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**Review**

# Identification and Reporting of Patient and Public Partner Authorship on Knowledge Syntheses: Rapid Review

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**Abstract**

**Background:** Patient and public involvement (PPI) in health research is an area of growing interest. Several studies have examined the use and impact of PPI in knowledge syntheses (systematic, scoping, and related reviews); however, few studies have focused specifically on the patient or public coauthorship of such reviews.

**Objective:** This study seeks to identify published systematic and scoping reviews coauthored by patient or public partners and examine the characteristics of these coauthored reviews, such as which journals publish them, geographic location of research teams, and terms used to describe patient or public partner authors in affiliations, abstracts, or article text.

**Methods:** We searched CAB Direct, CINAHL, Cochrane Database of Systematic Reviews (Ovid), Embase (Ovid), MEDLINE (Ovid), and PsycInfo from 2011 to May 2019, with a supplementary search of several PPI-focused databases. We refined the Ovid MEDLINE search by examining frequently used words and phrases in relevant search results and searched Ovid MEDLINE using the modified search strategy in June 2020.

**Results:** We screened 13,998 results and found 37 studies that met our inclusion criteria. In line with other PPI research, we found that a wide range of terms were used for patient and public authors in author affiliations. In some cases, partners were easy to identify with titles such as patient, caregiver or consumer representative, patient partner, expert by experience, citizen researcher, or public contributor. In 11% (n=4) of studies, they were identified as members of a panel or advisory council. In 27% (n=10) of articles, it was either impossible or difficult to tell whether an author was a partner solely from the affiliation, and confirmation was found elsewhere in the article. We also investigated where in the reviews the partner coauthors' roles were described, and when possible, what their specific roles were. Often, there was little or no information about which review tasks the partner coauthors contributed to. Furthermore, only 14% (5/37) of reviews mentioned patient or public involvement as authors in the abstract; involvement was often only indicated in the author affiliation field or in the review text (most often in the methods or contributions section).

**Conclusions:** Our findings add to the evidence that searching for coproduced research is difficult because of the diversity of terms used to describe patient and public partners, and the lack of consistent, detailed reporting about PPI. For better discoverability, we recommend ensuring that patient and public authorships are indicated in commonly searched database fields. When patient and public-authored research is easier to find, its impact will be easier to measure.

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**KEYWORDS**

PPI; patient and public involvement; coproduction; authorship; systematic review; participatory medicine; patient involvement; patient education; participatory research

## Introduction

### Background

Patient and public involvement (PPI) in health is an area of growing research interest. As this interest has increased, the need to effectively report on patient and public contributions to the research process has also increased. Reporting on PPI has several benefits, including the ability to identify, collate, and understand how such partnerships are undertaken and their impact on the research evaluated [1]. As PPI improves research quality and relevance, identifying studies that integrate PPI is important for practice and policy [2]. Considering this, we investigated the degree to which systematic, scoping, and related reviews identify patient and public partners as coauthors.

Multiple frameworks have been proposed to improve the reporting of patients' roles and levels of involvement in research [3-9]. Notably, in primary research, the GRIPP (Guidance for Reporting Involvement of Patients and Public) checklist was developed in 2011 [2]. A revision, GRIPP2, published in 2019, introduced short and long forms of the checklist [1]. These checklists guide authors to report on the methods used for PPI and the results and impacts of PPI in a study. In synthesis research, the ACTIVE (Authors and Consumers Together Impacting on Evidence) framework provides reporting guidance specifically for systematic reviews [10]. The framework's continuum of involvement breaks the systematic review process into 12 stages and describes 5 levels at which patients or the public can be involved at each stage: leading, controlling, influencing, contributing, and receiving.

Despite the development of these frameworks, the identification of PPI remains problematic. One issue is a lack of reporting; a 2019 review by Fergusson et al [11] found that from 2777 screened clinical trials, only 23 reported on patient engagement. The second issue is the lack of guidance on reporting structures that would allow discoverability of such research in databases of published research. Although the GRIPP2 long form suggests that the author supplied keywords "[i]nclude PPI, 'patient and public involvement,' or alternative terms" [1], a pervasive issue is the plethora of terms researchers may use to describe PPI [12,13]. These shift geographically, PPI itself being overwhelmingly used in the United Kingdom, whereas research in Australia, Canada, and the United States frequently uses divergent terms [14]. The concept of *participants* can vary widely, including *consumers*, *service users*, *lay people*, *carers* or *caregivers*, and the ambiguous term *stakeholders*, which may represent any number of roles not related to research methodology or implementation.

We were particularly interested in reporting PPI through authorship; an important aspect of PPI is the inclusion and recognition of contributions to research outputs. Neither GRIPP nor GRIPP2 address best practices on when and how to include patient and public partners as coauthors in primary research. Although the ACTIVE framework identifies "writing and

publishing the review" as one stage of potential involvement, it lacks specific guidance on including partners as coauthors. In a recent systematic review, Arnstein et al [15] presented a set of 21 recommended best practices for involving patient partners as coauthors in health research; one recommendation is "[d]ocument, in the manuscript, the involvement and role of patient authors (i.e. identify which authors are patients [e.g. Author Affiliation section] and describe their authorship contributions [e.g. Contributorship section])." In addition to these recommendations, they developed two versions of a patient authorship experience tool to assess the impact and quality of patient involvement.

Synthesis research (systematic and scoping reviews) frequently informs policy, guidelines, and point-of-care tools as well as first-line consultation tools used by practitioners. The prevalence and impact of PPI in systematic reviews have been the subject of many studies [16-25]. Evidence synthesis bodies have taken up the call to enhance use and reporting of PPI in reviews—Cochrane launched the ACTIVE project to encourage reviewers to meaningfully engage patients and the public in creating reviews [10,26], whereas in environmental research, the Stakeholder Engagement in Evidence Synthesis website hosts a plethora of resources on involving the public in reviews [27]. Identification of participation through authorship can clearly signal the integration of PPI in the synthesis process.

Our inquiry, to identify systematic and scoping reviews coauthored by patient and public partners, hoped to inform how, and how frequently, authorship in syntheses is being attributed. Our inquiry was informed by the following research question:

Among published systematic and scoping reviews, either on the topic of PPI or including PPI more generally, are the patient and public partners included as coauthors? If so, how are these studies identified and indexed?

### Objectives

Our process is guided by the following objectives:

1. Identify published systematic and scoping reviews coauthored by patient or public partners.
2. Identify if reviews in certain journals, countries, or disciplines are more likely to include patient or public partner authors.
3. Determine useful search terms to find reviews with patient or public partner authors, based on how such authors are described in affiliations, abstracts, or article texts.

## Methods

### Registration and Eligibility Criteria

We registered our protocol on OSF on August 23, 2019; the protocol and other supplementary materials for this review are available on OSF [28]. We defined our eligibility criteria as illustrated in [Textbox 1](#).

**Textbox 1.** Inclusion and exclusion criteria.**Inclusion Criteria**

- Systematic or scoping reviews on health topics that state that at least one author is a patient or public partner
- Anything that self-identifies as, or employs methodologies used in, a comprehensive review of the literature
- Published since 2011
- Must include a nonacademic partner
- Full text available in English

**Exclusion Criteria**

- Protocols
- Conference abstracts
- Reports on trials
- Case studies on patient engagement
- Where the patient or public partner has an academic title or affiliation

In interpreting PPI in papers that did not employ this specific terminology, we used National Institute for Health Research (NIHR) INVOLVE's definition of patient and public partners, as expressed in the study by Boote et al [16]. INVOLVE defines the public as "patients and potential patients; people who use health and social services; informal carers; parents or guardians; disabled people; members of the public who are potential recipients of health promotion programmes, public health programmes and social service interventions; organisations that represent people who use services." INVOLVE defines public involvement in research as "doing research 'with' or 'by' the public, rather than 'to', 'about' or 'for' the public."

We limited to systematic reviews, scoping reviews, or reviews employing recognized methodologies employed in these review types, published after 2011, aligning with the publication of GRIPP, the first published reporting guidelines on reporting on PPI [2].

**Study Selection**

Our search strategy was based on the validated filter for PPI published by Rogers et al [12]. This was further supplemented by terms derived from an analysis of 80 primary research articles on partnership research, derived from a previous survey of review articles [14]. Finally, terms identified by a canvas of previously published reviews on the subject were iteratively collected and compared against those from the above two sources. To limit to systematic and scoping reviews, we used the terms in PubMed's systematic review filter plus some additional terms for scoping reviews or other knowledge syntheses [29]. A librarian unaffiliated with the project peer reviewed the Ovid MEDLINE search strategy using the Peer Review of Electronic Search Strategies checklist [30]. [Multimedia Appendix 1](#) displays the initial Ovid MEDLINE search strategy.

Searches were run in 6 databases from 2011 to May 23, 2019: CAB Direct, CINAHL, Cochrane Database of Systematic Reviews (Ovid), Embase (Ovid), MEDLINE (Ovid), and PsycInfo (EBSCO).

