

# 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 patients with COPD and CHF in the USA and The Netherlands

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#### ABSTRACT

**Introduction** The USA 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 organise 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 and chronic obstructive pulmonary disease in the USA 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 USA. Multiple approaches will be used for dissemination of results,

#### 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 (ie, the organisation 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 rigour, trustworthiness of findings and privacy of participants across study sites.

including (inter)national research presentations and peer-reviewed publications. A website will be established to support the development of a community of practice.

#### BACKGROUND

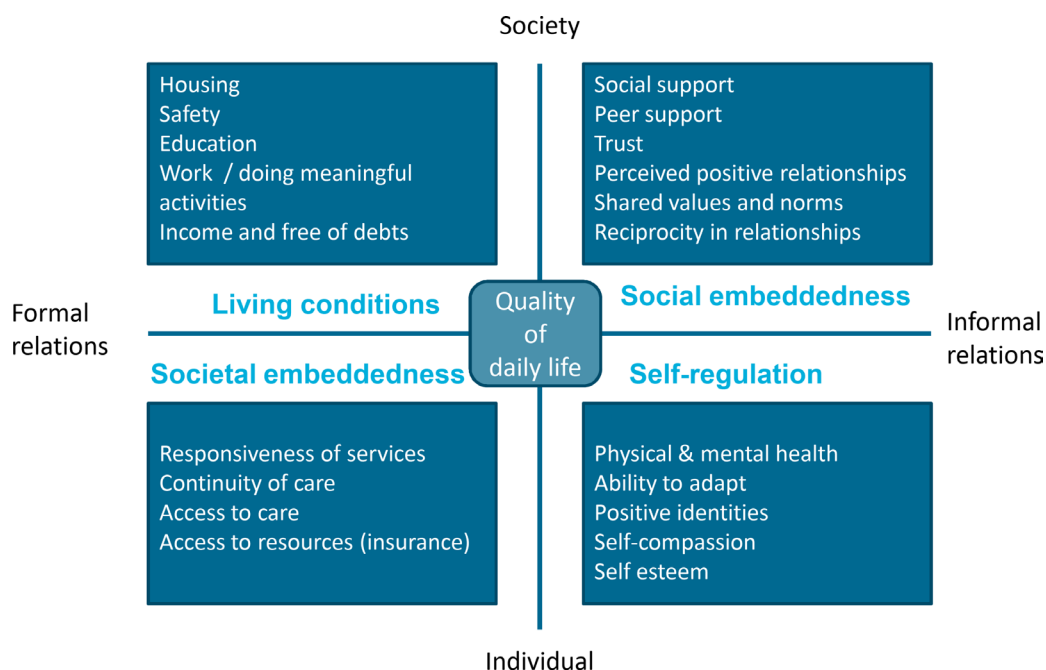
Despite having the highest per capita health spending, the USA lags behind other high-income countries in many health indicators.<sup>1 2</sup> Furthermore, the prevalence of, and

mortality from, chronic medical conditions in the USA is higher compared with other European high-income countries, including the Netherlands.<sup>3</sup> Recent international comparisons demonstrate marked differences in relative spending between healthcare and social services, which may account for differences in health outcomes.<sup>4</sup> This is plausible as social and economic factors have been reported to be the strongest determinants of health outcomes.<sup>5,6</sup>

