll's SurveyXact, an online digital survey software.[85] Reminders will be sent after two weeks to non-responders. For respondents who agree to receive the questionnaire in the future, we will invite consecutive sampling at convenient time points. Due to institutional policy, no financial or lottery incitement will be provided.? Sampling strategy is illustrated in figure 1.

### Population size

The sample size was selected in order to give sufficient power to detect subgroup differences. No formal sample-size calculation was performed due to various cohort outcomes examined. The sample of randomly selected adult Danes is estimated to contain around 460.000 individuals. The three subsamples also invited are estimated to contain appr. 40-50.000 cancer patients, 2-2.500 OHCAS and 20-25.000 COPD patients. Only unique CRS-numbers are included. If any of the subsample participants are also drawn randomly in the ten percent lot, they will only be included as subsample participants.

### Eligibility

Inclusion is limited to adult (age  $\geq 18$  yrs) Danes with valid CRS-numbers. Criteria for subgroup inclusion is relevant ICD-10 diagnoses (table 1). Participants are excluded if they are not alive at time of data-collection.

## Measurements

### Questionnaire outcomes

The EXICODE Questionnaire totals six pages and includes seven internationally validated instruments, two subscales from validated instruments and some ad hoc items (table 2).

Table 2. The EXICODE Questionnaire. Outcomes on existential and spiritual constructs.

Instrument	Outcome	Items	Scoring	Item example
WHO-5 [86]	Well-being	5	6-point scale from "0 – never" to "5 – all the time". Summed scores referred to 100% level.	<i>During the past two weeks... ...I have felt active and energetic.</i>
EQ-5D-5L [87]	Health status (5 levels)	5	5-point scale of decreasing health status (1 = good, 5 = poor)	<i>Today... ...have you felt pain / discomfort?</i>
BMLSS [88]	Life and support satisfaction	18	7-point Likert scale from "0 – very unsatisfied" to "7 – very satisfied". Score is mean ref. to a 100% level.	<i>How satisfied are you with... ...your family life?</i>
SpNQ [89]	Spiritual needs (four dimensions)	20	4-point scale from "0 – not at all" to "3 – very strong". Scores are means per dimension.	<i>During the last month did you have the need... ...to be forgiven?</i>
SpREUK-P [90] + GrAw-7 [91]	Spiritual practices (four dimensions) + gratitude	25	4-point scale from "0 – never" to "3 – regularly". Scores are means per dimension ref. to a 100% level	<i>How often do you engage in the following: I meditate.</i>
AKU (RGH and escape subscales) [92]	Adaptive coping (two dimensions)	8	5-point Likert scale from "0 – does not apply" to "4 – definitely applies". Scores are means per dimension ref. to a 100% level.	<i>My faith is my foundation, even in difficult times.</i>
MAPS	Meaning and purpose (two dimensions)	6	6-point Likert scale from "0 – don't agree" to "5 – totally agree".	<i>My life is meaningful.</i>
NDE-C [93]	Near-death experience content (five dimensions)	20	5-point scale from "0 – not at all" to "4 – extreme". Cut-off score of $\geq 37$ is indicative of an NDE.	<i>You met a presence and/or an entity (i.e. a deceased person).</i>
(S)FI [94]	Human flourishing (five(six) dimensions)	12	Scored on 0-10 VAS on different categories. Scores are means per dimension.	<i>How happy or unhappy do you usually feel?</i>

The instruments are all suited for secular societies such as Denmark. The selection of instruments, translation, cultural adaptation and qualitative pilot testing is not yet published. However, results from this process indicated that the compiled questionnaire was comprehensible and that the digital design was feasible. A quantitative field test by convenience sampling, was conducted to test the psychometric properties of instruments before distributing the EXICODE Questionnaire to the intended population.

#### Health registry outcomes

The Danish Health Data Authority (SDS), Statistics Denmark (DST) and the Danish Cardiac Arrest Registry (DCAR) are data sources for independent registry data outcomes (table 3) at individual level coded by unique CRS-numbers.

Table 3. Registries, tables, and examples of registry data variables.

Registry	Table	Examples of derived variables
Statistics Denmark (DST)	Demographic	Civil status, family type, region, ethnicity, e/immigration, highest completed education, income, SES, work status and sick leave
	Clinical administrative outcomes	Date, diagnosis and type of health care service use on hospital, out-patient clinic or general practitioners' clinic, Charlson Comorbidity Index
	Communal care	Homenursing, homecare
Danish Health Data Authority (SDS)	Drug use	ATC-codes, exp. date/price, vol., packages bought
	Clinical details on cancer patients	Date of diagnosis, ICD-10, TNM, treatment, NORDCAN-group
	Rehabilitation	Date and type of rehabilitation training
The Danish Cardiac Arrest Registry (CAR)	Clinical details on cardiac arrest survivors	Date of arrest, HLR done, first observed heart-rhythm, status at arrival to hospital

All registry data will be pooled at DST's researcher server where data analysis will take place. Survey data will be transferred to DST's researcher server from the University of Southern Denmark once collected. The data flow is illustrated in figure 2.