Several additional sources were hand searched in August and September 2019:

- Patient-Centered Outcomes Research Institute Engagement in Health Research Literature Explorer
- Patient-Centered Outcomes Research Institute in the Literature
- NIHR INVOLVE Publications Library and Evidence Library
- The Evidence for Policy and Practice Information and Co-ordinating-Centre systematic reviews
- Patient Experience Journal
- Journal of Participatory Medicine
- Centre of Excellence on Partnership with Patients and the Public
- McMaster University Public and Patient Engagement Collaborative

In addition, we reviewed the reference lists and studies included in other systematic reviews to identify further studies.

With the initial search results from May 2019, all 3 authors screened a sample of 100 titles and abstracts to determine interrater agreement; with 82% (82/100) consensus between all reviewers, we then split the results into 3 segments for title and abstract screening. One author screened, with a second author deciding on studies that were labeled unsure. At this stage, we included or noted reviews that either stated they incorporated PPI or were on topics that would likely involve patients as unsure, excluding reviews about preclinical or other research that does not lend itself to inclusion of patient expertise.

At the full-text screening stage for the initial search results, articles were divided into 3 segments, with one reviewer first screening for any studies that could clearly be excluded. We looked at author affiliations, methods, author contributions, and acknowledgment sections for indicators that one or more authors met our definition of a patient or public partner. All 3 authors then assessed all reviews marked as include or unsure; in cases of disagreement, we discussed reaching a consensus. Some relevant articles may have been excluded at this stage because

the partner author was not explicitly identified as required by our inclusion criteria.

The Ovid MEDLINE search was updated on June 8, 2020, using a modified search strategy. The new strategy was developed by examining the frequency of terms used in the titles and abstracts of the 953 articles that reached the initial full-text screening stage. We used R to extract the n-grams from the titles and abstracts of the 953 articles [31]. We then reviewed the most common n-grams and discussed which n-gram should be included in the modified version of the search. This process yielded new search terms for both the patient and public partner concept and the systematic review concept. The full modified Ovid MEDLINE search strategy is available in [Multimedia Appendix 2](#), and the R code for extracting the n-grams is available in OSF [28]. After removing duplicates, 1 author screened titles and abstracts, and 2 authors screened each full-text article; all 3 authors discussed articles marked as include or unsure to reach agreement.

### Data Extraction

Included reviews were divided into 3 groups, and each author extracted data from reviews in 1 group. The areas of ambiguity in data extraction were discussed by all 3 reviewers.

We extracted data about author affiliation of patient or public partners, journal, country of partners, how they have contributed to reviews, and in what sections of the reviews these contributions were described. Where sufficient information was

available, we coded the partners' roles in line with the 12 stages of a systematic review as outlined in the ACTIVE framework [10]: (1) develop question, (2) plan methods, (3) write and publish protocol, (4) develop search, (5) run search, (6) select studies, (7) collect data, (8) assess risk of bias, (9) analyze data, (10) interpret findings, (11) write and publish review, and (12) knowledge translation and impact.

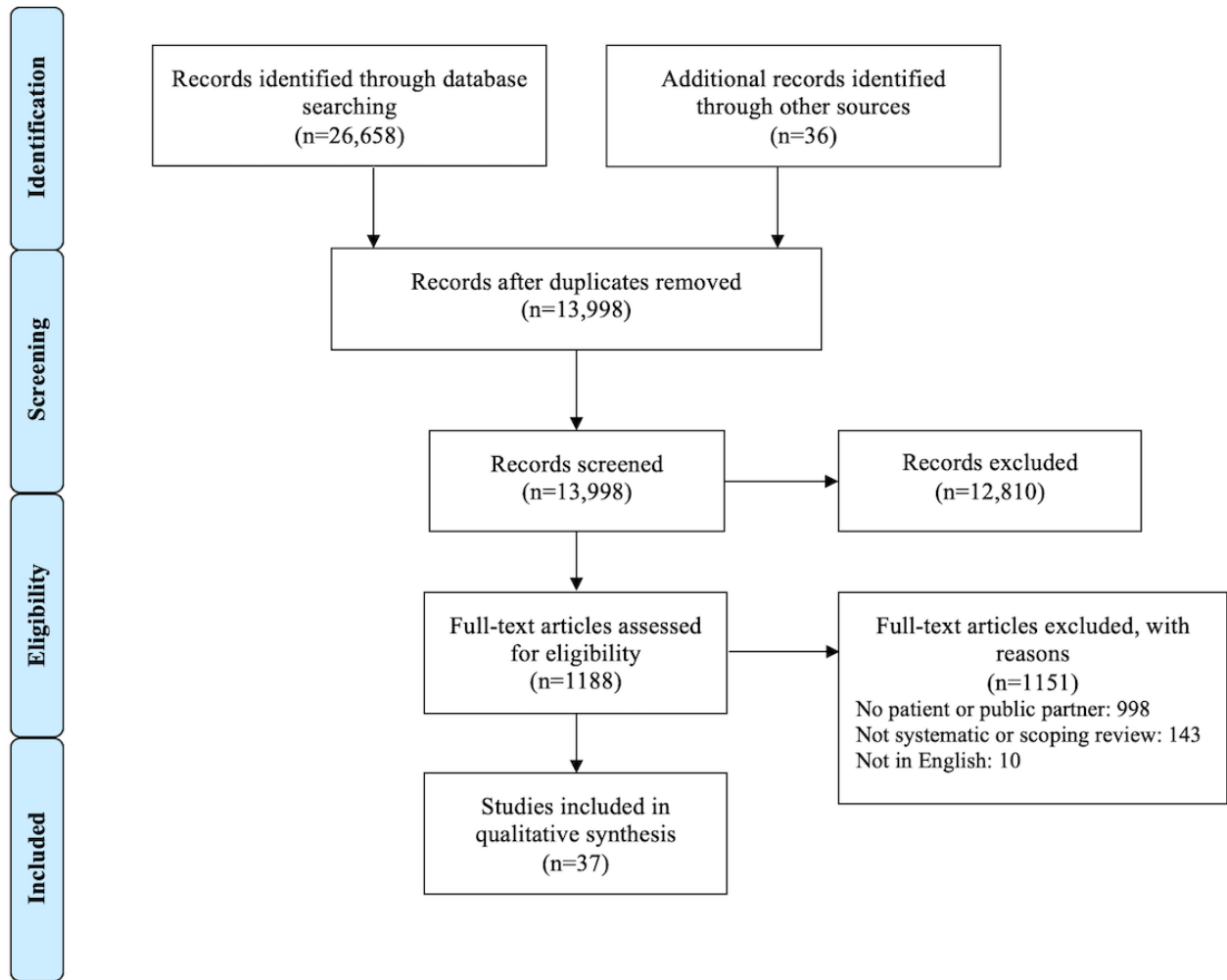
## Results

### Search Results and Screening

The initial database search in May 2019 returned 25,853 results, with an additional 35 results identified through other means such as cited reference searching; 13,958 results remained after deduplication. A total of 953 reviews were screened in the full text. Preliminary findings of our research, presenting the results of our initial database and supplementary hand search, were presented in a poster at the 26th Cochrane Colloquium [32].

An additional 805 results were found by the modified updated Ovid MEDLINE search run on June 8, 2020. One additional study was identified for inclusion because it was mentioned on social media after the search update was run, bringing the total number of studies identified through other means to 36. The PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) flow diagram presents the total number of search results, including the June 2020 update ([Figure 1](#)). A total of 37 articles were included in our overview.

**Figure 1.** PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) flow diagram.



**Characteristics of Included Studies**

The characteristics of the 37 included studies are summarized in Table 1. Reviews were published across 28 journals representing a range of health disciplines. Many terms were used to describe the patients and public partners in author affiliations. In some cases, partners were easy to identify with titles such as patient, caregiver or consumer representative, patient partner, expert by experience, citizen researcher, or public contributor. In others, they were identified as members of a panel or advisory council. Some studies identified *partner*

as members of a panel or advisory group; in 11% (n=4) of the articles, a panel or other body was named as an author rather than individual contributors [14,33-35]. Finally, in 27% (n=10) of articles, it was either impossible or difficult to tell whether an author was a partner solely from the affiliation, and confirmation was found elsewhere in the article.

The majority (21/37, 57%) of reviews had patients or public partners based in the United Kingdom (Table 2).

The number of reviews increased notably from 2018 onward (Figure 2).