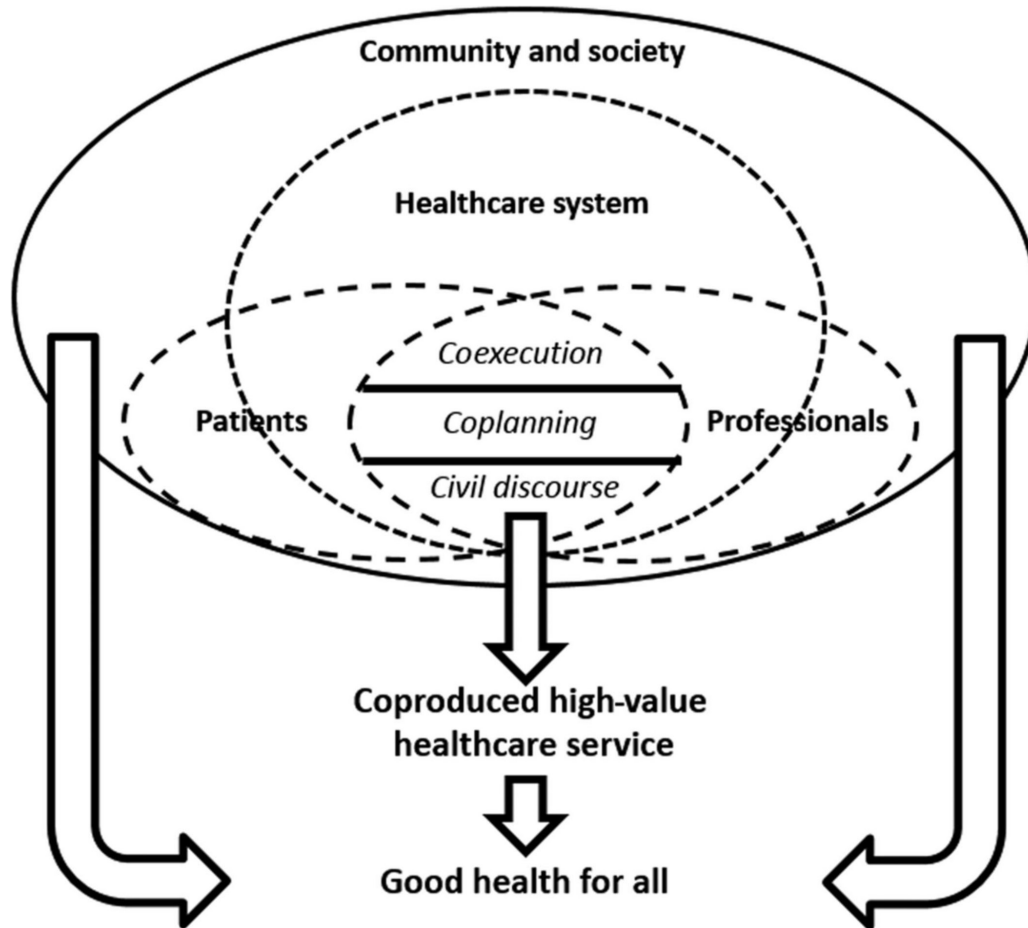
Though the association between the ratio of healthcare and social spending to health outcomes has been reported at the national population level, we do not yet have a clear understanding as to how the ratio of social and healthcare services influences the individual patient's health and well-being. Nor 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 coproduction 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'.<sup>7</sup> Social quality is considered increasingly important for understanding the social determinants of health and well-being next to the clinical determinants.<sup>8-10</sup> 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).<sup>7,11</sup> The first dimension—structural versus individual—reflects the fundamental tension between social structures and human agency. The second dimension—relational versus institutional—refers to the tension between informal relationships in the community (family, networks and groups) and the formal relationships in institutions (eg, healthcare, employment, educational and financial). Combining these two dimensions results in four necessary conditions for the participation and self-direction that determine the quality of daily life of citizens and are also essential for human recovery. The factors of the social quality model at the micro level give important clues to care providers as to what is necessary in the recovery process of patients. Second, well-coordinated care across settings and types of services is essential to the health of patients, especially to those with chronic conditions and multidisciplinary care needs. Good integration of healthcare and social services can reduce confusion by patients and overuse, delay, duplication and gaps in service delivery.<sup>12,13</sup> Third, the concept of coproducing healthcare services (see figure 2) is increasingly used in the context of providing healthcare and in managing chronic health conditions. Coproduction refers to: 'a relationship where professionals and citizens share power to plan and deliver support together, recognizing that both partners have vital contributions to make in order to improve quality of life for people and communities'.<sup>14</sup> Effective management of chronic, long-term conditions largely depends on care that is shaped around the specific priorities, preferences and routines of each patient. Therefore, health improvements cannot be driven by professionals alone but require the active involvement of patients. Empirical evidence suggests that the coproduction of healthcare by patients and professionals, rather than the production of healthcare as a



**Figure 1** The social quality model and conditions for participation and self-direction at the micro level.<sup>11</sup>



**Figure 2** Conceptual model of healthcare service coproduction by Batalden *et al.*<sup>15</sup>

‘good’ by professionals for patients,<sup>15</sup> may be effective in facilitating good health outcomes at lower costs.<sup>16 17</sup> We hypothesise that, at the patient level, greater access to or being in possession of factors highlighted in the model of social quality, along with the opportunity to coproduce care is associated with better quality of life in the setting of chronic disease. Our study aims to elucidate potential mechanisms underlying this hypothesised relationship from the patient’s perspective.

This paper describes the protocol for a cross-Atlantic comparative study of the mechanisms by which social quality (ie, the conditions for participation and self-direction) and service delivery (ie, the degree of integration between healthcare and social services and coproduction of services between patients and professionals) may impact health and well-being of patients with chronic conditions. RheLaunCh seeks to accomplish these aims by:

1. creating a detailed description and comparison of the national, regional and local contexts in regards to patient demographics, perceived well-being and quality of daily life, social quality and healthcare and social service use and spending
2. describing differences and similarities between the USA and the Netherlands in the receipt of and experience of healthcare and social service delivery

and ability of these services to meet the needs of patients with a chronic disease to govern their daily lives

3. developing a community of practice (CoP) for actors to facilitate continuous collaboration and the exchange of ideas, contacts, knowledge and experiences around strategies of change within the national, regional and local (ie, municipality, hospital, community or home) setting.

## 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 congestive heart failure (CHF) or chronic obstructive pulmonary disease (COPD) from the USA, 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.<sup>18</sup> 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 (eg, shortness of breath) and

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

Subject	Healthcare and social service systems	Demographics, social quality and clinical features	Healthcare and social services use and spending	Perceptions on integration and coproduction of services	Patient (un) met needs and underlying factors	Community of practice development
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

psychological comorbidity<sup>19 20</sup> 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 (USA) 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.

