ABSTRACT

Background  Awareness of patients’ innovative capabilities is increasing, but there is limited knowledge regarding the extent and nature of patient-driven innovations in the peer-reviewed literature.

Objectives  The objective of the review was to answer the question: what is the nature and extent of patient-driven innovations published in peer-reviewed scientific journals?

Eligibility criteria  We used a broad definition of innovation to allow for a comprehensive review of different types of innovations and a narrow definition of ‘patient driven’ to focus on the role of patients and/or family caregivers. The search was limited to years 2008–2020.

Sources of evidence  Four electronic databases (Medline (Ovid), Web of Science Core Collection, PsycINFO (Ovid) and Cinahl (EBSCO)) were searched in December 2020 for publications describing patient-driven innovations and complemented with snowball strategies.

Charting methods  Data from the included articles were extracted and categorised inductively.

Results  A total of 96 articles on 20 patient-driven innovations were included. The number of publications increased over time, with 69% of the articles published between 2016 and 2020. Author affiliations were exclusively in high income countries with 56% of first authors in North America and 36% in European countries. Among the 20 innovations reported, ‘Do-It-Yourself Artificial Pancreas System’ and the online health network ‘PatientsLikeMe’, were the subject of half of the articles.

Conclusions  Peer-reviewed publications on patient-driven innovations are increasing and we see an important opportunity for researchers and clinicians to support patient innovators’ research while being mindful of taking over the work of the innovators themselves.

BACKGROUND

Traditionally, patients have been considered as passive recipients of medical care, merely ‘buying’ and consuming the services and products that experts (eg, researchers, healthcare professionals, ‘medical producers’) have created. However, healthcare providers are increasingly regarding patients as experts in their own conditions, involving them and their family caregivers as active participants in care. Although most policies promote a more active patient role in care, research has found that in reality, patients’ role remains limited. Patients repeatedly report having too little influence over their care while their needs remain unmet in the current healthcare systems.

Many patients want to play a greater role in decisions about their care, to perform more effective self-care, and to engage in improving healthcare systems. For example, patient innovators take part in the development and spread of patient-driven innovations. The Patient Innovation website (www.patient-innovation.com), which was created to collect innovations by patients and/or family caregivers, lists over 1200 innovations. This gives an indication of significant activity by patients and their family caregivers driving health innovations, often independently of the health system. Patient innovators have been defined as ‘patients or their nonprofessional caregivers (eg, parents and family members), who modify or develop a treatment, a
technical aid product, or a medical device to cope with a health condition. Although the awareness of patients’ innovation capacity is increasing, there is still limited knowledge regarding the extent and nature of patient-driven innovations in the peer-reviewed literature. In the discussion section of this paper, we consider possible explanations for this. The objective of the review was to answer the following research question: What is the nature and extent of patient-driven innovations published in peer-reviewed scientific journals?

**METHOD**

**Design**

A scoping review method was chosen as the most appropriate for the objective of the study because our initial investigations revealed a diverse range of types of studies and publications, and the method is recommended as useful when examining emerging areas of research. It was performed according to the five-stage framework proposed by Arksey and O’Malley and is reported according to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses Extension for Scoping Reviews (PRISMA) Checklist (online supplemental appendix 1). Critical appraisals of articles were not performed since the aim was to explore the extent and nature of patient-driven innovations, not assess the quality of these. The review does not follow a preregistered protocol.

**Definition of key concepts**

To find a shared understanding of the concept ‘patient-driven innovation’, the research team performed a concept analysis inspired by Walker and Avant. The concept analysis was performed in a collaborative workshop with patient innovators and researchers where we used key articles to identify model cases of patient-driven innovation, and borderline cases, related cases and contrary cases. Using the concept analysis method, the team agreed to define ‘innovation’ based on the WHO definition of health innovation as ‘an innovation that identifies new or improved health policies, systems, products and technologies, or services and delivery methods that improve people’s health and well-being. The innovation aims to add value in the form of improved efficiency, effectiveness, quality, sustainability, safety and/or affordability. The innovation can be preventive, promotive, curative, rehabilitative, assistive and/or palliative care.’ The other part of the concept was ‘patient driven’ that we agreed consisted of two parts and was defined by: (1) The innovation is user driven, meaning that it is both initiated and driven (in development, implementation, etc) by patients and/or family caregivers and (2) The innovation responds to one or more unmet needs of the innovator. Unmet needs are defined by the innovator. This provided a definition broad enough to allow for a comprehensive review of the nature of patient-driven innovations but limited ‘patient driven’ to focus on the role of patients and/or family caregivers (see table 1).

