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# BMJ Open

## "Reframing Healthcare Services through the Lens of Co-Production" (RheLaunCh): a study protocol for a mixed methods evaluation of mechanisms by which healthcare and social services impact the health and well-being of COPD and CHF patients in the United States and the Netherlands

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3 **“Reframing Healthcare Services through the Lens of Co-Production”**  
4 **(RheLaunCh): a study protocol for a mixed methods evaluation of mechanisms**  
5 **by which healthcare and social services impact the health and well-being of**  
6 **COPD and CHF patients in the United States and the Netherlands**  
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## ABSTRACT

**Introduction:** The United States lags behind other high-income countries in many health indicators. Outcome differences are associated with differences in the relative spending between healthcare and social services at the national level. The impact of the ratio and delivery of social and healthcare services on the individual patient's health is however unknown. *"Reframing Healthcare Services through the Lens of Co-Production"* (RheLaunCh) will be a cross-Atlantic comparative study of the mechanisms by which healthcare and social service delivery may impact patient health with chronic conditions. Insight into these mechanisms is needed to better and cost-effectively organize healthcare and social services.

**Methods:** We will combine quantitative and qualitative methods to compare the socioeconomic background, needs of, and service delivery to patients with congestive heart failure (CHF) and chronic obstructive pulmonary disease (COPD) in the US and the Netherlands. We will conduct: 1) a literature scan to compare national and regional healthcare and social service systems; 2) a retrospective database study to compare patient's socioeconomic and clinical characteristics, and the service use and spending at the national, regional and hospital level; 3) a survey to compare patient perceived quality of life, receipt and experience of service delivery, and ability of these services to meet patient needs; and 4) multiple case studies to understand what patients need to better govern their quality of life and how needs are met by services.

**Ethics and dissemination:** Ethics approval was granted by the ethics committee of the Radboud university medical center (2016-2423) in the Netherlands and by the Human Subjects Research Committee of the Hennepin Health Care System, Inc. (HSR #16-4230) in the US. Multiple approaches will be used for dissemination of results, including (inter)national research presentations and peer reviewed publications. A website will be established to support the development of a Community of Practice.

## STRENGTHS AND LIMITATIONS OF THIS STUDY

- A systematic comparison of healthcare and social service delivery between two countries with different ratios of healthcare and social spending, and an in-depth exploration of the ability of these services to meet the needs of patients with a chronic disease (to govern their daily lives) is novel and would provide useful information for both the applied and research communities.
- The use of multiple methods of data collection enables triangulation of evidence, but is time and resource intensive for participants and researchers.
- Contextual differences at the national and regional policy level and at the level of the participating hospitals (i.e., the organization of services, the socioeconomic background of the served patient population and access to comparable clinical and socioeconomic data sources) may limit drawing comparisons between study sites.
- A quality assurance plan will ensure the methodological rigor, trustworthiness of findings, and privacy of participants across study sites.

## BACKGROUND

Despite having the highest per capita health spending, the United States lags behind other high-income countries in many health indicators.[1,2] Furthermore, the prevalence of, and mortality from, chronic medical conditions in the US is higher compared to other European high-income countries, including the Netherlands.[3] Recent international comparisons demonstrate marked differences in relative spending between healthcare and social services, which may account for differences in health outcomes.[4] This is plausible, as social and economic factors have been reported to be the strongest determinants of health outcomes.[5,6]

Though the association between the ratio of healthcare and social spending to health outcomes has been reported at the national population level, we do not yet have a clear understanding as to how the ratio of social and healthcare services influences the individual patient's health and well-being. Nor do we know the most efficient and appropriate delivery ratio of these services. As such, we designed the *Reframing Healthcare Services through the Lens of Co-Production* (RheLaunCh) study to explore the similarities and differences in experiences among patients with a chronic disease living in countries with different ratios of healthcare and social spending.

To systematically and deliberately explore the patient experience with healthcare and social services, we adapted three related frameworks/concepts in our study design: the model of social quality, integration of care services, and co-production of healthcare services. Social quality can be defined as: "the extent to which people are able to participate in the social and economic life of their communities under conditions which enhance their well-being and individual potential".[7] Social quality is considered increasingly important for understanding the social determinants of health and well-being next to the clinical determinants.[8-10] The model of social quality describes micro, meso and macro factors influencing the individual's quality of daily life and has two dimensions (see figure 1).[7,11] The first dimension – structural versus individual – reflects the fundamental tension between social structures and human agency. The second dimension – relational versus institutional

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3 – refers to the tension between informal relationships in the community (family, networks, groups)  
4 and the formal relationships in institutions (e.g., healthcare, employment, educational, financial).  
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7 Combining these two dimensions results in four necessary conditions for the participation and self-  
8 direction that determine the quality of daily life of citizens and are also essential for human recovery.  
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11 The factors of the social quality model at the micro level give important clues to care providers as to  
12 what is necessary in the recovery process of patients. Second, well-coordinated care across settings  
13 and types of services is essential to the health of patients, especially to those with chronic conditions  
14 and multidisciplinary care needs. Good integration of healthcare and social services can reduce  
15 confusion by patients and overuse, delay, duplication and gaps in service delivery.[12,13] Third, the  
16 concept of co-producing healthcare services (see figure 2) is increasingly used in the context of  
17 providing healthcare and in managing chronic health conditions. Co-production refers to: "a  
18 relationship where professionals and citizens share power to plan and deliver support together,  
19 recognizing that both partners have vital contributions to make in order to improve quality of life for  
20 people and communities".[14] Effective management of chronic, long term conditions largely  
21 depends on care that is shaped around the specific priorities, preferences and routines of each  
22 patient. Therefore, health improvements cannot be driven by professionals alone, but require the  
23 active involvement of patients. Empirical evidence suggests that the co-production of healthcare by  
24 patients and professionals, rather than the production of healthcare as a 'good' by professionals for  
25 patients,[15] may be effective in facilitating good health outcomes at lower costs.[16,17]  
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44 This paper describes the protocol for a cross-Atlantic comparative study of the mechanisms by  
45 which social quality (i.e., the conditions for participation and self-direction) and service delivery (i.e.,  
46 the degree of integration between healthcare and social services and co-production of services  
47 between patients and professionals) may impact health and well-being of patients with chronic  
48 conditions. RheLaunCh seeks to accomplish these aims by:  
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- 3 1. Creating a detailed description and comparison of the national, regional and local contexts in
- 4 regards to patient demographics, perceived well-being and quality of daily life, social quality,
- 5 and healthcare and social service use and spending.
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- 9 2. Describing differences and similarities between the US and the Netherlands in the receipt of
- 10 and experience of healthcare and social service delivery, and ability of these services to meet
- 11 the needs of patients with a chronic disease to govern their daily lives.
- 12
- 13 3. To develop a Community of Practice for actors to facilitate continuous collaboration and the
- 14 exchange of ideas, contacts, knowledge, and experiences around strategies of change within
- 15 the national, regional, and local (i.e., municipality, hospital, community or home) setting.
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**Figure 1. The Social Quality Model and conditions for participation and self-direction at the micro-level** [11]