**Table 1.** Selected characteristics of included studies.

Study	Author affiliation of patient or public partner	Journal
Brett et al [36]	UK Clinical Research Collaboration; University/Users Teaching and Research Action Partnership	The Patient
Brett et al [37]	UK Clinical Research Collaboration; University/Users Teaching and Research Action Partnership	Health Expectations
Aslakson et al [38]	Patient/family member coinvestigator, Architecture by Design	Journal of Comparative Effectiveness Research
Jones et al [39]	Patient representative, Colon Aid PPI <sup>a</sup> Group, Yeovil District Hospital Foundation Trust	Annals of Surgery
Whitton et al [40]	Cochrane Skin Group	Cochrane Database of Systematic Reviews
Garvelink et al [41]	Caregiver representative in the Population Health and Practice-Changing Research Group of the Research Centre, CHU de Québec	Health Affairs
Morley et al [20]	Consumer representative, Cochrane Pregnancy and Childbirth	Research Involvement and Engagement
Souleymanov et al [42]	Harm Reduction Peer Street Outreach Coordinator, Queen West Central Toronto Community Health Centre	BMC Medical Ethics
Clarkson et al [33]	Members of the HoSt - D <sup>b</sup> Programme Management Group	Journal of Advanced Nursing
Kronenberg et al [43]	Expert by experience	The British Journal of General Practice
Bethell et al [44]	Ontario Dementia Advisory Group	Dementia
Crocker et al [45]	National Institute for Health Research Oxford Biomedical Research Centre	BMJ
Evans et al [34]	North Bristol Microbiology Patient Panel	Health Expectations
Fergusson et al [11]	Patient Partner, SPOR <sup>c</sup> National Steering Committee	Research Involvement and Engagement
Jennings et al [46]	RECOLLECT Lived Experience Advisory Panel	BMC Psychiatry
Jorgensen et al [47]	Patient and Public Representative	Qualitative Health Research
Pollock et al [48]	None, just location	Systematic Reviews
Price et al [49]	Citizen Researcher	Journal of Evaluation in Clinical Practice
Baines et al [50]	Volunteer Mental Health Patient-Research-Partner	Journal of Health Services Research & Policy
Evans et al [51]	Mojatu Foundation	BMJ Open
Gonzalez et al [52]	Patient Representative, Federal Joint Committee, Gemeinsamer Bundesausschuss	BMJ Open
Greenhalgh et al [4]	Patient Adviser, Nuffield Department of Primary Care Health Sciences, University of Oxford	Health Expectations
McCarron et al [53]	Patient coinvestigators, Community Health Sciences, University of Calgary	Systematic Reviews
McGrath et al [54]	Public contributor	The International Journal on Drug Policy
Moore et al [55]	Biomedical Research Centre Patient & Public Involvement Group, University College London Hospitals	Health Technology Assessment
Oldfield et al [56]	General Patient and Family Advisory Council, Yale-New Haven Hospital	Journal of General Internal Medicine
Planner et al [57]	NIHR <sup>d</sup> School for Primary Care Research	Trials
Scholz et al [58]	Consumer representative	Palliative Medicine
Sherriff et al [35]	Health4LGTBI Network	Health Expectations
Bird et al [59]	Patient Partner, McMaster University	Health Expectations
Brush et al [60]	Friends of Parkside	Health Education & Behavior

Study	Author affiliation of patient or public partner	Journal
Gordon et al [61]	COMENSUS <sup>e</sup> Group	Medical Teacher
Graham et al [62]	Radcliffe Women’s Health Patient and Public Participation Panel	BJOG
Hoekstra et al [14]	SCI <sup>f</sup> Guiding Principles Consensus Panel	Health Research Policy and Systems
Hung et al [63]	Community Engagement Advisory Network	Dementia
Maidment et al [64]	PPI representative	BMC Geriatrics
Arnstein et al [15]	Consumer Forum, National Cancer Research Institute; Research Involvement and Engagement; International Alliance of Patients’ Organizations	Research Involvement and Engagement

<sup>a</sup>PPI: patient and public involvement.

<sup>b</sup>HoST-D: Home Support in Dementia.

<sup>c</sup>SPOR: strategy for patient-oriented research.

<sup>d</sup>NIHR: National Institute for Health Research.

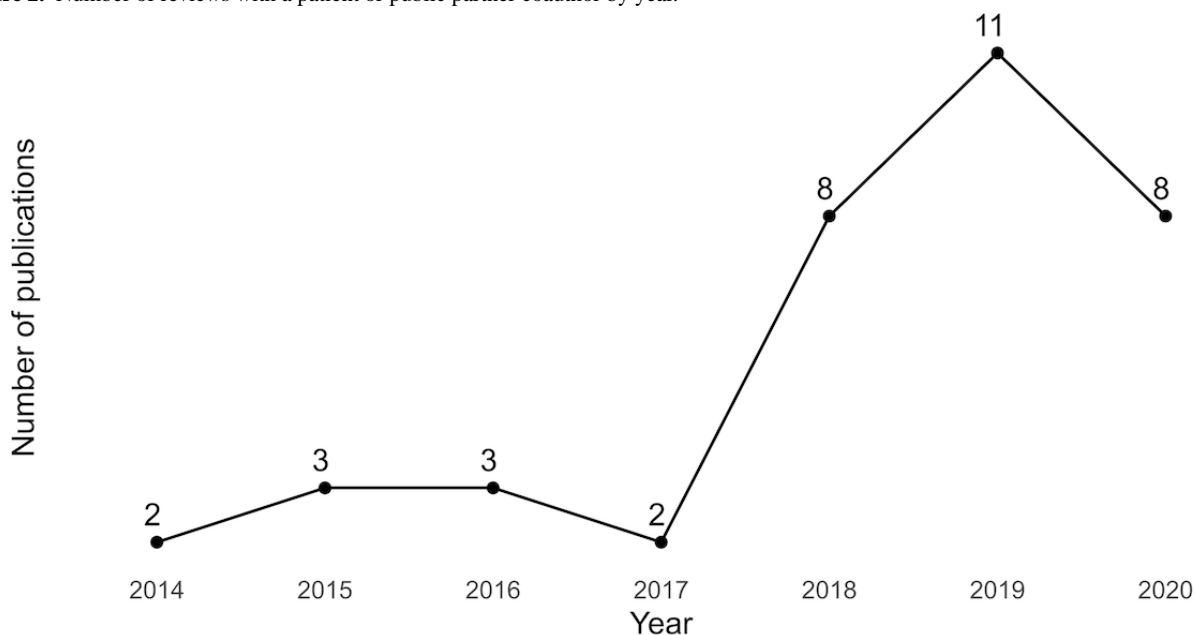
<sup>e</sup>COMENSUS: Community Engagement and Service User Support.

<sup>f</sup>SCI: spinal cord injury.

**Table 2.** Country of patient and public partner authors.

Country	Review, n (%)
United Kingdom	21 (57)
Canada	8 (22)
United States of America	3 (8)
Unknown or multi-state	2 (5)
Germany	1 (3)
Denmark	1 (3)
Australia	1 (3)

**Figure 2.** Number of reviews with a patient or public partner coauthor by year.



In many reviews, little information was provided about the specific roles of patients or public partners in the review (Table 3). In 24% (9/37) of the reviews, the author affiliation field was the only place in the paper indicating the involvement of a patient or public partner; these reviews are identified in

Multimedia Appendix 3. For reviews that described the partners’ contributions in the text, the most common location of this report was in the methods section (18/37, 49%). Only 14% (5/37) of reviews articulated patient and public contributions in a field routinely searched in databases of journal literature, the abstract.



**Table 3.** Sections of review besides author affiliation field indicating patient or public partner involvement.

Section	Review, n (%)
Methods	18 (49)
Contributions	9 (24)
Discussion	5 (14)
Abstract	5 (14)
Results	3 (8)
Introduction	2 (5)
Acknowledgments	2 (5)
Patient, service user or end user involvement	2 (5)
Limitations	1 (3)
Appendix	1 (3)

We coded patient and public partners' roles in reviews in alignment with the 12 review stages identified in the ACTIVE framework (Table 4). In 49% (18/37) of cases, insufficient detail was available on the stages of the review that partners

contributed to, and the authors coded these as *unclear*. More detailed information showing the location of reporting and specific partner roles for each included review is available in Multimedia Appendix 3.

**Table 4.** Patient involvement in the 12 review stages identified by the ACTIVE (Authors and Consumers Together Impacting on Evidence) framework.

Stage	Review, n (%)
Unclear	18 (49)
Develop question	8 (22)
Plan methods	4 (11)
Write and publish protocol	4 (11)
Develop search	6 (16)
Select studies	7 (19)
Collect data	4 (11)
Analyze data	9 (24)
Interpret findings	10 (27)
Write and publish review	12 (32)
Knowledge translation and impact	6 (16)

## Discussion

### Lack of Clarity in Reporting Public and Patient Partner Roles

There are many potential capacities in which PPI can take shape and many stages of the research cycle in which that PPI may be implemented. However, our final set of papers included a subset for which there was a lack of clarity in the terminology used to report and describe public and patient partner involvement, making it a challenge to classify partners' roles. The nuances surrounding the extent to which patient and public coauthors contribute to research vary and reflect their educational and experiential backgrounds.

This subset of papers used vague or nonspecific language to describe both roles and contributions. Three instances include Clarkson et al [33], Bethell et al [44], and Evans et al [34]. Clarkson et al [33] provide attribution in the acknowledgments section with a short description where the authors "thank...our

Patient, Public and Carer Involvement (PPCI) group for their comments from the synthesis." The comments referred to are not concretely linked to the Patient, Public and Carer Involvement group in the manuscript. In Bethell et al [44], a scoping review looking at dementia care, the partner role is described in a dedicated section, "Engagement of persons with dementia in the research process" as "[t]wo people with dementia, working with the Ontario Dementia Advisory Group (ODAG), were involved in the execution and translation phases of this project." Although useful to have a clearly delineated section to describe the partnership, it is unclear what *execution* means. Finally, in Evans et al [34], it is almost impossible to decipher the actual contributions of the partner from the authors' indeterminate description: "panel members were invited to contribute to shaping the discussion section." Although this describes participation, it does not describe contribution nor are actions like *invited* to and *shape* measurable.