#### Patient and Public Involvement statement

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4 The project is motivated based on previous studies and experiences with patients and public  
5 representatives. The project seeks to have a patient perspective as a central focus in all aspects of  
6 the research process. This process began by interviewing relevant end-users about their existential  
7 and spiritual needs, establishing the rationale and content validity of the project aims. Public  
8 dissemination of results and project milestones is prioritized.  
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### 13 **Statistical analysis plan**

14 Multiple statistical approaches will be applied to both survey and registry data. Responders will be  
15 presented using descriptive statistics and compared to non-responders on age, gender, socio-  
16 economic status and region of living. Various primary outcomes are surveyed: spiritual needs,  
17 spiritual practices, well-being, health status, satisfaction with life and support, flourishing,  
18 gratitude and awe, religious coping. Statistical analyses will be carried out with regards to each  
19 survey outcome measure to investigate associations to physical health outcomes from registry  
20 data. Subsamples of cases will be investigated with respect to outcomes, using hypothesis tests,  
21 explorative correlational analyses, and regression modelling. Subsamples will be analysed in a  
22 matched setup where healthy Danes from the cohort will be matched to diseased subsample cases  
23 1:5 based on age, gender, income, and educational level. Health economic analyses will be  
24 conducted to investigate associations between the surveyed outcomes and registry data variables  
25 proxying (1) health care cost, i.e. prescribed medicine, use of healthcare services etc., (2) loss of  
26 productivity, i.e. sick leave etc. and (3) social care costs, i.e. home nursing etc. Longitudinal  
27 mediation and causal inference analyses will be performed on consecutive data collections to  
28 establish a timeliness of associations.  
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37 All statistical analyses will be carried out in STATA 16.0 or above with a significance level ( $\alpha$ ) of  
38 5%.  
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### 41 **Data management**

42 A thorough data management plan has been prepared including codebook on all outcomes. These  
43 are available upon request. Although data will be FAIR [95], we will not be able to freely share all  
44 data collected in a repository due to legal and ethical limitations. Thus, we invite interested parties  
45 to reach out for collaborating projects on the data which will be available in EXICODE.  
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## 50 **ETHICS AND DISSEMINATION**

### 51 **Ethics and legal concerns**

52 The project is registered for legal and GDPR concerns at the *University of Southern Denmark Legal*  
53 *Services* (SDU RIO), journal number: 10.367. The project is approved by the institutional review  
54 board *University of Southern Denmark Research Ethics Committee* (SDU REC), journal number:  
55 20/39546. The project has been evaluated by the *Danish Regional Scientific Ethical Committee*, journal  
56 number: 20202000-116, and the *Danish Authority for Patient Security* (STPS); these two institutions  
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4 declared that the project did not fall under the type of project for which approval is required and  
5 thus waived the applications. The project follows *The Danish Code of Conduct for Research*  
6 *Integrity*[96] and is carried out in accordance with the *Helsinki Declaration*. [97] The interviewers for  
7 the pilot test were well-trained in noticing unease on behalf of the interviewee. Some of the  
8 scripted probes in the cognitive interviews were addressing the burden/discomfort of filling out  
9 the questionnaire or unease emerging from answering e.g. faith items. This is also the reason why  
10 we have obtained a rigorous ethical review of the protocol although it is not legally necessary to do  
11 so in a Danish context when conducting interviews or surveys. Participant consent is obtained at  
12 participation, and data is handled according to Danish law.  
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18 Ethical approvals and development of the EXICODE Questionnaire began in May 2020. Since  
19 access to registry data has been delayed due to COVID-19 we expect to perform the first data-  
20 collection on the cohort by Winter 2021.  
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### 24 **Dissemination**

25 The results of the project will be reported according to the STROBE statements,[98] and  
26 disseminated widely through publications in peer-reviewed scientific journals, international  
27 conferences, patient societies, mass and social media. A media strategy will be prepared together  
28 with publishers and funding organizations to increase public and academic reach.  
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### 32 **Perspectives**

33 EXICODE represents to the best of our knowledge the largest cohort with detailed individually  
34 linked registry- and survey data on existential and spiritual needs, practices and orientations ever  
35 conducted in Denmark, and quite possibly internationally. We anticipate that the project will  
36 establish the knowledge base upon which to build future clinical interventions in secular countries  
37 like Denmark aimed at supporting patients and relatives in receiving existential and spiritual care  
38 and health care professionals, such as oncologists, geriatricians, and general practitioners among  
39 others, in providing such care. We expect the results to translate into concrete interventions such  
40 as communication tools, communication courses with learning support measures, e-Health  
41 solutions and other patient support tools that can be included in healthcare practices – some of  
42 these interventions are already on the way. An interesting novel approach for the future would be  
43 to try and find meaningful ways to utilize AI, IoT, or computer-based-learning to enhance and  
44 deliver spiritual care – a kind of care, which is at the time of writing dominantly provided through  
45 human interaction. The ultimate effects are expected to be reflected in a changed attitude to and  
46 practice of existential and spiritual care and patient centered medicine. We believe that the project  
47 will have significant effects for patients, health professionals and the health care system in  
48 Denmark and similar secular countries.  
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### 58 **AUTHORS CONTRIBUTIONS**

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4 NCH, TKS, and JS constructed the protocol and design. TKS made the first draft of this  
5 manuscript, NCH and JS contributed by thorough evaluation and revising of the manuscript and  
6 all phases of the project. SW contributed with statistical advice and study design. SW, AB, HJ,  
7 KAR, FLH and CBL contributed with thorough evaluation of design, method, and the manuscript.  
8 All authors accepted the final manuscript version.  
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## 12 **COMPETING INTEREST**

13  
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Figure 1. Sampling strategy diagram.

Figure 2. Data and project flow diagram. \*DST = Statistics Denmark, SDS = The Danish National Health Data Authority, DCAR = The Danish Cardiac Arrest Registry.