**Figure 2. Conceptual model of healthcare service co-production by Batalden et al. [15]**



## METHODS

### Study design, population and settings

This study will combine quantitative and qualitative research methods across the US and Dutch study settings: 1) a literature scan; 2) a retrospective database study; 3) a survey; and 4) a series of qualitative case studies (Table 1). We will study patients diagnosed with CHF or COPD from the US, a country with a low ratio of healthcare to social spending, and the Netherlands, a country with a high ratio of healthcare to social spending.[18] We will focus on patients with CHF and COPD because these are two of the most common long-term and potentially preventable conditions with similar symptomatology (e.g., shortness of breath) and psychological co-morbidity,[19,20] while, at later stages both require intensive healthcare and social services for effective disease management. In the survey and in the case studies, patients from Hennepin County Medical Center (HCMC) in Hennepin County, Minnesota (US) will be compared with patients from the Radboud University Medical Center (RUMC) serving the Southeast Gelderland/Nijmegen region in the Netherlands. HCMC and RUMC are both large, urban public hospitals, with 441 and 953 beds, respectively. RUMC is the academic hospital affiliated with Radboud University, while HCMC is a teaching hospital that is affiliated with the University of Minnesota Medical School.

**Table 1. Study aims, settings, methods and data sources per study subject**

Subject	<i>Healthcare and social service systems</i>	<i>Demographics, social quality and clinical features</i>	<i>Healthcare and social services use and spending</i>	<i>Perceptions on integration and co-production of services</i>	<i>Patient (un)met needs and underlying factors</i>	<i>Community of Practice development</i>
Aim	1	1, 2	1, 2	2	2	3
Setting	National; regional; hospital	National; regional; hospital	National; regional; hospital	Hospital	Hospital	International
Methods	Literature scan	Database study; survey	Database study; survey	Survey; in-depth interviews	Survey; in-depth interviews; observations	Literature review; focus groups
Data sources	Published and unpublished reports, articles and presentations	Socioeconomic databanks, clinical registries; publications	Socioeconomic and clinical databases; patient cohorts	Patient cohorts (n=20)	Patient cohorts (n=20)	Best practices; experts

## Description of national healthcare and social service systems

We will create a detailed description of the US and Dutch national and regional healthcare and social services system by scanning national and international scientific publications, reports, and presentations. The description will include similarities and differences in policies, laws, regulation, and organization of services, providers, and finance structures.

### Database study

We will scan socioeconomic databanks, clinical registries, and publications to retrospectively compare data on demographics, population-based clinical characteristics (e.g., prevalence, incidence, mortality, and risk factors for CHF and COPD), factors related to social quality (e.g., housing, access to care, social support, physical health), and healthcare and social service use and expenditure indicators at the national, regional (Hennepin County versus Nijmegen region), and hospital (HCMC versus RUMC) level, that may better explain health outcomes of patients with chronic conditions in the US and the Netherlands. Relevant indicators will be defined by the project team in multiple iterative discussion rounds. Two researchers will scan for relevant data on the predefined indicators. Data have to meet the following criteria: 1) available for both countries; 2) presenting data that is measured in 2010 or in more recent years; 3) presented in relative measures (e.g., percentages, averages or per capita). Data will be presented in tabular form with the indicators and their unit of measurement, outcomes – for the US, the Netherlands and, if available, the average of high-income countries – and year of measurement. Differences and similarities between both countries as well as with the average of high-income countries will subsequently be described.

### Survey

#### *Aims*

We will conduct a survey to describe and compare at the hospital level:

1. the ratio of healthcare and social services use and spending for COPD and CHF patients;

2. perceived conditions and needs of COPD and CHF patients related to social quality (e.g., housing, living conditions, social support, physical health), and if these needs are met by healthcare and social services and informal support;
3. the perceptions of COPD and CHF patients towards co-production and profiles or typologies of patient groups with similar preferences to co-produce.

### *Questionnaire development*

The questionnaire will be developed using validated scales or subscales relevant for measuring conditions and needs related to the model of social quality, healthcare and social service use, integration of these services, and attitudes towards co-production. The selection of existing scales and subscales for our survey will depend on user-friendliness and accessibility (e.g., length, internal consistency, license costs). Items only available in English will be translated to the Dutch language using a forward-backward translation procedure.[21] The questionnaire will be pilot tested in both study settings on a sample of the target population (n=5) to evaluate the experiences with administering the questionnaire as well as the content of the questionnaire (i.e., order of items, clarity and relevance of items, length of questionnaire). Based on these findings appropriate changes will be made.

### *Sampling, recruitment and administration*

In both study sites, participants will be sampled using the following inclusion criteria: patients 18 years of age or older, diagnosed with COPD (stage 1- 4 GOLD classification) and/or with CHF (stage I-IV NYHA classification), under treatment at the RUMC or HCMC, and able to understand the national language. Patients with severe cognitive or physical problems will be excluded from the survey. The recruitment of patients and the administration of the questionnaire will vary between study sites, because of practical reasons (i.e., available time and resources by the local research team) and expected participant preferences. In the Netherlands, first all eligible patients will be invited to participate by mail. After four weeks, a nurse practitioner will invite eligible patients (who did not

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3 respond to the postal invitation) in consecutive order at the time of a clinic visit. Patients will have  
4 the option to complete the questionnaire on paper or online and to receive assistance by a  
5 researcher for completing the questionnaire. In the US, eligible study subjects will be screened prior  
6 to scheduled clinic visits using the electronic medical record. Those subjects agreeing to participate  
7 will meet with a researcher in the clinic and the survey questions will be read to them. Sample size at  
8 both study sites will be based on available resources and the likelihood of obtaining meaningful  
9 descriptive data.  
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### 18 *Data analysis*

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20 The answers and scores will be transferred into an electronic data collection platform (i.e.,  
21 REDCap/LimeSurvey). Data will be analyzed using Statistical Package for the Social Sciences (version  
22 22.0 for Windows, SPSS Inc., Chicago, IL, USA). Continuous variables will be analyzed with analysis of  
23 variance (ANOVA); categorical variables will be compared with chi-square tests.  
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## 30 **Multiple qualitative case studies**

### 31 *Aims*

32 We will conduct multiple in-depth qualitative case studies to:

- 33 1. better understand how patient needs related to social quality and actual service delivery are  
34 met by healthcare and social services and informal support;
- 35 2. identify patient perceptions of ability, willingness, and preferences for co-producing services;
- 36 3. better understand how co-production both facilitates and hinders patient pursuit of better  
37 health (if patients are willing and able to co-produce).  
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### 49 *Data collection*