Two instances in which the role of the patient or public partner was unclear include Price et al [49] and Baines et al [50]. In the

study by Price et al [49], it is difficult to determine which tasks were completed by a coauthor and which were completed by volunteers because the narrative reports the 2 together. In the section “Our PPI for this Systematic Overview,” although roles are clearly described, their assignment was unclear, making it impossible to distinguish between those activities completed by a volunteer from the Cochrane Task Exchange and those from the 3 volunteers from Empower. In Baines et al [50], although the authors describe a collaboration, “[a]ll research was conducted in collaboration with a volunteer mental health patient research partner who has extensive experience of receiving psychiatric care. Published principles of PPI were followed to support this involvement.” the role and contributions of this collaboration are not described.

Patient and partner expertise may impact the research and summary process in many ways; articulating the roles and contributions of these partners in clear and measurable language allows the reader to evaluate the strengths and limitations of a given study and its methodological rigor. The more closely aligned these descriptions are with an explicitly defined taxonomy, the easier is their interpretation. Our study focused on publications after the introduction of GRIPP in 2011; we wondered if the introduction of GRIPP for reporting on PPI would result in an increase in patient and public partner coauthored reviews, and more detailed descriptions of the roles of these coauthors. Although the number of studies we identified increased over the period 2011–2020, only one review, Arnstein et al [15], used a framework to report their PPI methods.

### Location of Reporting

One challenge of this study was identifying patient and public coauthored secondary research. Reproducible systematic and scoping reviews that contribute to the evidence base rely on abstracting and indexing databases that permit a search to be fully replicable irrespective of the computing environment used. Consequently, the discoverability of PPI contributions needs to be reported at a level captured by these indexing services. In general, titles, abstracts, and author-supplied keyword fields are the primary fields queried, whereas author affiliations can sometimes be queried, and some indexing services include additional controlled vocabulary fields to aid in discoverability. These controlled vocabularies often also capture study methods or publication types.

This challenge of discoverability is highlighted in our own findings, where only 14% (5/37) of the identified articles articulated patient and public contributions in a commonly indexed field, the abstract. The benefits of reporting PPI are limited if PPI cannot be readily identified in systems designed to index and access this research. We are certain that we did not identify all patient and public coauthored systematically conducted secondary research articles in the searched databases (in addition to reporting issues mentioned here, see *Limitations*), and this primarily suggests that not only does reporting need to be better but better guidance is required on where reporting should be done. Supplementation by controlled vocabularies or publication types would further bolster these efforts.

### Authorship Versus Acknowledgment

During full-text screening, we encountered many reviews that acknowledged significant contributions from patient or public partners but named no partners as coauthors. This is consistent with the findings of other publications in participatory research [65]. Recognizing partners as authors indicates that they had substantial involvement in the research; however, partners may not accept or receive authorship for various reasons. For instance, the authors may want to preserve their anonymity, as was noted in the review by Sherriff et al [35], where the coauthor was a collective entity (Health4LGBTI Network) and individuals were not named. Furthermore, many health journals require authors to meet the 4 ICMJE criteria, and some partners may be unable or unwilling to fulfill all of these criteria [66,67].

### Strengths and Limitations

#### Strengths

Our study adds to the literature on PPI in knowledge syntheses by collating 37 examples of reviews with patient and public coauthors; to our knowledge, no other study has identified as many instances of patient or public systematic or scoping review coauthors. Our initial search terms were sensitive; we searched numerous databases and other sources and screened nearly 14,000 unique search results. Our approach to updating our search by reviewing frequently used terms from the initial round of search results may be a useful technique for other researchers to adopt. Furthermore, the search terms we developed may help other researchers locate patient and public-authored research.

The data we extracted about author affiliations adds to existing evidence about the diversity of terms used to describe patients and public partners. Our extraction of where in reviews coauthor roles are described, as well as which review tasks they contributed to, provides insight on where current reporting practices are lacking.

#### Limitations

We limited our search to terms related to PPI and post-2011 publications in English because it was not feasible for us to screen all systematic and scoping reviews. These limitations may have introduced a bias. One flaw we discovered with our initial search strategy is that use of the string (patient\* adj3 involv\*) found many reviews that simply reported that the included studies “involved n patients,” with no actual PPI content.

During title and abstract screening, we limited inclusion to articles that either explicitly talked about PPI or described behavioral or lifestyle interventions, in line with the findings of Wale et al [68] about topics that are likely to engage patients. At the full-text screening stage, it was often impossible to verify that an author was a patient or public partner from the review itself. Furthermore, patients may have multiple roles—as a researcher and as a person with lived experience—or professional roles as patient representatives. Although these articles may have had patient or public authorship, a lack of detailed reporting made verification indeterminable.

This study focused on systematic, scoping, and other reviews that met the minimum criteria for knowledge synthesis:

searching more than one database, reporting at least one reproducible search strategy, and reporting the total number of results found and screened. Studies that used multiple methodologies in conjunction with some form of systematic search of the literature; studies that derived findings from other qualitative methods, for example, as consensus methods such as Delphi studies, were excluded. Therefore, we cannot suggest that our findings reflect all derivatives of systematic approaches to secondary research.

## Conclusions

For PPI research to be more fully used and its benefits realized, reporting of this research should be undertaken in such a way that allows for clear identification, which then permits discovery and retrieval. Although reporting frameworks and checklists exist to help guide researchers in both original and synthesis research, they are not harmonized with the current structure of the discovery tools—bibliographic databases—used in the search and retrieval of original research. This makes systematic discovery and retrieval of PPI research—and in particular PPI

coauthored research—a challenge, as evidenced by this study. In fact, the methods used to run our updated search strategy identified novel language used to describe both PPI and synthesis literature.

Our findings support previous research that suggests enhanced PPI reporting in systematic reviews allows for better interpretation of the study's design and results. Our findings also suggest that changes are needed to support the discovery of this research through bibliographic databases. This latter issue represents a point of potential collaboration between authors through enhanced reporting, publishers through encouragement to authors to report on these methodological approaches, and database providers, through added metadata fields to collate this research. One example of a database incorporating added metadata is NIHR INVOLVE's Evidence Library, which indicates whether patients or caregivers are authors of each included article. Such changes will make patient-authored research easier to identify in databases. When this research is easier to find, its impact will also be easier to measure.

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The authors thank Rebecca Rishar, MLIS, Senior Information Specialist at the ECRI Institute for peer reviewing the initial Ovid MEDLINE search strategy.

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## Conflicts of Interest

None declared.

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### Multimedia Appendix 1

Initial search strategy for Ovid MEDLINE and Epub ahead of print; in-process; and other nonindexed citations, daily, and versions (May 23, 2019).

[\[DOCX File, 14 KB - jopm\\_v13i2e27141\\_app1.docx\]](#)

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### Multimedia Appendix 2

Modified search strategy for Ovid MEDLINE and Epub ahead of print; in-process; and other nonindexed citations, daily, and versions (run June 8, 2020).

[\[DOCX File, 12 KB - jopm\\_v13i2e27141\\_app2.docx\]](#)

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### Multimedia Appendix 3

Location of reporting about patients and public partners and their roles when specified. When insufficient information was provided to connect the patient or partner role with any of the 12 review stages in the ACTIVE (Authors and Consumers Together Impacting on Evidence) framework, the authors have noted unclear.

[\[DOCX File, 9 KB - jopm\\_v13i2e27141\\_app3.docx\]](#)

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## Abbreviations

**ACTIVE:** Authors and Consumers Together Impacting on Evidence

**GRIPP:** Guidance for Reporting Involvement of Patients and Public

**NIHR:** National Institute for Health Research

**PPI:** patient and public involvement

**PRISMA:** Preferred Reporting Items for Systematic Reviews and Meta-Analyses

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Corrigenda and Addenda

# Correction: Data Sharing Goals for Nonprofit Funders of Clinical Trials

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In "Data Sharing Goals for Nonprofit Funders of Clinical Trials" (*J Particip Med* 2021;13(1):e23011) the authors noted two errors.

In the originally published manuscript, Lynn Matrisian was the last author listed in the order of authorship. This has been

corrected to place Lynn Matrisian fifteenth in the order of authorship, after Mary Jane Marchisotto and before Elizabeth Myers. Author affiliations have been renumbered accordingly.



As well, the affiliation for Mary Jane Marchisotto has been corrected from:

*MJM Advisory, LLC, McLean, VA, United States*

to:

*MJM Advisory, LLC, New York, NY, United States*

The complete list of authors and affiliations in the originally published paper was as follows:

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The correction will appear in the online version of the paper on the JMIR Publications website on June 30, 2021, together with the publication of this correction notice. Because this was made after submission to PubMed, PubMed Central, and other full-text repositories, the corrected article has also been resubmitted to those repositories.