**Eligibility criteria**

Eligibility criteria are presented in table 1. We included studies published in peer-reviewed journals (publication years 2008–2020) that covered health innovations initiated and driven by patients and/or family caregivers (hereafter referred to as patient-driven innovations, as defined in table 1, point 4.1–4.3.). Review articles were used to identify original articles, and review articles that

| Inclusion criteria | Exclusion criteria |
|--------------------|-------------------|
| 1. English language | Other language than English |
| 2. Published between January 2008 and December 2020 | Published earlier than 2008 or later than 2020 |
| 3. Published in a peer-reviewed journal | Not published in peer-review journal |
| 4. Reporting on patient-driven innovation(s) as defined by three criteria: | Article is out of scope (context other than healthcare) |
| 4.1. Based on WHO’s definition of health innovations the innovation identifies new or improved health policies, systems, products and technologies, or services and delivery methods that improve people’s health and well-being. The innovation aims to add value in the form of improved efficiency, effectiveness, quality, sustainability, safety and/or affordability. The innovation can be preventive, promotive, curative, rehabilitative, assistive and/or palliative care. | No innovation described |
| 4.2. The innovation is user driven, meaning that it is both initiated and driven (in development, implementation, etc) by patients and/or family caregivers. | Described innovation is not patient-driven |
| 4.3. The innovation responds to one or more unmet needs of the innovator. Unmet needs are defined by the innovator. | The innovation is used for data collection but not described in the article |
| 5. The innovation is the focus of the article | |

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presented original data not presented elsewhere were included. We limited the review to reports and publications made from the year 2008 and onwards because our initial searches found few reports or publications about patient innovations before 2008. Articles where the innovation (primarily the online platform PatientsLikeMe) was used solely for data collection were excluded.

Information sources
Four electronic databases were searched in October 2019 and the search was updated in December 2020: Medline (Ovid), Web of Science Core Collection, PsycINFO (Ovid) and Cinahl (Ebsco). We also employed snowball sampling: (1) The webpage www.patient-innovation.com was screened for names of innovators and innovations and those names were used to search records in PubMed (January 2020); (2) Reference lists of included articles were screened (August 2020) and (3) Names of identified patient innovators were used for author search in Web of Knowledge (August 2020).

Search
Key articles on patient-driven innovations were used by MR to form a search strategy in consultation with librarians at the Karolinska Institutet University Library. The search strategy was tested and refined three times to ensure that all key articles were identified. A complete search strategy for Web of Science is presented in table 2 and for all databases (Medline (Ovid), Web of Science Core Collection, PsycINFO (Ovid) and Cinahl (Ebsco) in online supplemental appendix 2.

Selection of sources of evidence
Records were screened by six authors (MR, AB, HJ, SR, HH and CW) and two research assistants (see the Acknowledgements section) in the open-source software Rayyan,16 according to eligibility criteria. To screen the large number of records identified at this stage, we first collected and applied the selection criteria to titles and abstracts of the papers discovered in the search. When

Table 2  Search strategy used in MEDLINE

| # | Searches                                                                 | Results |
|---|--------------------------------------------------------------------------|---------|
| 1 | (adult child* or patient* or caregiver* or caregiver* or carer* or family or husband* or “next of kin” or partner* or spouse* or user or wife or wives) adj1 (directed or driven or driving or initiated).ti,ab,kf. | 4150    |
| 2 | (co creat* or co design* or collaborative creation* or collaborativ* created or “do it yourself” or “doing it for themselves” or diy or e patient* or lead patient* or participatory design* or public driven or superuser*).ti,ab,kf. | 3444    |
| 3 | Patient participation/                                                   | 24568   |
| 4 | or/1–3                                                                  | 31910   |
| 5 | Equipment design/                                                       | 144620  |
| 6 | Inventions/                                                             | 1720    |
| 7 | Organisational innovation/                                              | 23978   |
| 8 | Diffusion of Innovation/                                                | 17239   |
| 9 | (innovat* or invention* or invented).ti,ab,kf.                          | 128952  |
| 10| Self-Management/                                                        | 1492    |
| 11| exp Self-Help Devices/                                                  | 11126   |
| 12| exp Self care/                                                          | 52825   |
| 13| (assistive technolog* or co care or self care or self help device* or self management* or self monitor* or self track*).ti,ab,kf. | 42096   |
| 14| or/5–13                                                                | 388764  |
| 15| 4 and 14                                                               | 3235    |
| 16| (co innovat* or patient* innovat* or patient design*).ti,ab,kf.        | 219     |
| 17| 15 or 16                                                               | 3443    |
abstracts were not available, we retrieved the full paper to decide if the selection criteria were met or not met to carry forward to the next stage of the review.