50 Data on patients' perceptions and experiences of the topics of interest will be collected through  
51 semi-structured interviews and observations. Patients will be purposively sampled from the survey  
52 population, based on varying health and social needs, and services and informal support provided.  
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3 Although it is difficult to judge how many participants will be required for interview until data  
4 saturation is reached, it is estimated that around 20 interviewees (10 patients diagnosed with COPD  
5 and 10 patients diagnosed with CHF) will be required per study site. If possible, patients will be  
6 interviewed at their home or current place of residence. After the interview, the interviewer will  
7 write a 1-2 page narrative about observations with regards to the patient's appearance (e.g., short of  
8 breath, functioning) and living situation (e.g., presence of mobility aids), the neighbourhood, and the  
9 presence of others (e.g., friends or relatives).  
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18 Experienced and trained researchers will conduct interviews using a topic guide. The topic guide  
19 will be developed and tested during the preparation and planning of the case studies. All interviews  
20 will be digitally recorded and transcribed in the native language according to a standardized format.  
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### 23 *Data analysis*

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27 The constant comparative method will be used for the analysis of the interview data.[22] Relevant  
28 data will be identified and structured by open, axial, and selective coding. Coding is the interpretative  
29 process in which conceptual labels are given to text fragments.[23] Two researchers in each country  
30 will independently code the transcripts and narratives to minimize subjectivity of findings. Codes will  
31 be developed in English so that they can be shared by the project group. However, the language  
32 fidelity and fluency of study participants in the respective countries requires that the analysis will be  
33 conducted on transcripts in the original language by the local research teams. During the data  
34 analysis phase, researchers from both countries will frequently share and discuss the meaning and  
35 uniqueness of generated codes, group codes that belong to a same category, and themes identified  
36 from the data. A preliminary thematic analysis,[24] will be undertaken by US and Dutch researchers  
37 after five interview transcripts have been coded at both study sites. Country-specific codes,  
38 categories and themes will be used as well to identify differences between study settings. The  
39 identified categories and themes will be considered and discussed using the Social Quality and Co-  
40 production Model (figure 1 and 2). Researchers will write separate reports on the local findings from  
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3 the case studies and a shared report on the differences and similarities between the US and Dutch  
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5 case study findings. Data analysis will be supported with the use of a qualitative data analysis  
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7 software program (i.e., MaxQDA/Atlas.ti).  
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## 10 **Community of Practice development**

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12 We will build a RHeLaunCh Community of Practice (CoP) for professionals, policy-makers,  
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14 patients, and patient representatives with the shared interest of improving the integration of social  
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16 and healthcare services and the co-production of service for patients with a chronic condition. The  
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18 CoP will consist of an online web-based library and communication platform to exchange ideas,  
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20 experiences, literature, and contacts. The online platform may facilitate continuous (inter)national  
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22 collaboration between researchers and professionals, for example by organizing site visits and  
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24 evaluating new strategies for reducing the burden of illness for people with CHF and COPD.  
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26 Interviews with experts in setting up a CoP and the analysis of similar types of CoPs will be the input  
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28 for building the RHeLaunCh CoP.  
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## ETHICS, GOVERNANCE AND DISSEMINATION

### Ethical considerations

The study was approved by the local ethics committee of the RUMC (2016-2423) in the Netherlands and the Human Subjects Research Committee of the Hennepin Health Care System, Inc. (HSR #16-4230) in the US. All study participants will receive written and oral information about the study. Patients who are unable to provide either oral or written consent will not be included in this study. Information will be collected for research purposes only. Unnecessary collection of personal data will be avoided, and participants will have the right to review outputs and withdraw consent. All personal data will be coded, removed from the data for analysis, and stored separately. Only designated research staff will have access to the keys linking the data with the personal information. Privacy of study participants will be assured across the study sites.

### Research governance

Project management will ensure regular communication between the project team members and engagement with patients or their representatives, formal and informal care givers, and policy-makers in a project Advisory Board. Regular face-to-face meetings and conference calls will be organized, during which the research team will discuss and decide upon the study proceedings, coordination of activities, encountered problems, and suggestions for change. Standard operating procedure (SOPs) will be written for the qualitative data collection and analysis, based on internationally recognized quality standards,[25,26] and existing templates provided by the HANDOVER consortium.[27]

### Dissemination of results

We will translate our research into policy and practice, working with key stakeholders on a national and local level. Specific methods of communicating research will include combinations of:

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- 2
- 3 1. Regular project review meetings and continuous engagement with patients, professionals, and
- 4 policy-makers;
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- 7 2. Delivering presentations at local and national meetings in the Netherlands and the US and
- 8 relevant international meetings and conferences;
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- 11 3. Developing press-releases, videos and interviews in the media aimed at communicating the
- 12 key project findings to the public in the US, the Netherlands, and more widely;
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- 15 4. Developing narratives of patient stories and the research process itself for education purposes;
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- 17 5. Developing a web-based electronic platform where the project results will be publicly
- 18 accessible by national and international policy-makers, professionals, students, patients, and
- 19 academics;
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- 22 6. Publication of articles in peer-reviewed academic journals with emphasis on open access;
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- 26 7. Developing a project research report for the funder, with a publishable executive summary.
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## CONCLUSION

By exploring the receipt of and experience with health and social service delivery, and the ability of these services to meet the needs of patients with COPD and CHF to govern their daily lives – using quantitative descriptive data and qualitative “thick descriptions” – this study aims to discover the significance of national and regional policy differences in the support, accessibility and integration of healthcare and social services. The study findings will inform and invite healthcare and social care services, policy-makers, patients, informal caregivers and researchers to consider new ways of preparing health professionals, involving and empowering patients, and introducing new organizational forms and structures aimed to provide more efficient and appropriate health and social service delivery to patients with long-term chronic conditions. As such, our study will contribute to building a "Culture of Health"[28] in which good health and well-being flourish across geographic, demographic, and social sectors.

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## Contributors

HW, PB and BB had the main idea of the study. HW, GH, JW, WG, SG, PB, JJ, BB, BR, MC and SJ contributed to the design of the study. GH and JJ drafted the manuscript. HW, WG, JW, PB, BB, MC and BR were involved in the editing of the manuscript. All authors read and approved the final manuscript.

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## Competing interests

None.

## Ethics approval

The study was approved by the local ethics committee of the RUMC (2016-2423) in the Netherlands and the Human Subjects Research Committee of the Hennepin Health Care System, Inc. (HSR #16-4230) in the United States.