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General population

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Oversampling of diseased groups

Cancer patients

Cardiac arrest survivors

COPD patients

10% random draw of adult Danes

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Cohort

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Project aims / research questions

Questionnaire Development

Identification of registry data outcomes

Population invited to digital survey (EXICODE Questionnaire)

Registry data applications to DST, SDS and DCAR\*

Survey data

Registry data

Pooled data linked at individual level at DST's research server

Consecutive sampling

Consecutive sampling

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# BMJ Open

## Protocol for EXICODE: The EXIstential health COhort DENmark – a register and survey study of adult Danes.

Journal:	<i>BMJ Open</i>
Manuscript ID	bmjopen-2021-058257.R1
Article Type:	Protocol
Date Submitted by the Author:	01-Apr-2022
Complete List of Authors:	<p>Stripp, Tobias Kvist; University of Southern Denmark, Research Unit of General Practice, Institute of Public Health  Wehberg, Sonja; University of Southern Denmark, Research Unit of General Practice, Institute of Public Health  Büssing, Arndt; Witten/Herdecke University, Quality of Life, Spirituality and Coping; Odense University Hospital, Academy of Geriatric Cancer Research (AgeCare)  Andersen-Ranberg, Karen; University of Southern Denmark, Danish Aging Research Center, Institute of Public Health; Odense University Hospital, Academy of Geriatric Cancer Research (AgeCare)  Jensen, Lars Henrik; Lillebaelt Hospital, Department of Oncology; University of Southern Denmark, Department of Regional Health Research  Henriksen, Finn ; Odense University Hospital, Cardiology; University of Southern Denmark, Department of Clinical Research  Laursen, Christian; Odense University Hospital, Research Unit at the Department of Respiratory Medicine; University of Southern Denmark, Department of Clinical Research  SØNDERGAARD, JENS; University of Southern Denmark, Research Unit of General Practice, Institute of Public Health  Hvidt, Niels Christian; University of Southern Denmark, Research Unit of General Practice, Institute of Public Health; Odense University Hospital, Academy of Geriatric Cancer Research (AgeCare)</p>
<b>Primary Subject Heading</b>:	Public health
Secondary Subject Heading:	Epidemiology, Health economics, Mental health, Public health
Keywords:	PUBLIC HEALTH, EPIDEMIOLOGY, MENTAL HEALTH, PRIMARY CARE

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Manuscripts



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4 **Protocol for EXICODE: The EXIstential health COhort DENmark – a**  
5 **register and survey study of adult Danes.**  
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## ABSTRACT

### Introduction

We established EXICODE to examine how existential and spiritual needs, practices and orientations in a secular culture are linked to health outcomes, illness trajectory, and overall cost of care in patients. Substantial literature demonstrates that existential and spiritual well-being has positive effects on health. While people turn to existential and spiritual orientations and practices during ageing, struggle with illness, and approaching death, patients with severe illnesses like e.g. cancer similarly experience existential and spiritual needs. These needs are often unmet in secular societies leading to spiritual pain, unnecessary suffering, worse quality of life and higher medical costs of care.

### Methods and analysis

EXICODE is a national cohort comprising a 10% random sample of the adult Danish population with individual-level register and survey data. Specific patient subgroups are oversampled to ensure diseased respondents. The questionnaire used in the survey consists of a collection of validated instruments on existential and spiritual constructs suited for secular culture as well as some ad hoc questions compiled in the comprehensive EXICODE Questionnaire.

### Ethics and dissemination

The project is registered for legal and GDPR concerns by the University of Southern Denmark, journal number: 10.367. Ethical approval was not required by Danish law since EXICODE collects only interview, survey, and register data, but due to institutional best practice policy an ethical evaluation and approval were nevertheless obtained from the University of Southern Denmark Research Ethics Committee (institutional review board), journal number: 20/39546. The project follows The Danish Code of Conduct for Research Integrity and is carried out in accordance with the Helsinki Declaration. Results will be disseminated widely through publications in peer-reviewed scientific journals, international conferences, patient societies as well as mass and social media.

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## STRENGTHS AND LIMITATIONS OF THIS STUDY

- The study takes advantage of the comprehensive, valid, and detailed longitudinal clinical and demographic information available in the Danish national registers that are based on administrative information established independently of the research questions.
- The study is limited by the well-known risk for selection bias with the possibility of leaving out the most distressed, ill, or low socio-economic-status patients, as well as low digital literacy participants as the survey, is administered digitally.
- Access to register data on non-responders will give the possibility to discuss results considering non-responder characteristics.
- The combination of the questionnaire consisting of validated instruments on existential and spiritual constructs and the detailed longitudinal clinical and sociodemographic register data which can be linked at an individual level entails the possibility for an internationally unique, large, and high-quality cohort.

## INTRODUCTION

People within secular cultures who suffer from serious illnesses experience existential and spiritual needs.[1] While many patients in general practice also have such needs and would like their doctor to inquire about them, healthcare professionals rarely do.[2, 3] There are various reasons for this, one is a lack of knowledge on what effects existential and spiritual needs, engagement practices and orientations have in the secular culture and the implications of these for health care and cost of care.[1] Consequently, without the necessary knowledge to guide and back up societal and clinical policies, the administration of spiritual care is lacking.[4] Being a highly secular country, this is also true for Denmark which has been called the least religious culture in the world.[5] A culture in which 74% of the population are members of an organized church (the protestant Christian state church) that only 2% regularly visit.[6] We established EXICODE to examine these relations to provide solid evidence upon which to build clinical interventions, eHealth solutions and patient, relatives, and health care professional support measures, which can aid in providing spiritual care.

### Terminology

Since the field of faith and health is limited by a heterogenous use of terms, a clarification of how EXICODE operationalizes the concepts is in order.[7] Various relevant frameworks could be used in this process, e.g. the definitions used by Park, Breitbart, Folkman, Schnell and others.[8-11] In the manuscript 'existential and spiritual' (in Danish: *eksistentiel og "åndelig"*, not "*spirituel*") will be used to nominate the existential. Further, the definition by la Cour and Hvidt (12) of the term existential provides the framework of this manuscript as comprising three aspects of meaning-making, being; (1) religious, e.g. related to specific religious connotation, community, theology, relation to God/higher power etc., (2) spiritual, e.g. often a more universal and subjective experience of the transcendent or salient/sacred features in the environment, with or without specific theology etc., or (3) secular, e.g. related to personal values, meaning in life, relation to nature or other persons.[12, 13] The term 'spiritual care' refers to caring for existential and spiritual needs.[14]

EXICODE refers to EXIstential health COhort DENmark, but the name bears more meaning than such. The project is also named thus as we are attempting to put the difficult to grasp constructs of existential and spiritual needs, orientations, and practices on some sort of "code" – that we may address these issues and their impact on secular society quantitatively. This is done with the utmost respect that such concepts will for some people always remain larger than what may be embedded in even the most comprehensive survey.