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Original Paper

# Improving Health for People Living With Heart Failure: Focus Group Study of Preconditions for Co-Production of Health and Care

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## Abstract

**Background:** Co-production of health and care involving patients, families of patients, and professionals in care processes can create joint learning about how to meet patients' needs. Although barriers and facilitators to co-production have been examined previously in various health care contexts, the preconditions in Swedish chronic cardiac care contexts are yet to be explored. This study is set in the health system of the Swedish region of Jönköping County and is part of system-wide efforts to promote better health for persons with heart failure (HF).

**Objective:** The objective of this study was to test the usefulness of the Capability, Opportunity, and Motivation Behavior (COM-B) model when assessing the barriers to and facilitators of co-production of health and care perceived by patients with HF, family members of patients with HF, and professionals in a Swedish chronic cardiac care context as a guide for subsequent initiatives.

**Methods:** Data collection involved 1 focus group interview (FGI) with patients with HF (n=5), 1 FGI with family members of patients with HF (n=5), 1 FGI with professionals in primary care (n=7), and 1 FGI with professionals in cardiac care (n=4). In addition, patients with HF kept diaries of their thoughts regarding co-production. Using a deductive approach to content analysis, underpinned by the COM-B model, barriers and facilitators were categorized into capabilities, opportunities, and motivations to co-produce health and care.

**Results:** The participants showed limited understanding of co-production as a practice. They appeared to view it as a privilege to be offered to patients on top of traditional care and rarely as an approach for improving health care processes. The interviews revealed the limited health literacy among patients and the struggle of professionals to convey health information to these patients. Co-production was considered to be more resource-intensive than traditional care. Different expectations of stakeholders' roles were revealed: professionals expected older patients not to want to co-produce health and care, and all participants expected professionals to be in charge of health care services. The family members' position involved trying to balance their desire to support their relatives with understanding when, how, and with whom to co-produce. Presumed benefits motivated stakeholders: co-production was recognized to motivate patients to improve self-care. However, the participants recognized that motivation to get involved in health and care decisions varies over time among stakeholders.

**Conclusions:** Co-production can be facilitated by the stakeholders' motivation. However, varying levels of understanding of co-production, patients' limited health literacy, unease with power sharing between patients and professionals, and resource constraints are barriers that need to be managed to promote co-produced care and better health for persons living with HF. Further

research is warranted to explore how to co-produce health care services with patients with HF and how leaders can facilitate the inevitable cultural change it requires and represents.

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## KEYWORDS

co-production of health and care; capability; motivation; opportunity; Capability, Opportunity, and Motivation Behavior model; focus groups; heart failure; Sweden; primary care; cardiology; co-production

## Introduction

### Background

Promotion of the best possible health for persons living with chronic disease is challenging for health systems worldwide. There is growing interest in co-production of health care services—involving patients, families of patients, and professionals in care processes—to create joint learning about how to meet patients' needs, thus promoting the best possible health [1-6]. Although barriers and facilitators to co-production have been examined previously in various health care contexts [1,2,7-19], the preconditions in Swedish chronic cardiac care contexts are yet to be explored. The present study is set in the health system of the Swedish region of Jönköping County and is part of system-wide efforts to promote better health for persons with heart failure (HF).

### Co-Production of Health and Care

Despite many attempts to define co-production of health care, there is no consensus [2,6,8,20-26]. Loeffler et al [21] proposed that the concept implies a collaboration between patients, families, and professionals at many stages of health care processes: co-planning, co-design, co-delivery, and co-assessment. Osborne et al [6] highlighted the importance of learning about how to co-produce effectively and how to apply the lessons for service improvement, indicating co-learning. In this paper, co-production of health and care is understood to be when patients, family members, and professionals collaborate with shared power in health care processes.

The goal for co-production is best possible health and care [1-6]. Understanding barriers to and facilitators of co-production, previously examined in diverse health care contexts, can in turn guide subsequent improvement initiatives. Patient-related barriers include acute illness [2,9], frailty and old age [9,15], limited health literacy (HL) [9-11], and low self-efficacy and engagement [9,11]. In addition, a reluctance of some professionals to use new ways of working is a barrier to co-production [2,14]. Insufficient communication skills among professionals can also hinder co-production [9-11]. Further barriers are resource constraints, such as staff shortages, poor continuity, and shorter appointments [1,7,9,12,14]. Conditions that can facilitate co-production include individual motivation [13], support from leaders [15-19], and “learning networks” that include patients, nonformal caregivers, and professionals [2].

### Co-Producing Health and Care With Persons Living With HF

HF is a common chronic heart disease that affects 10% of people over the age of 70 years [27]. HF occurs when the heart muscle becomes unable to pump enough blood to meet the body's needs for blood and oxygen. This causes dyspnea (difficult or labored breathing) and edema (abnormal fluid accumulation in the body) with weight gain and worsened quality of life. Patients with HF usually present with several comorbidities, which add to the burden of disease [27]. Patients with HF also present with cognitive impairment, dementia, and low levels of HL [28-31]. This, in turn, reduces the person's self-care abilities, with increased use of emergency care, frequent hospitalizations, and a higher mortality rate [32-37].

Clinical guidelines, which promote evidence-based care for HF aimed at reducing mortality and improving quality of life, support a multidisciplinary team approach to HF care including optimal medical and device management, patient involvement in symptom monitoring, and adequate patient education [27]. Self-care skills to include in patient education are understanding HF symptoms, monitoring and recognizing symptoms and signs, and knowing when and how to self-manage diuretic therapy and fluid intake [27,38]. Behaviors of professionals to optimize learning by patients with HF and facilitate shared decision making include recognizing HF disease barriers to communication and providing individualized information [27]. This approach aligns with the idea of co-production, with patients, family members, and professionals collaborating with shared power in health care processes aiming for best possible care.

When preparing co-production initiatives for and with patients with HF in a Swedish cardiac care context, we found a lack of knowledge about barriers and facilitators in this context. To inform future improvement efforts with and for persons with HF, we sought to better understand the contextual conditions and their implications for co-production of health and care. Our exploration of barriers to and facilitators of behavior change in line with co-production was underpinned by a theoretical model of intentional behavior: the Capability, Opportunity, and Motivation Behavior (COM-B) model [39,40].

### Objective

The objective of this study was to test the usefulness of the COM-B model when assessing barriers to and facilitators of co-production of health and care perceived by patients with HF, family members of patients with HF, and professionals in a Swedish chronic cardiac care context, as a guide for subsequent initiatives.

## Methods

### Study Design

This was an explorative qualitative study involving 4 stakeholder groups: (1) patients with HF, (2) family members of patients with HF, (3) professionals working in specialized cardiac care, and (4) professionals working in primary care. Data collection involved focus group interviews (FGIs) [41,42] and participating patients' health diaries [43,44] kept specifically for this study. The study was vetted and approved by the Swedish Ethical Review Authority (Dnr: 2019-03530). All quotes presented in this paper were anonymized and cannot be traced to specific individuals participating in this study.

### Study Context

The study was conducted in the Highland health district in Region Jönköping County (RJC), Sweden. Primary care centers (PCCs) serve the 115,000 inhabitants in the area. Heart disease, including HF, accounts for a major part of the disease burden in the district's aging population. Patients with heart disease receive care mostly in PCCs, with access to emergency care and specialized cardiac care in the Highland district hospital as needed. To enable the best possible health and care for these patients, health professionals in primary care and specialty care are expected to cooperate with each other to meet the needs of patients and their family members.

In recent years, RJC—with its long history of systematic improvement efforts [45-48]—has launched several projects involving different stakeholders in society. The “Tillsammans” (“Together”) initiative aims to improve the lives and health of all residents and to shift more care services closer to them, from hospitals to PCCs [49]. The promotion of co-production of health and care is central to this initiative. Although the concept of “co-production of health and care” has lately become more familiar to professionals in RJC, few departments and PCCs have fully adopted the concept.

### Recruitment and Participants

A nurse who was working with patients with HF in primary care but was not a member of the research team suggested eligible patients with HF and their family members for inclusion in this study. Individuals were excluded for the following reasons: (1) under age 18 years; (2) unable to consent to study participation due to acute illness, cognitive impairment, or lack of proficiency in the Swedish language; or (3) had received care from the main author (a practicing cardiologist in the study context). Professionals working in a PCC or in a cardiac ward in RJC were invited by the lead researcher (A-MS) to join the study during workplace meetings and through information letters sent via email. None of the other researchers (JT, AMMN, SK, or KAJ) had a care or working relationship with study participants. The participant characteristics are shown in [Table 1](#).

**Table 1.** Participant characteristics.

Study participants	Gender	Age (years)	Profession
<b>Patients (n=5)</b>			
#1	Male	74	N/A <sup>a</sup>
#2	Male	66	N/A
#3	Male	70	N/A
#4	Female	81	N/A
#5	Female	76	N/A
<b>Family members (n=5)</b>			
#1	Male	85	N/A
#2	Female	83	N/A
#3	Female	89	N/A
#4	Female	67	N/A
#5	Female	45	N/A
<b>Primary care professionals (n=7)</b>			
#1	Male	43	Physician
#2	Female	23	Physiotherapist
#3	Female	49	Nurse
#4	Female	46	Nurse
#5	Female	54	Nurse
#6	Female	31	Physician
#7	Female	44	Physician
<b>Cardiac care professionals (n=4)</b>			
#1	Male	38	Physician
#2	Male	37	Physiotherapist
#3	Female	50	Nurse
#4	Female	57	Nurse

<sup>a</sup>N/A: not available.