For peer review only

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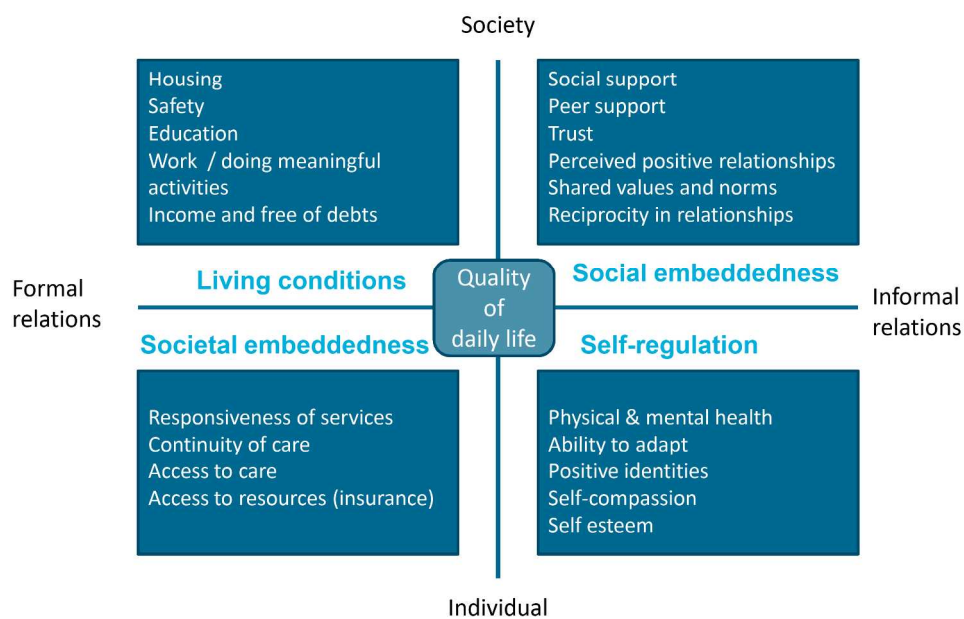
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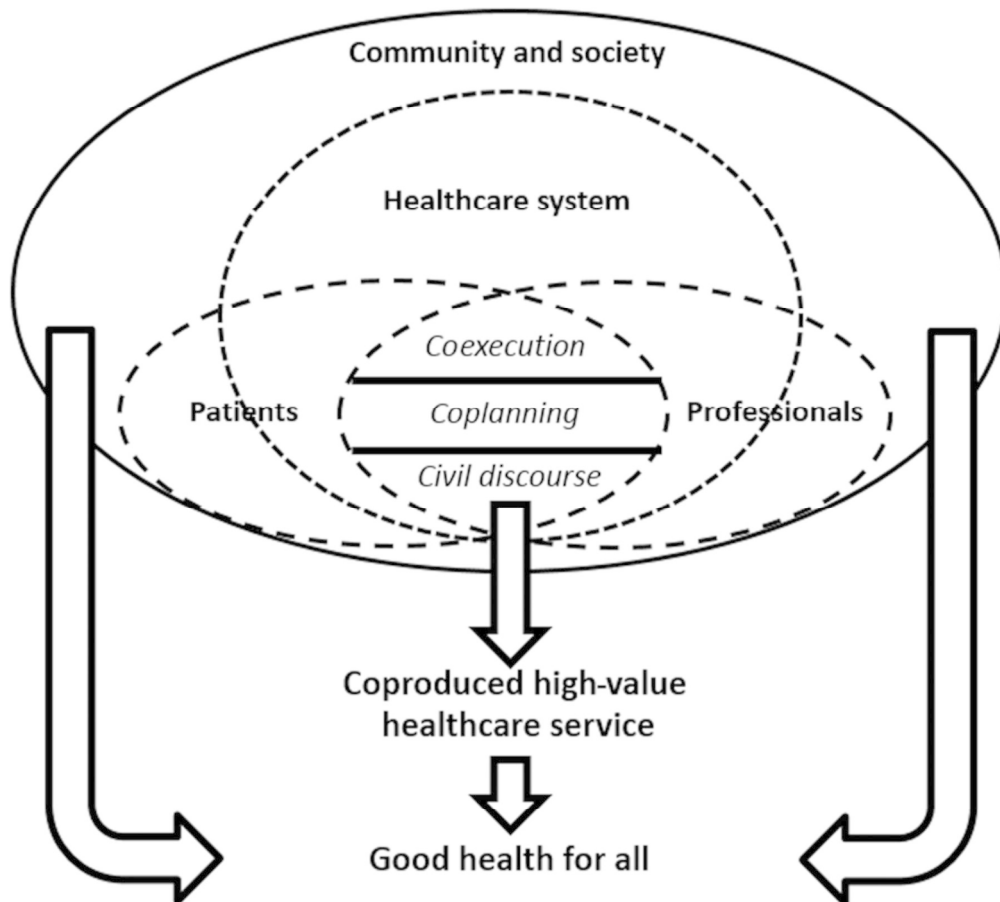
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The Social Quality Model and conditions for participation and self-direction at the micro-level©[11]

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Conceptual model of healthcare service co-production by Batalden et al. [15]

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# BMJ Open

## "Reframing Healthcare Services through the Lens of Co-Production" (RheLaunCh): a study protocol for a mixed methods evaluation of mechanisms by which healthcare and social services impact the health and well-being of COPD and CHF patients in the United States and the Netherlands

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3 **“Reframing Healthcare Services through the Lens of Co-Production”**  
4 **(RheLaunCh): a study protocol for a mixed methods evaluation of mechanisms**  
5 **by which healthcare and social services impact the health and well-being of**  
6 **COPD and CHF patients in the United States and the Netherlands**  
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## ABSTRACT

**Introduction:** The United States lags behind other high-income countries in many health indicators. Outcome differences are associated with differences in the relative spending between healthcare and social services at the national level. The impact of the ratio and delivery of social and healthcare services on the individual patient's health is however unknown. *"Reframing Healthcare Services through the Lens of Co-Production"* (RheLaunCh) will be a cross-Atlantic comparative study of the mechanisms by which healthcare and social service delivery may impact patient health with chronic conditions. Insight into these mechanisms is needed to better and cost-effectively organize healthcare and social services.

**Methods:** We designed a mixed methods study to compare the socioeconomic background, needs of, and service delivery to patients with congestive heart failure (CHF) and chronic obstructive pulmonary disease (COPD) in the US and the Netherlands. We will conduct: 1) a literature scan to compare national and regional healthcare and social service systems; 2) a retrospective database study to compare patient's socioeconomic and clinical characteristics, and the service use and spending at the national, regional and hospital level; 3) a survey to compare patient perceived quality of life, receipt and experience of service delivery, and ability of these services to meet patient needs; and 4) multiple case studies to understand what patients need to better govern their quality of life and how needs are met by services.

**Ethics and dissemination:** Ethics approval was granted by the ethics committee of the Radboud university medical center (2016-2423) in the Netherlands and by the Human Subjects Research Committee of the Hennepin Health Care System, Inc. (HSR #16-4230) in the US. Multiple approaches will be used for dissemination of results, including (inter)national research presentations and peer reviewed publications. A website will be established to support the development of a Community of Practice.