### Spirituality and health in secular culture

Links between religiosity, spirituality, and health have been well established over the last decades.[15] Generally, it has been shown that spiritual well-being, understood in terms of meaningfulness, hope, trust and coherence with a higher power, is a positive predictor of better

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4 physical, mental and social health including reduced morbidity, increased longevity, faster  
5 recovery, and a happier life.[15] Strong evidence from well-designed longitudinal studies supports  
6 that especially religious activity (i.e. attendance)[16-19] and meaningfulness and purpose in life[20]  
7 promotes various aspects of health. Spiritual needs or struggles may emerge from patients'  
8 existential or spiritual convictions during a health crisis (or life crisis in healthy individuals).[21]  
9 Also, people turn to existential and spiritual orientations and practices the more they age, struggle  
10 with illness, or approach death.[22-24] Some of these needs and struggles may be related to health  
11 impairment, well-being, depressive intention to escape from illness, etc.[25-30] A  
12 phenomenologically specific experience that may give rise to substantial spiritual needs, as it  
13 accompanies serious illness, is the near-death experience (NDE). Experienced in all cultures and  
14 throughout all times, an NDE can be a life-changing event that may require professional  
15 support.[31]

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23 Being diagnosed with cancer represents such a health crisis. North American studies with cancer  
24 patients suggest that between 66-83% of patients want their physicians to inquire about religiosity  
25 or spiritual issues,[2, 32] and 21% of cancer patients in a Danish study reported one or more  
26 "spiritual / religious concerns".[33] In another Danish study among general practitioners 45% of  
27 physicians reported that they addressed spiritual issues less than once a year or never.[3]  
28 Conversely, spirituality has been found to be a positive resource in cancer coping, to be positively  
29 associated with quality of life, and to improve symptom tolerance in ageing cancer  
30 populations.[34-40] Also important to cancer patients is spiritual well-being, which may explain  
31 some of the health-related quality of life above what can be ascribed solely to physical or mental  
32 health measures.[41] Studies, also from Denmark, have even found spirituality to be associated  
33 with increased longevity and reduced risk of cancer.[42-45] These findings have been replicated in  
34 various cultural settings.[46] It is noteworthy, that even in more secular European societies,  
35 spirituality is a relevant resource to cope with chronic and serious illnesses.[47-58]

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43 There is a large amount of research into various cardiac arrest survivor outcomes, i.e. [59-64]  
44 However, there is limited knowledge about existential and spiritual needs related to surviving a  
45 cardiac arrest.[65] Research highlights the importance of attention to these needs.[65-68] Many  
46 studies suggest that survivors have increased anxiety, depression and other psychological needs,  
47 and a comprehensive Danish study has shown an increased risk of suicide after cardiac arrest with  
48 successful resuscitation.[69, 70] Many patients with cardiovascular disease experience high levels  
49 of unfulfilled existential and spiritual needs, associated with poorer existential, mental, and  
50 physical well-being.[71]

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55 Likewise, Chronic Obstructive Pulmonary Disease (COPD) patients, who suffer from dyspnoea as  
56 the major symptom, may have unmet spiritual needs. The risk of suffocation entails physical and  
57 psychological distress – distress that has been found to lead to existential and spiritual distress and  
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4 prompt spiritual needs. Thus, a review regarding palliative and end-of-life care for patients with  
5 severe COPD identified spiritual care as one of the most neglected but important areas of care for  
6 COPD.[72, 73] A Danish study found similar spiritual needs in Danish COPD patients. Existential  
7 or spiritual resources help COPD patients cope with life and consider life valuable and beautiful,  
8 despite severe disease.[74] Nevertheless, COPD patients across various cultural settings have few  
9 to talk to about spiritual issues, which may partly be due to stigma and a sense of self-blame.[75-  
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15 While these tendencies pertaining to the links between health and existential, spiritual, or religious  
16 aspects and care are relevant for cancer patients, COPD patients, and cardiac arrest survivors, they  
17 may also be relevant to a much broader spectrum of patients. Such tendencies are similarly  
18 observed in patients with chronic neurological diseases, e.g. in patients with Alzheimer's  
19 disease[78, 79] and patients suffering from Huntington's disease, the latter having a relatively  
20 rapid decline compared to Alzheimer's disease and being rarer and ultimately lethal.[80]

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25 The pathophysiologic processes behind suffering from cancer, cardiac arrest or COPD are very  
26 different, resulting in different situations for the patient. Cancer diagnoses have very  
27 heterogeneous expressions, cardiac arrest is often a sudden event characterized among other  
28 things by the potential of (full) recovery (however, seldom recovery from the underlying cause),  
29 while COPD is a slowly progressing disease with no possibility of being cured, and with focus on  
30 coping, relief of symptoms, and halting of disease progression. The latter may also be the case for  
31 some cancer patients. Likewise, existential and spiritual needs and practices may also be very  
32 different across age groups.