#### 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 (eg, the US Department of Health and Human Services; the Dutch Ministry of Health, Welfare and Sport; WHO; and 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 organisation 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 (eg, prevalence, incidence, mortality and risk factors for CHF

and COPD), factors related to social quality (eg, housing, access to care, social support and 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 USA 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; and (3) presented in relative measures (eg, percentages, averages or per capita). Data will be presented in tabular form with the indicators and their unit of measurement, outcomes—for the USA, 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.

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

## 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 patients with COPD and CHF related to social quality (eg, housing, living conditions, social support and physical health) and if these needs are met by healthcare and social services and informal support;
3. the perceptions of patients with COPD and CHF towards coproduction and profiles or typologies of patient groups with similar preferences to coproduce.

### Questionnaire development

The questionnaire will be developed using validated scales or subscales relevant for measuring conditions and needs related to social quality (figure 1): the patient's physical and mental health (eg, the Quality of Life in *Respiratory Illness Questionnaire and the Mental Health Recovery Measure*), social participation (eg, the Duke Social Support Index) and living conditions (eg, the *Lehman Quality of Life Questionnaire*). The questionnaire will also ask about healthcare and social service use, informal support, attitudes towards coproduction and the perceived integration of services. We will estimate costs per patient based on rates of service utilisation and multiplying by average cost of that service. The final selection of existing scales and subscales for our survey will depend on user-friendliness and accessibility (eg, length, internal consistency, languages available and licence costs). Items only available in English will be translated to the Dutch language using a forward-backward translation procedure.<sup>21</sup> 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 (ie, order of items, clarity and relevance of items and 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 (stages 1–4 Global Initiative for Chronic Obstructive Lung Disease classification) and/or with CHF (stages I–IV New York Heart Association 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 (ie, 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 4 weeks, a nurse practitioner will invite eligible

patients (who did not respond to the postal invitation) in consecutive order at the time of a clinic visit. Patients will have the option to complete the questionnaire on paper or online and to receive assistance by a researcher for completing the questionnaire. In the USA, eligible study subjects will be screened prior to scheduled clinic visits using the electronic medical record. Those subjects agreeing to participate will meet with a researcher in the clinic and the survey questions will be read to them. Sample size at both study sites will be based on available resources and the likelihood of obtaining meaningful descriptive data.

### Data analysis

The answers and scores will be transferred into an electronic data collection platform (ie, REDCap/LimeSurvey). Data will be analysed using Statistical Package for the Social Sciences (V.22.0 for Windows). Continuous variables will be analysed with analysis of variance; categorical variables will be compared with  $\chi^2$  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 coproducing services
3. better understand how coproduction both facilitates and hinders patient pursuit of better health (if patients are willing and able to coproduce).

### Data collection

Data on patients' perceptions and experiences of the topics of interest will be collected through semistructured 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 (eg, short of breath and functioning) and living situation (eg, presence of mobility aids), the neighbourhood and the presence of others (eg, friends or relatives).

Experienced and trained researchers will conduct the interviews using a topic guide (online supplementary appendix) that will be tested during the preparation and planning of the case studies. All interviews will be digitally recorded and transcribed in the native language according to a standardised format.

### Data analysis

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

### Community of practice development

We will build a RHeLaunCh CoP for professionals, policy makers, patients and patient representatives with the shared interest of improving the integration of social and healthcare services and the coproduction of service for patients with a chronic condition. The CoP will consist of an online web-based library and communication platform—hosted in the USA by the Robert Wood Johnson Foundation—to exchange ideas, experiences, literature and contacts. The online platform may facilitate continuous (inter)national collaboration between researchers and professionals, for example, by organising site visits and evaluating new strategies for reducing the burden of illness for people with CHF and COPD. Interviews with experts in setting up a CoP and the analysis of similar types of CoPs will be the input for building the RHeLaunCh CoP.

## 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 USA. 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 organised, during which the research team will discuss and decide on the study proceedings, coordination of activities, encountered problems and suggestions for change. Standard operating procedure will be written for the qualitative data collection and analysis, based on internationally recognised quality standards<sup>25 26</sup> and existing templates provided by the HANDOVER consortium.<sup>27</sup>

### Dissemination of results

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

1. regular project review meetings and continuous engagement with patients, professionals and policy makers;
2. delivering presentations at local and national meetings in the Netherlands and the USA and relevant international meetings and conferences
3. developing press releases, videos and interviews in the media aimed at communicating the key project findings to the public in the USA, the Netherlands and more widely
4. developing narratives of patient stories and the research process itself for education purposes
5. developing a web-based electronic platform where the project results will be publicly accessible by national and international policy makers, professionals, students, patients and academics
6. publication of articles in peer-reviewed academic journals with emphasis on open access
7. developing a project research report for the funder, with a publishable executive summary.

## CONCLUSIONS

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, by 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 organisational 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'<sup>28</sup> in which good health and well-being flourish across geographic, demographic and social sectors.

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**Competing interests** None declared.

**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 USA.

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**Data sharing statement** Only designated research staff will have access to data collected in this study.

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