## STRENGTHS AND LIMITATIONS OF THIS STUDY

- A systematic comparison of healthcare and social service delivery between two countries with different ratios of healthcare and social spending, and an in-depth exploration of the ability of these services to meet the needs of patients with a chronic disease (to govern their daily lives) is novel and would provide useful information for both the applied and research communities.
- The use of multiple methods of data collection enables triangulation of evidence, but is time and resource intensive for participants and researchers.
- Contextual differences at the national and regional policy level and at the level of the participating hospitals (i.e., the organization of services, the socioeconomic background of the served patient population and access to comparable clinical and socioeconomic data sources) may limit drawing comparisons between study sites.
- A quality assurance plan will ensure the methodological rigor, trustworthiness of findings, and privacy of participants across study sites.

## BACKGROUND

Despite having the highest per capita health spending, the United States lags behind other high-income countries in many health indicators.[1,2] Furthermore, the prevalence of, and mortality from, chronic medical conditions in the US is higher compared to other European high-income countries, including the Netherlands.[3] Recent international comparisons demonstrate marked differences in relative spending between healthcare and social services, which may account for differences in health outcomes.[4] This is plausible, as social and economic factors have been reported to be the strongest determinants of health outcomes.[5,6]

Though the association between the ratio of healthcare and social spending to health outcomes has been reported at the national population level, we do not yet have a clear understanding as to how the ratio of social and healthcare services influences the individual patient's health and well-being. Nor do we know the most efficient and appropriate delivery ratio of these services. As such, we designed the *Reframing Healthcare Services through the Lens of Co-Production* (RheLaunCh) study to explore the similarities and differences in experiences among patients with a chronic disease living in countries with different ratios of healthcare and social spending.

To systematically and deliberately explore the patient experience with healthcare and social services, we adapted three related frameworks/concepts in our study design: the model of social quality, integration of care services, and co-production of healthcare services. Social quality can be defined as: "the extent to which people are able to participate in the social and economic life of their communities under conditions which enhance their well-being and individual potential".[7] Social quality is considered increasingly important for understanding the social determinants of health and well-being next to the clinical determinants.[8-10] The model of social quality describes micro, meso and macro factors influencing the individual's quality of daily life and has two dimensions (see figure 1).[7,11] The first dimension – structural versus individual – reflects the fundamental tension between social structures and human agency. The second dimension – relational versus institutional

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3 – refers to the tension between informal relationships in the community (family, networks, groups)  
4 and the formal relationships in institutions (e.g., healthcare, employment, educational, financial).  
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7 Combining these two dimensions results in four necessary conditions for the participation and self-  
8 direction that determine the quality of daily life of citizens and are also essential for human recovery.  
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11 The factors of the social quality model at the micro level give important clues to care providers as to  
12 what is necessary in the recovery process of patients. Second, well-coordinated care across settings  
13 and types of services is essential to the health of patients, especially to those with chronic conditions  
14 and multidisciplinary care needs. Good integration of healthcare and social services can reduce  
15 confusion by patients and overuse, delay, duplication and gaps in service delivery.[12,13] Third, the  
16 concept of co-producing healthcare services (see figure 2) is increasingly used in the context of  
17 providing healthcare and in managing chronic health conditions. Co-production refers to: "a  
18 relationship where professionals and citizens share power to plan and deliver support together,  
19 recognizing that both partners have vital contributions to make in order to improve quality of life for  
20 people and communities".[14] Effective management of chronic, long term conditions largely  
21 depends on care that is shaped around the specific priorities, preferences and routines of each  
22 patient. Therefore, health improvements cannot be driven by professionals alone, but require the  
23 active involvement of patients. Empirical evidence suggests that the co-production of healthcare by  
24 patients and professionals, rather than the production of healthcare as a 'good' by professionals for  
25 patients,[15] may be effective in facilitating good health outcomes at lower costs.[16,17] We  
26 hypothesize that, at the patient level, greater access to or being in possession of factors highlighted  
27 in the model of social quality, along with the opportunity to co-produce care is associated with better  
28 quality of life in the setting of chronic disease. Our study aims to elucidate potential mechanisms  
29 underlying this hypothesized relationship from the patient's perspective.  
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52 This paper describes the protocol for a cross-Atlantic comparative study of the mechanisms by  
53 which social quality (i.e., the conditions for participation and self-direction) and service delivery (i.e.,  
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3 the degree of integration between healthcare and social services and co-production of services  
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5 between patients and professionals) may impact health and well-being of patients with chronic  
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7 conditions. RheLaunCh seeks to accomplish these aims by:  
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10 1. Creating a detailed description and comparison of the national, regional and local contexts in  
11 regards to patient demographics, perceived well-being and quality of daily life, social quality,  
12 and healthcare and social service use and spending.
- 13  
14 2. Describing differences and similarities between the US and the Netherlands in the receipt of  
15 and experience of healthcare and social service delivery, and ability of these services to meet  
16 the needs of patients with a chronic disease to govern their daily lives.
- 17  
18 3. To develop a Community of Practice for actors to facilitate continuous collaboration and the  
19 exchange of ideas, contacts, knowledge, and experiences around strategies of change within  
20 the national, regional, and local (i.e., municipality, hospital, community or home) setting.  
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31 **Figure 1. The Social Quality Model and conditions for participation and self-direction at the micro-**  
32 **level** [11]  
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37 **Figure 2. Conceptual model of healthcare service co-production by Batalden et al. [15]**  
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## METHODS

### Study design, population and settings

This study will combine quantitative and qualitative research methods across the US and Dutch study settings: 1) a literature scan; 2) a retrospective database study; 3) a survey; and 4) a series of qualitative case studies (Table 1). We will study patients diagnosed with CHF or COPD from the US, a country with a low ratio of healthcare to social spending, and the Netherlands, a country with a high ratio of healthcare to social spending.[18] We will focus on patients with CHF and COPD because these are two of the most common long-term and potentially preventable conditions with similar symptomatology (e.g., shortness of breath) and psychological co-morbidity,[19,20] while, at later stages both require intensive healthcare and social services for effective disease management. In the survey and in the case studies, patients from Hennepin County Medical Center (HCMC) in Hennepin County, Minnesota (US) will be compared with patients from the Radboud University Medical Center (RUMC) serving the Southeast Gelderland/Nijmegen region in the Netherlands. HCMC and RUMC are both large, urban public hospitals, with 441 and 953 beds, respectively. RUMC is the academic hospital affiliated with Radboud University, while HCMC is a teaching hospital that is affiliated with the University of Minnesota Medical School.