### 33 34 35 36 37 38 **Implications for secular Denmark**

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40 Secular societies are among other things characterized by a strong separation of church and state.  
41 This is also the case in Denmark where religion plays a minor role in public discourse and church  
42 attendance is unusually low.[81-85] There are multiple reasons for this secularism of the Danish  
43 culture. In line with this, Danes consider "faith and religion" to be the largest taboo just after  
44 "mental illness".[86] This attitude is reflected in the health care system with regards to the spiritual  
45 care administered. Health professionals are generally convinced existential, and spiritual resources  
46 have a positive impact on patients' health and handling of disease,[87, 88] just as they agree  
47 spiritual care should be administered.[89, 90] However, patients are largely not receiving such  
48 spiritual care.[2, 4, 32, 89-93] It is reasonable to expect that this is similar in other secular cultures  
49 as well. Studies from relatively more religious regions in North America show that palliative  
50 patients who experience low levels of existential and spiritual support have a lower quality of life,  
51 encounter more complications, and higher overall medical care costs.[94-96] Thus, a focus on  
52 alleviating existential and spiritual pain may embed a large financial potential for the health  
53 economy in secular cultures as well. Supporting researchers, clinicians, and policymakers in  
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providing existential and spiritual care for the patients and relatives in need of such, may also have a large impact on public health. The imaginable approaches and interventions are numerous, some already on their way. While in secular societies such as Denmark, the physical, psychological, and social aspects of health have for decades been utilized and exploited. With the proper evidence, perhaps it is time to invite existential and spiritual resources of patients and relatives to contribute to their health.

## Objectives

This paper reports the protocol for EXICODE – the EXistential health COhort DENmark. The overall aim of the cohort is to examine existential and spiritual constructs in the secular Danish setting and establish evidence on the links between existential and spiritual constructs of interest with clinical, economic, and demographic variables.

## METHODS AND ANALYSIS

### Study design

EXICODE is designed as a national cohort based on register and survey data.

### Registers

The Danish national health registers collect detailed administrative data on all Danish citizens, including sociodemographic data and data on health care utilization, hospitalization, medications used etc.[97] All Danish citizens are registered in the Danish Civil Registration System (CRS) with a unique identification number enabling accurate linkage between registers at an individual level.[98]

### Participant selection and recruitment

All participants are identified through the CRS. Participants are a random selection of 10% of the adult (age >18yrs) Danish population. Furthermore, to ensure diseased participation, three subsamples are invited: (1) cancer patients diagnosed with either of the ten most frequent cancer diagnosis groups in Denmark during 2020 (based on NORDCAN classification [99]), (2) out-of-hospital cardiac arrest survivors (OHCAS) registered in 2016 through 2020, and (3) COPD patients hospitalized for COPD in 2020 (table 1). Since timeliness of disease events is considered important with regards to the outcomes investigated, the latest available register data was sought. These diverse diagnosis categories are intended to contribute to nuanced understandings in the relation of health and existential needs as they span different age groups, disease progressions and severities and hope for a cure.

Table 1. Yearly incident cases of the ten most frequent cancer diagnoses, out-of-hospital cardiac arrest, and chronic obstructive pulmonary disease (hospitalized) in Denmark.

<i>ICD-10</i>	Men	Women	Total
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<b>Cancer (NORDCAN 2016)</b>				
Colorectal	<i>DC18-21</i>	2904	2400	5304
Breast	<i>DC50</i>	46	4714	4760
Lung (incl. trachea)	<i>DC33-34</i>	2335	2367	4702
Prostate	<i>DC61</i>	4519	N/A	4519
Kidney, bladder, and other urinary tract	<i>DC65-68, DD09.0-1, DD30.1-9, DD41.1-9</i>	2254	891	3145
Malignant melanoma of the skin	<i>DC43</i>	1220	1388	2608
Esophagus, stomach, pancreas	<i>DC15, DC16, DC25</i>	1267	801	2068
Gynaecological	<i>DC54, DC56.9, DC57.0-4</i>	N/A	1862	1862
Brain and central nervous system	<i>DC70-72, DC75.1-3, DD32-33, DD42-43</i>	647	775	1422
Lip, oral, pharyngeal	<i>DC00-14\DC10.1</i>	711	298	1009
<b>Total</b>				31399
<b>Cardiac arrest (Danish Cardiac Arrest Register 2016)</b>				
Out-of-hospital cardiac arrest (OHCA) (30d survival: 10.40%)	<i>DI46*</i>	2230	1251	3481
<b>Chronic Obstructive Pulmonary Disease (Lash et. al 2011)</b>				
Mucopurulent bronchitis, chronic bronchitis, emphysema, or COPD as primary diagnosis <b>OR</b> Pneumonia, respiratory insufficiency as primary with (J41-44) as secondary diagnosis	J41-44* <b>OR</b> Primary: J96+J13-18 + Secondary: J41-44	~5980	~7020	~13.000

All participants are invited digitally via 'e-Boks' (a secure national online e-post service that most Danes utilize; a small portion of older Danes do not use e-Boks) through their CRS number to participate and fill out a digital survey. e-Boks will automatically retain letters erroneously sent to CRS numbers of deceased individuals. The invitation letter includes information about how the individual was identified (thus, there are four slightly different letters), the study, information and



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4 legal notice on data management, consent to participate as well as a personal link to the  
5 questionnaire. e-Boks digital letters and the survey will be realized by Ramboll's SurveyXact, an  
6 online digital survey software.[100] Reminders will be sent after three weeks to non-responders.  
7 For respondents who agree to receive the questionnaire in the future, we will invite consecutive  
8 sampling at convenient time points. Due to institutional policy, no financial or lottery incitement  
9 will be provided.  
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### 14 **Population size**

15 The sample size was selected to give sufficient power to detect subgroup differences. No formal  
16 sample size calculation was performed due to the various cohort outcomes examined. The sample  
17 of randomly selected adult Danes is estimated to contain around 460.000 individuals. The three  
18 subsamples also invited are estimated to contain appr. 40-50.000 cancer patients, 20-25.000 COPD  
19 patients, and 2-2.500 OHCAS. Unique CRS numbers are included. If any of the sub-sample  
20 participants are also drawn randomly in the 10% lot, they will only be included as subsample  
21 participants.  
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### 27 **Eligibility**