## Data Collection

Between November 2019 and January 2020, the lead researcher (A-MS) conducted 4 separate FGIs in Swedish with patients with HF, family members of patients with HF, professionals in primary care, and professionals in cardiac care. All participants provided informed written consent prior to data collection. The focus groups were guided by 3 semistructured interview guides developed by the authors, which addressed stakeholders' perspectives on capabilities, opportunities, and motivations to co-produce health and care (ie, the behavior of interest, all according to the COM-B model). The guides were pilot tested with 2 patients with HF and 2 professionals and revised accordingly prior to the interviews: the word "co-production" was deemed unclear and replaced by "cooperation." This reflects the difficulty in translating the word "co-production" into Swedish, both semantically and as a previously unfamiliar phenomenon.

The FGIs started with a general question about the participants' experiences of living with HF or experiences of caring for these

individuals. The participants were then encouraged to share their experiences and perspectives of cooperation in health care, assisted by the interview guide. During the FGIs, the interviewer and lead researcher (A-MS) explained co-production of health and care to be when patients, family members, and professionals collaborate with shared power to improve health and care. All interviews ended with participants being given the opportunity to add anything of relevance regarding cooperation in health care that had not been covered during the interviews.

Each FGI lasted for approximately 1 hour. The interviews took place in a conference room in a PCC or the hospital. All interviews were audio-recorded, transcribed verbatim, and deidentified by a clinical documentation assistant with a duty of confidentiality or by the lead researcher.

In addition to the interview, participants living with HF were asked to write diary entries as often as they wanted during a 2-week period about their experiences and thoughts regarding the co-production of health and care to add data to the study. Data collection through patient diaries has previously been shown to be useful for involving patients in health care

development [43,44]. All 5 participants living with HF agreed to write a diary entry at home following the FGI and mailed it to the lead researcher.

**Data Analysis**

First, the lead researcher (A-MS) performed a qualitative latent content analysis according to Elo and Kyngäs [50]. The analysis included reading through the interview transcripts and patient diaries several times to become familiar with, and make sense of, the data. This was followed by open coding of the material, writing notes and headings in the text while reading it. These notes and headings were transferred to coding sheets and categorized into 2 categories: (1) barriers to and (2) facilitators of co-production of health and care.

Using a deductive approach, these barriers and facilitators were then coded into a categorization matrix developed from the COM-B model (Table 2). The COM-B model highlights conditions in 3 domains that affect behavior change: capability (physical and psychological), opportunity (physical and social), and motivation (reflective and automatic) [39]. Physical capability refers to physical ability, strength, and skills, whereas

psychological capability refers to comprehension, knowledge, capacity to engage in the necessary thought processes, memory, and cognition [9,39,51]. Physical opportunity refers to the opportunity afforded by the environment (eg, time, facilities, resources, and availability), whereas social opportunity refers to the opportunity afforded by the milieu (eg, cultural norms and roles, interpersonal influences, and inequalities) [9,39,51]. Reflective motivation refers to intentions, plans, convictions, and considerations, whereas automatic motivation refers to wishes, needs, feelings, and habits [39,51]. This model has previously proven useful in efforts to identify barriers and facilitators to co-production of health and care [9,14] and other co-production-related behaviors such as patient participation in health care safety promotion [52], patients planning advanced care [53], and shared decision making [54].

The quotes chosen to illustrate the results were translated from Swedish into English. The first draft of the analysis was discussed in depth with one of the researchers (KAJ), then further revised before being discussed among all researchers (A-MS, JT, AMMN, SK, and KAJ) until a consensus was reached.

**Table 2.** Barriers and facilitators to co-production of health and care.

COM-B <sup>a</sup> model domain and condition	Barriers	Facilitators
<b>Capability</b>		
Physical	<ul style="list-style-type: none"> <li>Impaired physical strength (ie, dyspnea or fatigue)</li> </ul>	<ul style="list-style-type: none"> <li>Sufficient physical strength to engage in co-production</li> </ul>
Psychological	<ul style="list-style-type: none"> <li>Lack of knowledge about co-production</li> <li>Impaired mental health</li> <li>Insufficient coping strategies</li> <li>Difficulties understanding health information</li> <li>Difficulties applying health information</li> <li>Difficulties among professionals in handling individuals with poor health literacy</li> <li>Inadequate communication skills</li> </ul>	<ul style="list-style-type: none"> <li>Capability to understand health information</li> <li>Adequate communication skills</li> <li>Existing working practices that promote co-production</li> <li>Capability to adapt to new work methods</li> <li>Support from family members</li> </ul>
<b>Opportunity</b>		
Physical	<ul style="list-style-type: none"> <li>Fragmented health care system</li> <li>Insufficient leadership support</li> <li>Time and resource constraints</li> </ul>	<ul style="list-style-type: none"> <li>Accessible health care support</li> </ul>
Social	<ul style="list-style-type: none"> <li>Expectations of the patients' role</li> <li>Expectations of the professionals' role</li> <li>Family members' role variations</li> </ul>	
<b>Motivation</b>		
Reflective	<ul style="list-style-type: none"> <li>Belief that co-production is unachievable</li> </ul>	<ul style="list-style-type: none"> <li>Belief that co-production improves care</li> <li>Belief that co-production leads to efficient use of resources</li> <li>Plans for how to co-produce</li> </ul>
Automatic	<ul style="list-style-type: none"> <li>Reluctance to co-produce</li> </ul>	<ul style="list-style-type: none"> <li>Desire to co-produce</li> </ul>

<sup>a</sup>COM-B: Capability, Opportunity, and Motivation Behavior.

**Results**

The results from the qualitative analysis are summarized in Table 2 and described in detail below.

## Capability to Co-Produce Health and Care

### Physical Capabilities

Some patients with HF reported having the physical capability to co-plan and co-evaluate their own health and care. However, all participants acknowledged varying and sometimes impaired physical health as a real-life challenge for many patients:

*You want to live as usual but can't do anything; you have no energy and are constantly tired. [Diary entry, Patient #4]*

This was understood to influence the patients' physical capability to participate in co-production of their own health and care.

### Psychological Capabilities

#### Understanding of "Co-Production of Health Care"

Patients and family members assumed that knowledge about the organization was necessary to be able to design health care processes and that their lived experiences would not be useful when designing care:

*I mean, if you don't have the knowledge you can come up with any kind of claim, which there is no value in [...] To participate in designing the health care services [...] My views obviously wouldn't be worth anything. [FGI with patients]*

This opinion, which exposed a gap in patients' sense of capability regarding how to use their lived experiences in health care design, mirrored the professionals' understanding of co-production. The professionals agreed that patients and family members needed more organizational and medical knowledge to participate in co-production of health care. The professionals' understanding of co-production included a fear of patients taking charge of medical decisions, and ultimately co-production was understood as a service to be offered to patients on top of traditional health care rather than as an approach to operating and improving health care:

*I mean, before we can say that we can implement having patients involved in making decisions concerning their own care, then we must have a good concept to deliver to them and we are not there yet. [FGI with professionals in cardiac care]*

#### Understanding and Applying Health Information

Poor capability to understand health information was recognized as a major barrier for co-production with patients with HF:

*Then, when it comes to information sharing with this group of patients, one notices quite clearly that ... I mean if you have pretty severe heart failure, then you don't have that ability to take in this information and, therefore, it is even more important, at virtually every encounter, to repeat, or to add some new information. [FGI with professionals in cardiac care]*

Professionals also recognized many patients' poor capability to apply health information. One example was the fear and difficulty in following instructions of patients with HF related to taking extra diuretics when HF symptoms got worse. While

recognizing many patients' difficulties in understanding and applying health information, the professionals still struggled to get the information across to their patients. Rather than changing strategies to connect with the patients, a common approach seemed to be simply to provide even more information:

*The patients don't have enough knowledge or understanding of what we want to convey to them. Of course, we have to convey more and more, and we have to get them on the track. [FGI with professionals in primary care]*

The participants recognized that support from family members was important for patients with low levels of HL. Hence, the lack of family member support was identified as a challenge to effective co-production among them:

*The problem is that the family members are often not present at health care visits [...] [FGI with professionals in cardiac care]*

### Working Practices

Not being invited to co-produce health and care was acknowledged as hindering co-production. Family members, in particular, described how they were often overlooked as a natural part of the clinical microsystem (ie, the frontline place where patients, families, and care teams meet and cooperate in health care) [55]:

*But I guess I feel that when you as a family member seek contact [with the health care services], then it has gone quite far [...] then it is quite well thought through and then, when you get turned down or receive a cool response, it gets really tough. [FGI with family members]*

Professionals noted that they could invite patients and family members to co-produce health and care more frequently:

*I think that I could be better at inviting the patient and their family members to participate in the health care services. In other words, to ask questions—"What could you do on your own?" or "What do you think about the treatment?" or something like that. "What would suit you?" [FGI with professionals in primary care]*