**Table 1. Study aims, settings, methods and data sources per study subject**

Subject	<i>Healthcare and social service systems</i>	<i>Demographics, social quality and clinical features</i>	<i>Healthcare and social services use and spending</i>	<i>Perceptions on integration and co-production of services</i>	<i>Patient (un)met needs and underlying factors</i>	<i>Community of Practice development</i>
Aim	1	1, 2	1, 2	2	2	3
Setting	National	National; regional; hospital	National; regional; hospital	Hospital	Hospital	International
Methods	Literature scan	Database study; survey	Database study; survey	Survey; in-depth interviews	Survey; in-depth interviews; observations	Literature review; focus groups
Data sources	Published and unpublished reports, articles and presentations	Socioeconomic and health insurance databanks, clinical registries; publications	Socioeconomic and clinical databases; patient cohorts	Patient cohorts (n=20)	Patient cohorts (n=20)	Best practices; experts
Timeline	May-September 2017	June-December 2017	June-December 2017	June 2017-April 2018	June 2017-April 2018	April-December 2018

## Description of national healthcare and social service systems

We will create a detailed description of the US and Dutch national and regional healthcare and social services system based on national and international literature. We will seek relevant and up-to-date scientific publications, reports, and presentations by: a) searching key websites (e.g., the US Department of Health and Human Services; the Dutch Ministry of Health, Welfare and Sport; the World Health Organisation; The Commonwealth Fund); b) searching in academic databases (Scopus, OVID and Google Scholar); c) identifying relevant material in the reference lists of other reports or articles; and d) the input of national and international experts in the field of health policy and social care. The description will include similarities and differences in policies, laws, regulation, and organization of services, providers, and finance structures.

### Database study

We will use data from existing socioeconomic and healthcare insurance databanks, and data from published studies to retrospectively compare general population demographics, population-based clinical characteristics (e.g., prevalence, incidence, mortality, and risk factors for CHF and COPD), factors related to social quality (e.g., housing, access to care, social support, physical health), and public and private healthcare and social service use and expenditure at the national level, that may better explain health outcomes of patients with chronic conditions in the US and the Netherlands. Relevant indicators will be defined by the project team in multiple iterative discussion rounds. Two researchers will scan for relevant data on the predefined indicators. Data have to meet the following criteria: 1) available for both countries; 2) presenting annual data measured in 2010 or in more recent years; 3) presented in relative measures (e.g., percentages, averages or per capita). Data will be presented in tabular form with the indicators and their unit of measurement, outcomes – for the US, the Netherlands and, if available, the average of high-income countries – and year of measurement. Differences and similarities between both countries as well as with the average of high-income countries will subsequently be described.



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3 We will use data from socioeconomic databanks to compare general population demographics,  
4 clinical characteristics, factors related to social quality, and service use and expenditure at the  
5 regional (i.e., Nijmegen municipality and Hennepin County) level. We will also retrospectively analyze  
6 data from healthcare insurance databanks and clinical registries of the participating hospitals to  
7 compare healthcare service use at the hospital (RUMC and HCMC) level. Data will be collected on  
8 diagnostic care, medical treatment and medication use of patients with CHF or COPD who died in  
9 2013. We will compare the service use of patients between both hospitals in different time periods:  
10 12, 6, 3 and 1 month(s) before the patient's death. Outcomes will be reported in relative measures:  
11 e.g., percentage of patients visiting the ED, admitted to the intensive care unit or receiving a CT scan.  
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## 23 Survey

### 24 Aims

25 We will conduct a survey to describe and compare at the hospital level:

- 26 1. the ratio of healthcare and social services use and spending for COPD and CHF patients;
- 27 2. perceived conditions and needs of COPD and CHF patients related to social quality (e.g.,  
28 housing, living conditions, social support, physical health), and if these needs are met by  
29 healthcare and social services and informal support;
- 30 3. the perceptions of COPD and CHF patients towards co-production and profiles or typologies of  
31 patient groups with similar preferences to co-produce.  
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### 43 Questionnaire development

44 The questionnaire will be developed using validated scales or subscales relevant for measuring  
45 conditions and needs related to social quality (figure 1): the patient's physical and mental health  
46 (e.g., the Quality of Life in Respiratory Illness Questionnaire; the Mental Health Recovery Measure),  
47 social participation (e.g., the DUKE Social Support Index), living conditions (e.g., the Lehman Quality  
48 of Life Questionnaire). The questionnaire will also ask about healthcare and social service use,  
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3 informal support, attitudes towards co-production and the perceived integration of services. We will  
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5 estimate costs per patient based on rates of service utilization and multiplying by average cost of  
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7 that service. The final selection of existing scales and subscales for our survey will depend on user-  
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9 friendliness and accessibility (e.g., length, internal consistency, languages available, license costs).  
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11 Items only available in English will be translated to the Dutch language using a forward-backward  
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13 translation procedure.[21] The questionnaire will be pilot tested in both study settings on a sample  
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15 of the target population (n=5) to evaluate the experiences with administering the questionnaire as  
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17 well as the content of the questionnaire (i.e., order of items, clarity and relevance of items, length of  
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19 questionnaire). Based on these findings appropriate changes will be made.  
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### 22 23 *Sampling, recruitment and administration*

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25 In both study sites, participants will be sampled using the following inclusion criteria: patients 18  
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27 years of age or older, diagnosed with COPD (stage 1-4 GOLD classification) and/or with CHF (stage I-  
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29 IV NYHA classification), under treatment at the RUMC or HCMC, and able to understand the national  
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31 language. Patients with severe cognitive or physical problems will be excluded from the survey. The  
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33 recruitment of patients and the administration of the questionnaire will vary between study sites,  
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35 because of practical reasons (i.e., available time and resources by the local research team) and  
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37 expected participant preferences. In the Netherlands, first all eligible patients will be invited to  
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39 participate by mail. After four weeks, a nurse practitioner will invite eligible patients (who did not  
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41 respond to the postal invitation) in consecutive order at the time of a clinic visit. Patients will have  
42  
43 the option to complete the questionnaire on paper or online and to receive assistance by a  
44  
45 researcher for completing the questionnaire. In the US, eligible study subjects will be screened prior  
46  
47 to scheduled clinic visits using the electronic medical record. Those subjects agreeing to participate  
48  
49 will meet with a researcher in the clinic and the survey questions will be read to them. Sample size at  
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51 both study sites will be based on available resources and the likelihood of obtaining meaningful  
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53 descriptive data.  
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### *Data analysis*

The answers and scores will be transferred into an electronic data collection platform (i.e., REDCap/LimeSurvey). Data will be analyzed using Statistical Package for the Social Sciences (version 22.0 for Windows, SPSS Inc., Chicago, IL, USA). Continuous variables will be analyzed with analysis of variance (ANOVA); categorical variables will be compared with chi-square tests.

## **Multiple qualitative case studies**

### *Aims*

We will conduct multiple in-depth qualitative case studies to:

1. better understand how patient needs related to social quality and actual service delivery are met by healthcare and social services and informal support;
2. identify patient perceptions of ability, willingness, and preferences for co-producing services;
3. better understand how co-production both facilitates and hinders patient pursuit of better health (if patients are willing and able to co-produce).