28 Inclusion is limited to adult (age  $\geq 18$  yrs) Danes with valid CRS numbers. Criteria for subgroup  
29 inclusion are relevant ICD-10 diagnoses (table 1). Participants are excluded if they are not alive at  
30 the time of data collection.  
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### 34 **Data collection**

35 The first wave of survey data was collected between the 1<sup>st</sup> of November and the 13<sup>th</sup> of December  
36 2021. Due to technical and feasibility reasons, 25% of the cohort was invited to participate. Register  
37 data were collected in January and February 2022.  
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### 41 **Measurements**

#### 42 Questionnaire outcomes

43 The EXICODE Questionnaire totals six pages and includes seven internationally validated  
44 instruments, two subscales from validated instruments (table 2) and some ad hoc items tapping  
45 religious, spiritual, and existential affiliations and convictions.  
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50 Table 2. The EXICODE Questionnaire. Outcomes on existential and spiritual constructs.

51 Instrument	52 Outcome	53 Items	54 Scoring	55 Item example
56 WHO-5 [101]	57 Well-being	58 5	59 6-point scale from "0 – never" to "5 – all the time". Summed scores referred to 100% level.	60 <i>During the past two weeks... ...I have felt active and energetic.</i>

EQ-5D-5L [102]	Health status (5 levels)	5	5-point scale of decreasing health status (1 = good, 5 = poor)	<i>Today... ...have you felt pain / discomfort?</i>
BMLSS [103]	Life and support satisfaction	18	7-point Likert scale from "0 – very unsatisfied" to "7 – very satisfied". Score is mean ref. to a 100% level.	<i>How satisfied are you with... ...your family life?</i>
SpNQ [104, 105]	Spiritual needs (four dimensions)	20	4-point scale from "0 – not at all" to "3 – very strong". Scores are means per dimension.	<i>During the last month did you have the need... ...to be forgiven?</i>
SpREUK-P [106] + GrAw-7 [107]	Spiritual practices (four dimensions) + gratitude	25	4-point scale from "0 – never" to "3 – regularly". Scores are means per dimension ref. to a 100% level	<i>How often do you engage in the following: I meditate.</i>
AKU (RGH and escape subscales) [108]	Adaptive coping (two dimensions)	8	5-point Likert scale from "0 – does not apply" to "4 – definitely applies". Scores are means per dimension ref. to a 100% level.	<i>My faith is my foundation, even in difficult times.</i>
MAPS	Meaning and purpose (two dimensions)	6	6-point Likert scale from "0 – don't agree" to "5 – totally agree".	<i>My life is meaningful.</i>
NDE-C [109]	Near-death experience content (five dimensions)	20	5-point scale from "0 – not at all" to "4 – extreme". Cut-off score of $\geq 37$ is indicative of an NDE.	<i>You met a presence and/or an entity (i.e. a deceased person).</i>
(S)FI [110]	Human flourishing (five(six) dimensions)	12	Scored on 0-10 VAS on different categories. Scores are means per dimension.	<i>How happy or unhappy do you usually feel?</i>

The instruments are all suited for secular societies such as the Danish. The manuscript describing the selection of instruments, translation, cultural adaptation and qualitative pilot testing is in submission. However, results from this process indicated that the compiled questionnaire was comprehensible and that the digital design was feasible. We conducted a quantitative field test by convenience sampling to test the psychometric properties of instruments before distributing the EXICODE Questionnaire to the intended population.

#### Register outcomes

The Danish Health Data Authority (SDS), Statistics Denmark (DST) and the Danish Cardiac Arrest Register (DCAR) are data sources for independent register data outcomes (table 3) at individual levels coded by unique CRS numbers.

Table 3. Registries, tables, and examples of register data variables.

Register	Table	Examples of derived variables	Period
Statistics Denmark (DST)	Demographic	Civil status, family type, region, ethnicity, e/immigration, highest completed education, income, SES, work status and sick leave	1995-2020
	Clinical administrative outcomes	Date, diagnosis and type of health care service use in hospitals, out-patient clinic or general practitioners' clinic, Charlson Comorbidity Index	
	Municipal care	Home nursing, homecare	
Danish Health Data Authority (SDS)	Drug use	ATC-codes, exp. date/price, vol., packages bought	1995-2020
	Clinical details on cancer patients	Date of diagnosis, ICD-10, TNM, treatment, NORDCAN-group	
	Rehabilitation	Date and type of rehabilitation training	
The Danish Cardiac Arrest Register (CAR)	Clinical details on cardiac arrest survivors	Date of arrest, HLR done, first observed heart rhythm, status at arrival to the hospital	2016-2020

All register data will be pooled at DST's researcher server where data analysis will take place. Survey data will be transferred to DST's researcher server from the University of Southern Denmark once collected. The cohort data construction is exemplified in figure 1.

### Patient and Public Involvement statement

The project is motivated based on previous studies and experiences with patients and public representatives. The project seeks to have a patient perspective as a central focus in all aspects of the research process. This process began by interviewing relevant end-users about their existential and spiritual needs, establishing the rationale and content validity of the project aims. Public dissemination of results and project milestones is prioritized.

### Statistical analysis plan

Various papers are expected from the cohort, and as such, the statistical analyses will be thoroughly described in each paper according to the relevant methods used. However, an overview of the major analytical approaches shall be outlined here. Multiple statistical approaches will be applied to both survey and register data according to the outcome data type (e.g. continuous, binary, count, categorical). These approaches will primarily be regression modelling, structural equation modelling, and causal mediation analysis. Responders will be presented using descriptive statistics. Responders/non-responders will be compared with a  $\chi^2$ -test based on

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4 gender, age, education, income, living status, region of living, work situation, marital status, and  
5 comorbidity status to assess selection bias. The same covariates will serve in confounder control as  
6 well. Sensitivity analyses using e-values will be applied where applicable.[111] In the digital  
7 survey, “validation rules” were set up to avoid missing observations, i.e. the respondent will have  
8 to answer each question before the software allows the respondent to move to the next page.  
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10 Consequently, there will be no missing values internally in the survey dataset for responders who  
11 finish the questionnaire. However, it is expected that some participants drop off after having  
12 answered some of the questions (partial responders). Some missing values in the register data are  
13 expected. The survey responses of these participants will be included as “missings”.