Professionals anticipated growing expectations and willingness to adopt new working procedures:

*But, over time, I think that more people [patients] will question [things] and want to participate. [...] And I think that this [shift] might apply to professionals as well. We also change. [FGI with professionals in primary care]*

### Communication

The participants recognized that communication skills were a key capability for co-production. Patients' ability to communicate with professionals will typically be impaired when they suffer from acute illness. Professionals discussed how patients' willingness and capability to communicate with professionals could vary across generations:



*But the older person[s], they just assume that the doctor is right. So, they don't question [things].* [FGI with professionals in primary care]

Professionals talked about their own capability to listen to patients and notice their needs, rather than to educate and inform them through one-way communication. Patients declared that not being listened to by professionals could potentially lead to hesitation in seeking care:

*They [the physicians] just don't listen. They merely look over your head. [...] You feel like you're in their way and therefore, one simply hesitates to call here even when feeling bad.* [FGI with patients]

## Opportunity to Co-Produce Health and Care

### Physical Opportunities

The participants in all 4 focus groups considered the overall organization of the health care systems to be important for successful co-production. Patients and professionals noted that when care is provided by multiple stakeholders in parallel, it is difficult for patients and professionals to know when and which stakeholder to co-produce health and care with:

*It is difficult with doctors. In my case, I had a stroke [...] If I have trouble with something that has to do with the stroke, then I will call that doctor, and then there are two other doctors who take care of the heart. [...] It's a real mess, I think. You do not know who to turn to.* [FGI with patients]

Furthermore, they suggested that good continuity of care could facilitate care and support.

All participants expected co-production to be more time- and resource-intensive than traditional care. One physician presumed that insufficient time for health care visits would reduce professionals' willingness to ask questions and listen to, and consider, the patients' answers and needs. Patients agreed:

*I think that they [the health professionals] would be happy to know more about how we feel, but the question, obviously, is if they have the time to sit and listen to us?* [FGI with patients]

One nurse expressed doubts regarding the organization's resources to individualize care:

*They [the patients] may need even more support and then the question is can we give—can we tailor it—as much as we would need to?* [FGI with professionals in cardiac care]

### Social Opportunities

The FGIs revealed expectations on the roles of patients, family members, and professionals. These role expectations, reflective of a somewhat traditional (“doctor knows best”) health care system, challenge a shift toward patients being treated as equal partners in health care.

### Patients' Role

Some professionals said that they thought older persons would have difficulties co-producing health and care. They assumed that older patients were familiar with, and expected, physicians

to be in charge. Some professionals also considered patients to be just passive recipients of health information. Still, the professionals expected the patients to take the initiative to acquire more health education:

*The patients have to communicate that they want more information and an opportunity to ask questions [...] If this kind of initiative doesn't come from the patients it is very difficult to justify why we should come up with this.* [FGI with professionals in cardiac care]

Some patients, reflecting a feeling of inferiority in their role relative to that of professionals, imagined that professionals would not appreciate their opinions about organizational and medical matters:

*You do not want to be bothersome.* [FGI with patients]

Also, patients who experienced health care resource constraints felt an obligation to let others with supposedly greater needs get priority.

### Professionals' Role

An expectation of the professionals, expressed by both professionals and patients, was that they should be in charge of health care processes. This uneven power balance between patients and clinicians could be caused by old traditions but also by professionals' discomfort over allowing patients to have more influence over their own health and care:

*It is known that HF patients want to take more responsibility for their own illness, that they want to be involved, and it may be we who think that this is our responsibility and may not dare to hand it over to the patient.* [FGI with professionals in primary care]

### Family Members' Role

Family members expressed much worry for their sick relatives while wishing to support them. However, they also expressed uncertainty over when and how to co-produce health and care:

*Sometimes you don't know when to intervene [...] and then you think that then, they [the health care professionals] are surely on top of it all.* [FGI with family members]

Not all patients expected family members to be involved in their health care:

*Well, it's not something one counts on, to be able to get help [from family members] every day.* [FGI with patients]

Uncertainty over expectations as well as over when and how to co-produce health and care put family members in a difficult position.

## Motivation to Co-Produce Health and Care

### Reflective and Automatic Motivations

The participants predominantly spoke about co-producing in one-on-one interactions. Only 1 primary care nurse mentioned having experienced patient participation in health care process co-design efforts. Although there was motivation to co-produce,

participants noted that some patients might not want to be actively involved in their own care:

*Some [patients] want to do a lot and be heavily involved and become great experts on their own illness, while others become more passive and just say: "You decide." [FGI with professionals in primary care]*

This calls for organizational flexibility, which may be difficult to get to work in practice. Some participants even imagined that co-production was unachievable:

*Of course, it's a dream scenario that [a] patient, family members and health care professionals work together but I don't really believe in that possibility! [Diary entry, Patient #2]*

Several participants pointed to co-production benefits. On the frontline level, participants talked about how cooperation promoted patients' and family members' sense of security in everyday life and improved the quality of health and care. One patient acknowledged that co-production could promote professionals' learning about living with the disease, thus improving the capability to design appropriate care:

*They [the physicians] read a lot about it when they educate themselves, but this does not say anything about how we feel and how we experience it [living with disease]. It varies. So, it must be nice for a doctor to find out how we feel, to be able to do the right things. [FGI with patients]*

Professionals thought that co-production could potentially encourage patients to perform better self-care supported by improved team communication and a patient-centered approach focused on the patients' needs.

All participants assumed that health care visits focusing on cooperation to meet patients' care needs would be more time-consuming (than the usual care provided today) but still worthwhile in the long run for both patients and organizations:

*It takes time there and then, but in the long run there will probably be fewer care visits. [FGI with professionals in primary care]*

Professionals assumed a reduction in unplanned care utilization:

*I can imagine that if they [patients] feel involved and can cooperate there will perhaps be fewer readmissions. [FGI with professionals in cardiac care]*

## Discussion

### Principal Findings

Most barriers to co-production of health and care concerned the domain of capability, including difficulty understanding the term "co-production." Participants had limited understanding of the concept as a practice and appeared to view it as a privilege to be offered to patients on top of traditional care and rarely as an approach for improving health care processes. The FGIs revealed poor HL and low self-efficacy in co-producing among patients. Professionals' struggle to convey useful information to patients could be viewed as an indication of insufficient

organizational HL. Communication skills and the inclusion of stakeholders in co-production emerged as key facilitating capabilities.

In terms of physical opportunities, co-production was considered to demand more time and resources than traditional care. Regarding social opportunities, different role expectations of patients, family members, and professionals were revealed. Professionals expected older patients in particular not to want to be involved in their own health and care. Both professionals and patients expected the professionals to be in charge of and responsible for health care services. The data revealed that family members are in a difficult position when balancing their desire to support their sick relative with uncertainty of when, how, and with whom to co-produce health and care.

In terms of motivation, presumed benefits were identified. It was recognized that co-production of health meant working with a patient-centered approach that promoted patients' and family members' sense of security in everyday life and motivated patients to improve their self-care. This was believed to improve the quality of health and care and, ultimately, to reduce unplanned care in favor of more planned care. However, the participants recognized that motivations to co-produce health and care vary over time among patients and professionals.

### Comparison With Prior Work

In this study, respondents believed that co-production could improve the quality of health and care by considering patients' experiences when designing health care services and promoting patients' self-care abilities. These beliefs mirror those found in previous studies [1-5]. Vennik et al [1] suggested that co-production facilitates health care process improvement through the use of patients' experiences. Elwyn et al [3] proposed that co-production of health and care empowers people to cope with disease through the promotion of patient resilience and autonomy. However, the professionals recognized that not all patients and family members want to participate in health and care decisions, highlighting patient and family member diversity regarding capabilities and health status as challenges to standardization of co-production [2]. Virleé et al [11] suggested that patients' motivations to engage in health care depend on barriers and facilitators on 3 levels: individual, relational, and systemic. Similarly, our study results indicate that the motivations of patients with HF to co-produce health care are influenced by (1) individual factors (HL and self-efficacy), (2) relational factors (patients' and professionals' listening and communication skills), and (3) systemic factors (understanding of co-production, health care culture, and resource constraints).

### Individual and Relational Factors Influencing Co-Production

Mirroring previous research, our findings indicate that patients with HF have low levels of HL [31,56,57]. This includes insufficient skills to actively participate in everyday activities and apply new information to new circumstances as well as insufficient skills to analyze information and get greater control over life. Participating professionals suggested that patients' willingness and capability to communicate with health care

professionals might vary across generations. This represents a barrier to co-production—particularly among older persons—if it causes patients to refrain from communicating their own needs. Low self-efficacy, indicated here by patients' assumption that their lived experiences would not be useful when designing care, has previously been acknowledged as a barrier to co-production [9].