Screening was blinded and a minimum of two researchers conducted the screening for each article. Inclusion/exclusion decisions were compared. In 7% of the cases, researchers disagreed about inclusion/exclusion, and these conflicts were resolved by consensus through discussion among authors based on a full-text screening.

Data charting process and data items
A template for data charting in Microsoft Excel 2013 was developed iteratively by all authors, who worked in pairs to extract data. Extractions were compared within the pairs by those who extracted the data and merged by MR.

The final extraction form included items on the characteristics of the studies (journal, publication year, first author country of affiliation, publication type, study aim, study design, data and sample size), and on the innovations (name of innovation, name of innovator(s), description of innovation, unmet needs that the innovations aimed to fulfill, and medical condition). Extracted data is published in online supplemental appendix 3.1–3.3.

Analysis of review findings
MR performed an initial overview of the extracted data and proposed preliminary categories for each data item. PM, CW, CS, HH, AB and HJ worked in pairs with sorting the data according to suggested categories and refined the categories and suggested additional categories when needed. Detailed description of the categorisation of data is presented in online supplemental appendix 4.

Patient and public involvement
This study was performed within the auspices of the cocreated research programme ‘Patients in the driver’s seat! A multimethod partnership programme on patient-driven innovations’, where patient innovators are engaged as equal partners in research. The research programme members were engaged in the research meetings and contributed to the research questions, definition of patient-driven innovations and selection of sources of evidence (see the Acknowledgements section). Furthermore, SR, a patient researcher living with Parkinson’s disease, coauthored the current paper and was involved in all stages of the process.

FINDINGS
The systematic search generated 7220 records after duplicates were removed; the snowball sampling generated 559 additional records. In total, 7629 records were screened by title and abstract and 414 records were screened in full text for eligibility. Of these, 96 articles on 20 patient-driven innovations were included. The study selection process is reported in a PRISMA flow diagram (figure 1).

The nature of patient-driven innovations
The 20 identified innovations addressed the unmet needs of patients and family caregivers with diabetes (7 innovations, 46 publications); cancer (1 innovation, 1 publication); rare diseases (3 innovations, 5 publications); gastrointestinal diseases (2 innovations, 4 publications); disabilities (2 innovations, 3 publications); Parkinson’s disease (2 innovations, 3 publications) and mental illness (1 innovation, 2 publications). There were also innovations targeting unmet needs of multiple conditions (2 innovations, 32 publications). Data by innovation are presented in table 3.

Many of the innovations involved digital technologies, with four mobile apps, four collaborative networks, five technical innovations for diabetes care and one sensor that measures output volume from one’s ostomy. Other innovations included one jacket with pockets for postoperative drain tubes, one pen-and-paper form for personalised medical records, a painted staircase (optical illusion) to prevent gait freezing, and ingestion of pig-worms to improve symptoms from Crohn’s disease. Among the 20 innovations reported, the Do-It-Yourself Artificial Pancreas System (DIYAPS) and PatientsLikeMe.com, an online health-related social network, accounted for half of the articles.