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16 Primary survey outcomes are: spiritual needs, spiritual practices, well-being, health status,  
17 satisfaction with life and support, human flourishing, gratitude and awe, religious coping. These  
18 survey outcomes will be investigated with regression analysis with various register outcomes as  
19 explanatory factors, such as hospital admissions, medication use, mortality, visits to a general  
20 practitioner or depression. Reverse regressions with the survey variables as explanatory factors for  
21 register outcomes may also be applied.  
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27 Subsamples of cases will be investigated in a matched setup where healthy Danes from the cohort  
28 will be matched to diseased subsample cases 1:5 based on age, gender, income, and educational  
29 level.  
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33 Health economic analyses will be conducted to investigate associations between the surveyed  
34 outcomes (e.g. spiritual needs, spiritual practices, gratitude and awe etc.) and register data  
35 variables proxying (1) health care cost, i.e. prescribed medicine, use of healthcare services etc., (2)  
36 loss of productivity, i.e. sick leave etc. and (3) social care costs, i.e. home nursing etc.  
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40 All statistical analyses will be carried out in STATA 16.0 or above with a significance level ( $\alpha$ ) of  
41 5%.  
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#### 44 **Data management**

45 A thorough data management plan has been prepared including a codebook on all outcomes.  
46 These are available upon request. Although data will be FAIR [112], we will not be able to freely  
47 share all data collected in a repository due to legal and ethical limitations. Thus, we invite  
48 interested parties to reach out for collaborating projects on the data which will be available in  
49 EXICODE.  
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### 53 **ETHICS AND DISSEMINATION**

#### 54 **Ethics and legal concerns**

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56 The project is registered for legal and GDPR concerns at the *University of Southern Denmark Legal*  
57 *Services* (SDU RIO), journal number: 10.367. The project has been evaluated by the *Danish Regional*  
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*Scientific Ethical Committee*, journal number: 20202000-116, and the *Danish Authority for Patient Security (STPS)*; these two institutions declared that the project did not require approval by Danish law due to EXICODE only collecting interview, survey, and register data and thus waived the applications. However, due to institutional best practices, the project was evaluated and approved by the institutional ethics review board *University of Southern Denmark Research Ethics Committee (SDU REC)*, journal number: 20/39546. The project follows *The Danish Code of Conduct for Research Integrity*[113] and is carried out in accordance with the *Helsinki Declaration*.<sup>[114]</sup> The interviewers for the pilot test were well-trained in noticing unease on behalf of the interviewee. Some of the scripted probes in the cognitive interviews were addressing the burden/discomfort of filling out the questionnaire or unease emerging from answering e.g. faith items. This is also the reason why we have obtained a rigorous ethical review of the protocol although it is not legally necessary to do so in a Danish context when conducting interviews or surveys. Participant consent is obtained at participation, and data is handled according to Danish law.

Ethical approvals and development of the EXICODE Questionnaire began in May 2020. Access to register data has been delayed due to COVID-19.

### Dissemination

The results of the project will be reported according to the STROBE statements,<sup>[115]</sup> and disseminated widely through publications in peer-reviewed scientific journals, international conferences, patient societies, mass and social media. A media strategy will be prepared together with publishers and funding organizations to increase public and academic reach. A website has been prepared for participants and other stakeholders to be able to follow the progress of EXICODE: [www.sdu.dk/da/almenpraksis/exicode](http://www.sdu.dk/da/almenpraksis/exicode) (currently only available in Danish).

### Perspectives

EXICODE will be an internationally unique cohort with a large amount of data that is exceptionally rich and of high quality. The linkage of individual survey data to longitudinal register data represents a special opportunity for epidemiologic and public health research in the field of existential aspects and health in a secular culture. We anticipate that the project will establish the knowledge base upon which to build future clinical interventions in secular countries like Denmark. The aim of such interventions should be to support patients and relatives in receiving existential and spiritual care, and to support health care professionals, such as oncologists, geriatricians, and general practitioners among others, in providing such care.

We expect the results to translate into concrete interventions such as communication tools, communication courses with learning support measures, eHealth solutions and other patient support tools that can be included in healthcare practices – some of these interventions are already on the way. An interesting novel approach for the future would be to try and find meaningful

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4 ways to utilize AI, IoT, or computer-based learning to enhance and deliver spiritual care – a kind  
5 of care, which at the time of writing is predominantly provided through human interaction. The  
6 ultimate effects are expected to be reflected in a changed attitude to and practice of existential and  
7 spiritual care and patient-centered medicine. We believe that the project will have significant  
8 effects on patients, health professionals and the health care system in Denmark and similar secular  
9 countries.  
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#### 14 **AUTHORS CONTRIBUTIONS**

15  
16 NCH, TKS, and JS constructed the protocol and design. TKS made the first draft of this  
17 manuscript, NCH and JS contributed by a thorough evaluation and revising of the manuscript and  
18 all phases of the project. SW contributed with statistical advice and study design. SW, AB, LHJ,  
19 KAR, FLH and CBL contributed with a thorough evaluation of the design, method, and  
20 manuscript. All authors accepted the final manuscript version.  
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#### 24 **COMPETING INTEREST**