Our findings suggest that professionals struggle to convey information to persons with low levels of HL, indicating that there is room for improvement in the organization's HL (ie, professionals' capabilities and communication skills as they relate to meeting the special needs of people with limited HL). Quality improvement efforts addressing HL issues and strengthening the professionals' communication skills can increase organizational HL [58]. Palumbo and Manna [10] argued that limited organizational HL is a barrier to co-production when preventing the “evolution of health care providers from disease relievers—that is to say self-reliant and specialized healers of ill health status—to enablers—that is to say facilitators of patients' activation and involvement in the provision of care.” Furthermore, professionals tend to overestimate patients' HL levels, thus impairing patient-professional communication [59,60]. Although not explicitly expressed by the professionals in our study, an overestimation of patients' HL levels could explain the struggle of professionals to convey health information to patients. Inviting family members to co-produce health and care might compensate for patients' low levels of HL [61] and improve patients' quality of life [62]. However, our findings mirror those from a study in the US Veterans' Health Administration that suggest that family members want to participate in health and care decisions with and for patients with HF but feel excluded from care teams [63].

### Systemic Factors Influencing Co-Production

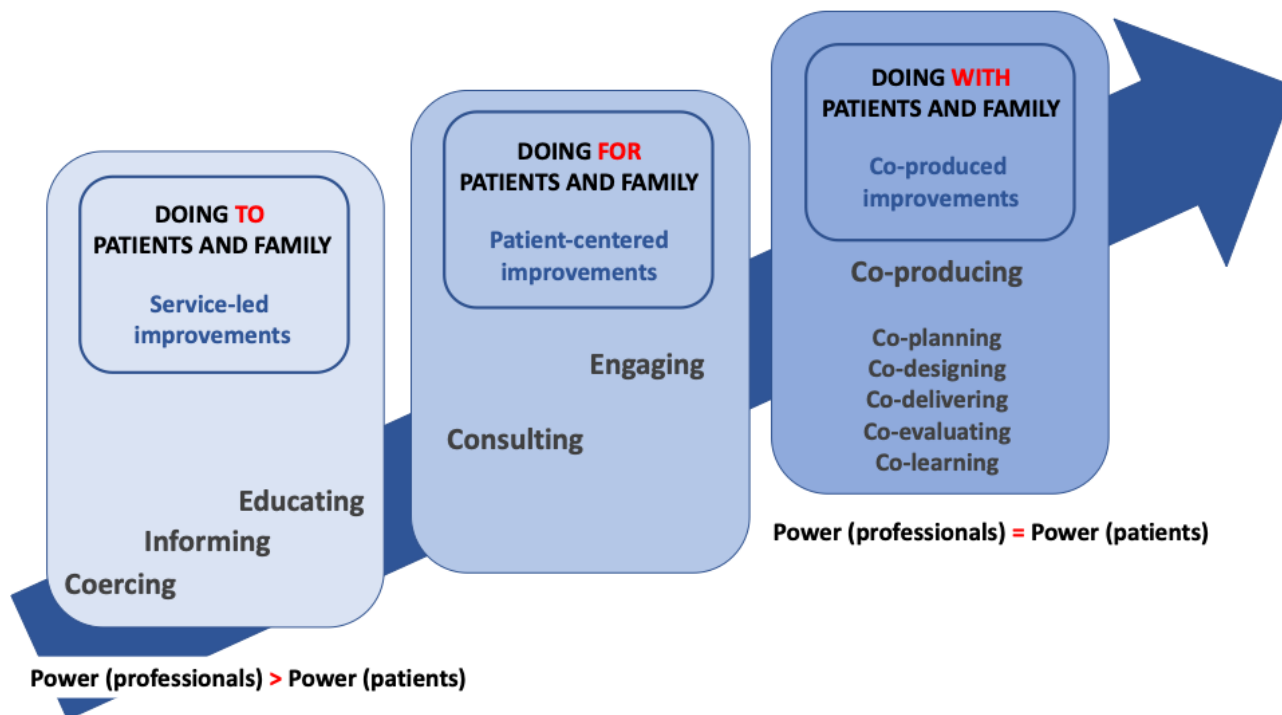
The study participants understood co-production to be the addition of something “new” on top of traditional health care. This mirrors the results of Alami et al [64], who found that citizen-patient involvement in shared decision making, a key

component in co-production, was understood as a theoretical idea rather than a current practice in health care. Even after explanation of co-production as an approach to improving health care processes on different organizational levels, it was mainly discussed regarding one-on-one interactions and rarely as an approach for improving health care on system levels. Gilardi et al [65] proposed that co-production can be seen from different perspectives: the first perspective focuses on patients and professionals interacting around clinical issues in the microsystem, and the second perspective focuses on multiple stakeholders from different organizations interacting on many organizational levels in different service delivery phases. Our findings indicate that the system perspective on co-production was not yet established among our respondents in chronic care settings.

Our Swedish study participants tell of a rather traditional “doctor-knows-best” health care context with professionals being in charge. As stated by some of the professionals in this study, old traditions, not having the time to invite patients and family members to co-produce health and care, and professionals' fear of losing control over health care visits and processes may perpetuate the unequal balance of power between stakeholders [1,7-9,12,14]. Arnstein [66] proposed a “citizen ladder of participation” that drew attention to the power balance between stakeholders on a spectrum of participation, from manipulation to citizen control. Figure 1 shows a modified ladder, describing different levels of patient participation [66-68].

In our study, patient participation was described in terms of “informing” and “educating” patients and family members, sometimes moving over to “consulting” them (Figure 1). This implies that quality improvements in health and care in our study context are usually service-led rather than co-produced. Managing the barriers reported here—varying levels of understanding of the concept of co-production, limited individual and organizational HL, unease with power sharing between patients and professionals, and resource constraints—is key to moving toward a more equal balance of power between stakeholders in our study context.

**Figure 1.** The co-production pathway (modified by lead researcher A-MS after Arnstein [66], Slay and Stephens [67], and Williams and Caley [68]).



**Methodological Considerations**

This study was limited to one particular setting. The barriers and facilitators to co-production reported here may be different from those in other health care contexts. For example, HL can vary between patients suffering from chronic diseases other than HF. Also, stakeholder understanding of co-production of health and care and experience with involving patients and family members in care processes can vary across health care organizations, leading to preconditions other than those reported in this study. This limits the generalizability of our study findings. However, the findings from this study can be useful to reflect upon for other health care and chronic care settings when considering adopting co-production approaches.

Individuals who were unable to consent to participation and individuals without knowledge of the Swedish language were excluded from this study. The researchers recognize that this might have limited the selection of participants to individuals who are considered easy to co-produce health and care with, thus limiting the generalizability of the study findings. However, being able to participate in interviews in Swedish made it easy for the participants to share experiences in depth. Among patients and family members, there could have been a selection bias if only participants with positive experiences of health care had been invited and/or decided to participate. There were no indications that this was the case, as the participants shared both positive and negative experiences in the FGIs. Because of the similarities between the interview guides for different stakeholders, the guides were not tested with family members

prior to the interview. There were no indications of family members not understanding the interview questions. Because of privacy concerns, patients’ and family members’ backgrounds, such as level of education and profession, were not mapped. This may hamper the ability to generalize the study findings.

The lead researcher (A-MS) works as a cardiologist in the study context. Thus, there might be a risk of bias due to the researcher’s close relationships with the professionals. In particular, there may be a risk of “social desirability” to influence their responses [69]. While good contextual knowledge is valuable when interpreting data, there is a risk that the lead researcher’s deep preunderstanding of this context could have made her unaware of some perspectives. Data analyses were reviewed with senior researchers (all coauthors)—a form of investigator triangulation—to strengthen the study’s trustworthiness.

**Conclusions**

Co-production can be facilitated by stakeholders’ motivations. However, varying levels of understanding of co-production, limited HL, unease with power sharing between patients and professionals, and resource constraints are barriers that need to be managed to promote co-produced care and better health for persons living with HF. Further research is warranted to explore how to co-produce health care services with patients with HF in ways that are resource efficient and how leaders can facilitate the inevitable cultural change it requires and represents.

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Research data at the School of Health and Welfare, Jönköping University, are regulated under the Freedom of the Press Act (1949:105) and the Public Access to Information and Security Act (2009:4) as public records/official documents. Research data that are registered and archived at the School of Health and Welfare, Jönköping University, can be requested anonymously by anyone for a fixed fee according to the Fee Regulation (1992:191). If the research data contain sensitive information, such as personal data and/or trade secrets, that information is protected by confidentiality and secrecy by the Public Access to Information and Security Act, and requests of such information will be denied with the possibility to appeal the denial in the Court of Appeals. Secret or confidential research data can be accessed by other researchers if they receive permission from the Swedish Ethical Review Authority. The lawful basis for transmission of secret and/or confidential information is then based on the Law of Ethics Review for Research on Humans (2003:460).

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### Authors' Contributions

Lead researcher A-MS, the main author, conducted the interviews with patients, family members, and professionals. She was responsible for the primary data analysis, which she discussed in depth with KAJ. A-MS was responsible for the first draft of the paper, which she then discussed with the other authors and revised accordingly. The authors confirm that each author participated sufficiently in the work to take public responsibility for the content. All authors granted final approval of the version of the manuscript to be published.

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### Conflicts of Interest

None declared.

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## Abbreviations

**COM-B:** Capability, Opportunity, and Motivation Behavior

**FGI:** focus group interview

**HF:** heart failure

**HL:** health literacy

**PCC:** primary care center

**RJC:** Region Jönköping County

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