### *Data collection*

Data on patients' perceptions and experiences of the topics of interest will be collected through semi-structured interviews and observations. Patients will be purposively sampled from the survey population, based on varying health and social needs, and services and informal support provided. Although it is difficult to judge how many participants will be required for interview until data saturation is reached, it is estimated that around 20 interviewees (10 patients diagnosed with COPD and 10 patients diagnosed with CHF) will be required per study site. If possible, patients will be interviewed at their home or current place of residence. After the interview, the interviewer will write a 1-2 page narrative about observations with regards to the patient's appearance (e.g., short of breath, functioning) and living situation (e.g., presence of mobility aids), the neighbourhood, and the presence of others (e.g., friends or relatives).

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3 Experienced and trained researchers will conduct the interviews using a topic guide (appendix 1)  
4 which will be tested during the preparation and planning of the case studies. All interviews will be  
5 digitally recorded and transcribed in the native language according to a standardized format.  
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### 9 10 *Data analysis*

11 The constant comparative method will be used for the analysis of the interview data.[22] Relevant  
12 data will be identified and structured by open, axial, and selective coding. Coding is the interpretative  
13 process in which conceptual labels are given to text fragments.[23] Two researchers in each country  
14 will independently code the transcripts and narratives to minimize subjectivity of findings. Codes will  
15 be developed in English so that they can be shared by the project group. However, the language  
16 fidelity and fluency of study participants in the respective countries requires that the analysis will be  
17 conducted on transcripts in the original language by the local research teams. During the data  
18 analysis phase, researchers from both countries will frequently share and discuss the meaning and  
19 uniqueness of generated codes, group codes that belong to a same category, and themes identified  
20 from the data. A preliminary thematic analysis,[24] will be undertaken by US and Dutch researchers  
21 after five interview transcripts have been coded at both study sites. Country-specific codes,  
22 categories and themes will be used as well to identify differences between study settings. The  
23 identified categories and themes will be considered and discussed using the Social Quality and Co-  
24 production Model (figure 1 and 2). Researchers will write separate reports on the local findings from  
25 the case studies and a shared report on the differences and similarities between the US and Dutch  
26 case study findings. Data analysis will be supported with the use of a qualitative data analysis  
27 software program (i.e., MaxQDA/Atlas.ti).  
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### 49 **Community of Practice development**

50 We will build a RHeLaunCh Community of Practice (CoP) for professionals, policy-makers,  
51 patients, and patient representatives with the shared interest of improving the integration of social  
52 and healthcare services and the co-production of service for patients with a chronic condition. The  
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3 CoP will consist of an online web-based library and communication platform – hosted in the United  
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5 States by the Robert Wood Johnson Foundation – to exchange ideas, experiences, literature, and  
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7 contacts. The online platform may facilitate continuous (inter)national collaboration between  
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9 researchers and professionals, for example by organizing site visits and evaluating new strategies for  
10  
11 reducing the burden of illness for people with CHF and COPD. Interviews with experts in setting up a  
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13 CoP and the analysis of similar types of CoPs will be the input for building the RHeLaunCh CoP.  
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## ETHICS AND DISSEMINATION

### Ethical considerations

The study was approved by the local ethics committee of the RUMC (2016-2423) in the Netherlands and the Human Subjects Research Committee of the Hennepin Health Care System, Inc. (HSR #16-4230) in the US. All study participants will receive written and oral information about the study. Patients who are unable to provide either oral or written consent will not be included in this study. Information will be collected for research purposes only. Unnecessary collection of personal data will be avoided, and participants will have the right to review outputs and withdraw consent. All personal data will be coded, removed from the data for analysis, and stored separately. Only designated research staff will have access to the keys linking the data with the personal information. Privacy of study participants will be assured across the study sites.

### Research governance

Project management will ensure regular communication between the project team members and engagement with patients or their representatives, formal and informal care givers, and policy-makers in a project Advisory Board. Regular face-to-face meetings and conference calls will be organized, during which the research team will discuss and decide upon the study proceedings, coordination of activities, encountered problems, and suggestions for change. Standard operating procedure (SOPs) will be written for the qualitative data collection and analysis, based on internationally recognized quality standards,[25,26] and existing templates provided by the HANDOVER consortium.[27]

### Dissemination of results

We will translate our research into policy and practice, working with key stakeholders on a national and local level. Specific methods of communicating research will include combinations of:

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- 2
- 3 1. Regular project review meetings and continuous engagement with patients, professionals, and
- 4 policy-makers;
- 5
- 6
- 7 2. Delivering presentations at local and national meetings in the Netherlands and the US and
- 8 relevant international meetings and conferences;
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- 10
- 11 3. Developing press-releases, videos and interviews in the media aimed at communicating the
- 12 key project findings to the public in the US, the Netherlands, and more widely;
- 13
- 14
- 15 4. Developing narratives of patient stories and the research process itself for education purposes;
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- 17
- 18 5. Developing a web-based electronic platform where the project results will be publicly
- 19 accessible by national and international policy-makers, professionals, students, patients, and
- 20 academics;
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- 24 6. Publication of articles in peer-reviewed academic journals with emphasis on open access;
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- 27 7. Developing a project research report for the funder, with a publishable executive summary.
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## 29 **Conclusions**

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32 By exploring the receipt of and experience with health and social service delivery, and the ability  
33 of these services to meet the needs of patients with COPD and CHF to govern their daily lives – using  
34 quantitative descriptive data and qualitative “thick descriptions” – this study aims to discover the  
35 significance of national and regional policy differences in the support, accessibility and integration of  
36 healthcare and social services. The study findings will inform and invite healthcare and social care  
37 services, policy-makers, patients, informal caregivers and researchers to consider new ways of  
38 preparing health professionals, involving and empowering patients, and introducing new  
39 organizational forms and structures aimed to provide more efficient and appropriate health and  
40 social service delivery to patients with long-term chronic conditions. As such, our study will  
41 contribute to building a "Culture of Health"[28] in which good health and well-being flourish across  
42 geographic, demographic, and social sectors.  
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## Contributors

HW, PB and BB had the main idea of the study. HW, GH, JW, WG, SG, PB, JJ, BB, BR, MC and SJ contributed to the design of the study. GH and JJ drafted the manuscript. HW, WG, JW, PB, BB, MC and BR were involved in the editing of the manuscript. All authors read and approved the final manuscript.

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## Competing interests

None.

## Ethics approval

The study was approved by the local ethics committee of the RUMC (2016-2423) in the Netherlands and the Human Subjects Research Committee of the Hennepin Health Care System, Inc. (HSR #16-4230) in the United States.