25  
26 None declared.  
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29  
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34 and will not have an influence on data collection or analysis.  
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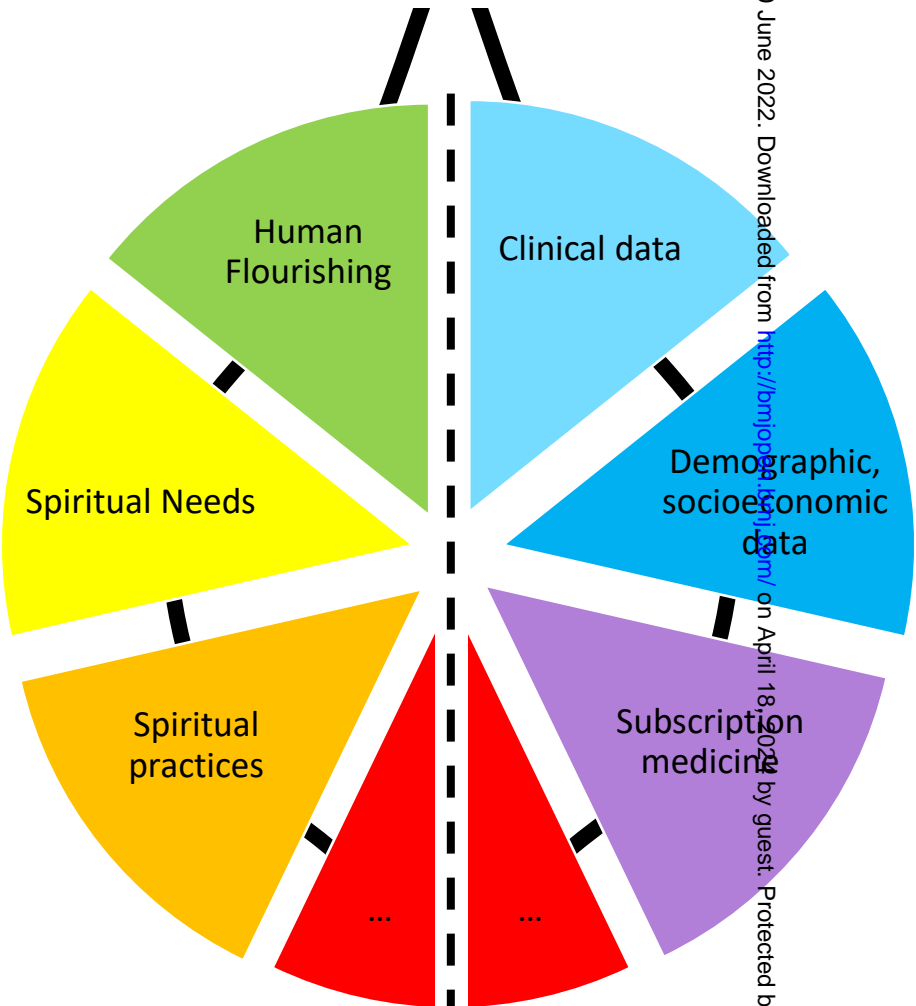
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For peer review only

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**COHORT**



**EXICODE DATASET**



STROBE Statement—Checklist of items that should be included in reports of *cohort studies*

	Item No	Recommendation	Page(s)	Line(s)
<b>Title and abstract</b>	1	(a) Indicate the study's design with a commonly used term in the title or the abstract	1	5
		(b) Provide in the abstract an informative and balanced summary of what was done and what was found	2	9-46
<b>Introduction</b>				
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported	4-7	-
Objectives	3	State specific objectives, including any prespecified hypotheses	7	16-20
<b>Methods</b>				
Study design	4	Present key elements of study design early in the paper	7	24
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection	7, 9	7:38-46, 9:36-39
Participants	6	(a) Give the eligibility criteria, and the sources and methods of selection of participants. Describe methods of follow-up	7, 9	7:39-52, 9:29-32
		(b) For matched studies, give matching criteria and number of exposed and unexposed	12	27-30
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable	9-11	9:42- 11:37
Data sources/ measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group	9-11	9:41- 11:37
Bias	9	Describe any efforts to address potential sources of bias	11-12	11:59- 12:8
Study size	10	Explain how the study size was arrived at	9	15-25
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why	NA	NA
Statistical methods	12	(a) Describe all statistical methods, including those used to control for confounding	11-12	11:49- 12:42
		(b) Describe any methods used to examine subgroups and interactions	11-12	11:58- 12:14
		(c) Explain how missing data were addressed	12	7-16
		(d) If applicable, explain how loss to follow-up was addressed	NA	NA
		(e) Describe any sensitivity analyses	12	7-8
<b>Results</b>				
Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed	NA	NA
		(b) Give reasons for non-participation at each stage	NA	NA
		(c) Consider use of a flow diagram	NA	NA

1	Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders	NA	NA	
2			(b) Indicate number of participants with missing data for each variable of interest	NA	NA	
3			(c) Summarise follow-up time (eg, average and total amount)	NA	NA	
4						
5	Outcome data	15*	Report numbers of outcome events or summary measures over time	NA	NA	
6						
7	Main results	16	(a) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included	NA	NA	
8				(b) Report category boundaries when continuous variables were categorized	NA	NA
9				(c) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period	NA	NA
10						
11	Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses	NA	NA	
12						
13	<b>Discussion</b>					
14	Key results	18	Summarise key results with reference to study objectives	NA	NA	
15	Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias	3	12-15	
16						
17	Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence	NA	NA	
18						
19	Generalisability	21	Discuss the generalisability (external validity) of the study results	NA	NA	
20						
21	<b>Other information</b>					
22	Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based	14	19-24	
23						

\*Give information separately for exposed and unexposed groups.

**Note:** An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at <http://www.plosmedicine.org/>, Annals of Internal Medicine at <http://www.annals.org/>, and Epidemiology at <http://www.epidem.com/>). Information on the STROBE Initiative is available at <http://www.strobe-statement.org>.