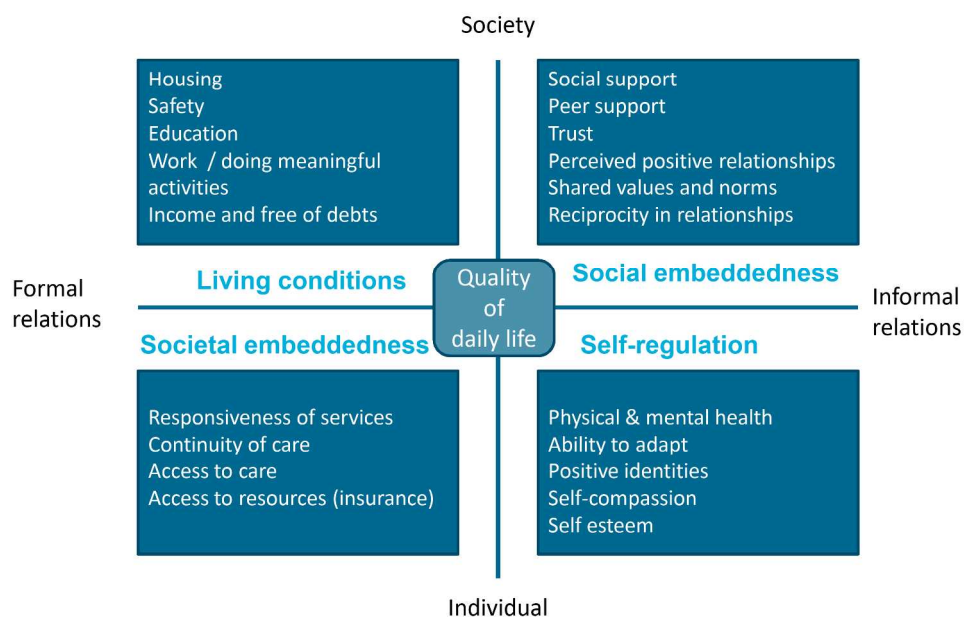
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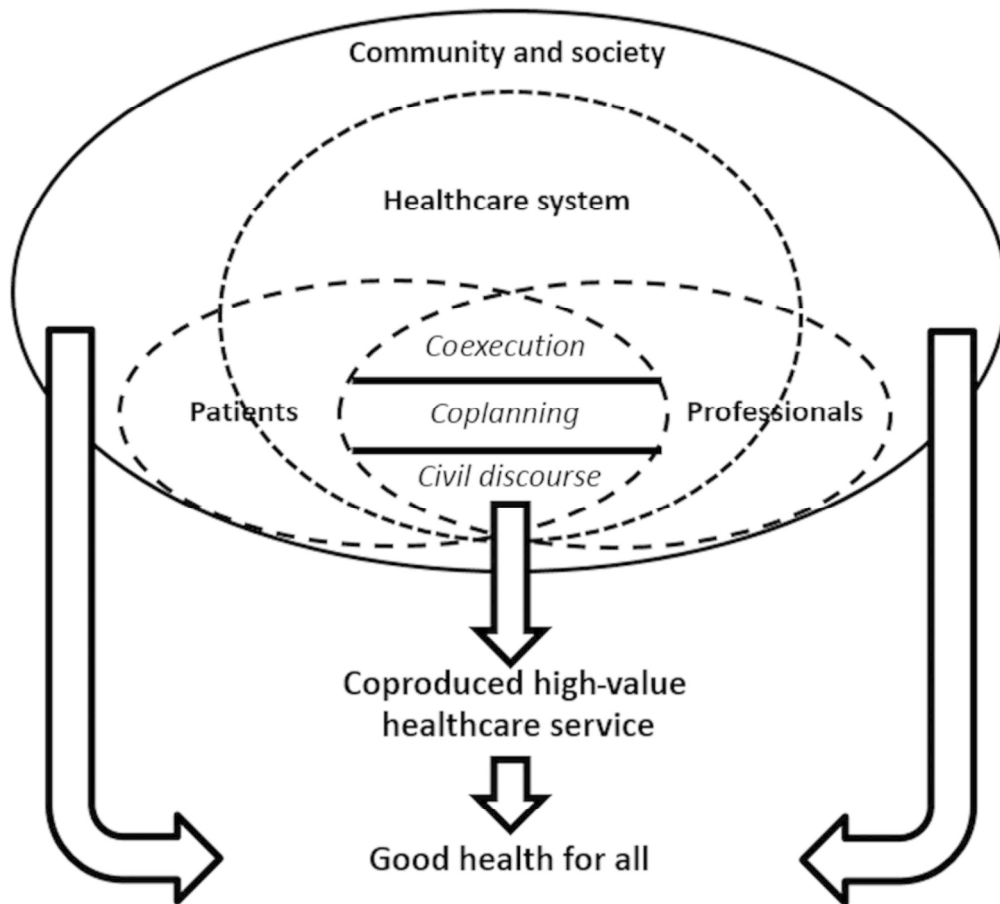
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The Social Quality Model and conditions for participation and self-direction at the micro-level©[11]

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Review only



Conceptual model of healthcare service co-production by Batalden et al. [15]

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## Appendix 1. Topic guide

- Initial questions
- Probes

### 1. Introduction

Purpose of study/consent/approval for audio recording

### 2. Health history

- When did you first begin to think that something was wrong with your health?
- When were you diagnosed with COPD/HF? What was it like to receive the diagnosis?
- What were major health events/care episodes from the moment of diagnosis until now?
- How is your life different now after your diagnosis compared to before your diagnosis?
- Do you feel satisfied with the way things are going now?

### 3. Impact of illness on daily life

- How did COPD/HF change your daily life/routines?
  - Physical health/complaints
  - Daily functioning
  - Social life/contacts/participation
  - Mental health (mood, feelings, stress, memory, etc.)
- What is the most challenging part of having COPD/HF?

### 4. Coping experiences with disease/ care needs

- How does an average day for you look like (what are specific routines/habits)?
  - Self-care (e.g. washing, cooking, shopping, medication intake)
  - Use of medical and social care
  - Informal support
  - Social activities
- What makes a day a good day for you? What do you hope for at the start of a new day?
- What helps in taking care of yourself/your health condition? What have been helpful 'tips'?
  - Self-regulation (e.g. positive attitudes, knowledge, functioning, reciprocity)
  - Social embeddedness (e.g. peer support, social support, reciprocity)
  - Living conditions (e.g. housing, work, hobbies, financial situation)
  - Societal embeddedness (e.g. access to medical and social services, patient-centeredness, continuity of care)

### 5. Barriers and facilitators for accessing/using needed services or support

- In the questionnaire, you mentioned the need for care/support on...:
 

Mention one or more of the following needs (based on positive answers on the needs items):

  - Physical health/complaints
  - Daily functioning
  - Mental health
  - Social services (mobility aids, social benefits, legal support, etc.)
  - Social life
  - Safety
  - Living situation
- Do you receive the necessary care or support for these needs? Why (not)?
  - Financial barriers
  - Not knowing where to ask/apply for a service
  - Shame
- What kind of services/support do you receive that we haven't talked about? Satisfied? Why (not)?

### 6. Patient perceptions on co-producing services

- How would you describe your relationship with your main healthcare provider(s)
  - Attention for your personal life, needs and preferences
  - Involving you in decisions on treatment
  - Way of communicating/ trust/ respect
- How does this relationship facilitate or hinder you in pursuing better health?
- What could be improved in your relationship with healthcare providers?