Extent of publications
Author affiliations were exclusively in high income countries with 56% of first authors with affiliations in North America, followed by 36% from European countries (see table 4). One first author had their affiliation in Asia and six in Oceania. The number of publications increased in later years, with 69% of articles published 2016–2020.
| Medical condition                      | Innovation                                      | N articles | Innovator(s) mentioned in the article(s) | Type of innovation                          | Innovator(s) listed as author |
|----------------------------------------|-------------------------------------------------|------------|-------------------------------------------|---------------------------------------------|------------------------------|
| Cancer (breast cancer)                 | Jacki Jacket                                    | 1          | Cathy McGrath                             | Patient clothing                           | No                           |
| Diabetes                               | Autosens                                        | 1          | Dana Lewis, Scott Leibrand                | Technical innovation for diabetes care     | Yes                          |
|                                        | Autotune                                        | 1          | Dana Lewis, Scott Leibrand                | Technical innovation for diabetes care     | Yes                          |
|                                        | DIYAPS, Do-It-Yourself Artificial Pancreas System | 21         | #wearenotwaiting-community, Dana Lewis, Adrien Tappe, Bastian Hauck, Tebbe Ubbe, Saskia Wolf, Timothy Omer | Technical innovation for diabetes care     | Yes                          |
|                                        | MySugr                                          | 2          | Fredrick DeBong                           | Mobile app                                 | Yes                          |
|                                        | Nightscout (CGM in the cloud)                   | 3          | #Nightscout movement, specific innovators not reported | Technical innovation for diabetes care     | Yes                          |
|                                        | Omnipod                                         | 2          | John Brooks III                           | Technical innovation for diabetes care     | Yes                          |
|                                        | T1resources.uk                                  | 1          | Mike Kendall                              | Online network                             | Yes                          |
|                                        | Webdia                                          | 1          | Jean-Luc Mando                            | Mobile app                                 | Yes                          |
| Disabilities                           | Upsee                                           | 2          | Debby Elnatan                             | Wearable devise                            | No                           |
|                                        | (No name) Auditory stimulation                  | 1          | Debby Elnatan                             | Auditory stimulation                       | Yes, last author             |
| Gastrointestinal diseases              | Ostom-i-Alert                                   | 3          | Michael Seres                             | Technical                                  | Single author or not author |
|                                        | (No name) Helminth therapy                      | 1          | Sean Ahrens                               | Alternative treatment                      | Single author                |
| Mental illness                         | No name (self-tracking number of hallucinations)| 2          | Spencer Roux                              | Technical innovation for self-tracking     | Yes                          |
| Multiple                               | PatientsLikeMe                                  | 29         | Jamie Heywood, Benjamin Heywood, Jeff Cole | Online network                             | Yes in some                  |
|                                        | Medistory                                       | 1          | Olive O’Connor                            | pen and paper medical journal              | Yes                          |
| Parkinson’s disease                    | No name (A painted staircase)                   | 2          | Mileha Soneji                             | Paint on floor, optical illusion           | Yes                          |
|                                        | No name (a smartphone app for collecting data on drug intake and well-being) | 1          | Sara Riggare                              | Mobile app                                 | Yes                          |
| Rare diseases (22q11 deletion syndrome)| (No name) patient driven collaborative initiative | 1          | Anne Lawlor                               | Collaborative network                      | Yes                          |
| Rare diseases (cystic fibrosis (CF))   | Upstream dream, Genia                           | 2          | Andreas Hager                             | Mobile app                                 | Yes                          |
|                                        | Sweden CF Coalition                             | 2          | Andreas Hager                             | Collaborative network                      | Yes                          |

DIYAPS, Do-It-Yourself Artificial Pancreas System.
A majority (65%) of the studies were published in journals with a scope of general or specialised medicine, with some in journals focused on research or healthcare processes (12%), or journals focused on digital health (10%). One article was published in a journal focused on patients’ health. About half of the studies were classified as peer-reviewed research with 38% original articles, 2% short reports, 2% protocols and 6% reviews that published original results. Remaining articles were published in a peer-reviewed journal but in formats that commonly are not peer-reviewed: 24% Letters to the editor/commentaries, 18% published conference abstracts, 6% editorials and 3% in special sections dedicated to patients. Patient innovators mentioned in articles were listed as authors in most, but not all, publications. The articles seldom described the patient innovator’s role in the research process.

### Aims and design of included articles

Almost half of the studies (47%) used a descriptive design, while smaller proportions used an observational design (15%) or experimental design (9%) and 29% of the articles were categorised as not having a study design, for

| Study design          | N studies (%) |
|-----------------------|--------------|
| Descriptive           | 42 (44)      |
| Observational         | 11 (11)      |
| Experimental          | 8 (8)        |
| Design not presented  | 35 (36)      |

| Sample size           | N studies (%) |
|-----------------------|--------------|
| 1                     | 8 (8)        |
| 2–100                 | 21 (21)      |
| 101–500               | 9 (9)        |
| 501–1000              | 2 (2)        |
| >1000                 | 11 (11)      |
| Sample size not presented | 45 (47) |

### Table 4 General characteristics of studies

| Continent (first author affiliation) | N studies (%) |
|--------------------------------------|--------------|
| Europe                               | 35 (36)      |
| North America                        | 54 (56)      |
| South America                        | 0            |
| Asia                                 | 1 (1)        |
| Oceania                              | 4 (6)        |
| Africa                               | 0            |

| Publication year | N studies (%) |
|------------------|--------------|
| 2008             | 3 (3)        |
| 2009             | 2 (2)        |
| 2010             | 3 (3)        |
| 2011             | 4 (4)        |
| 2012             | 2 (2)        |
| 2013             | 2 (2)        |
| 2014             | 5 (5)        |
| 2015             | 6 (6)        |
| 2016             | 10 (10)      |
| 2017             | 10 (10)      |
| 2018             | 15 (16)      |
| 2019             | 19 (20)      |
| 2020             | 15 (16)      |

| Type of journal               | N studies (%) |
|-------------------------------|--------------|
| General medicine              | 20 (21)      |
| Specialised medicine          | 51 (53)      |
| Process related               | 14 (14)      |
| Digital health                | 10 (10)      |
| Patient oriented health       | 1 (4)        |

| Publication type              | N studies (%) |
|-------------------------------|--------------|
| Original research             | 34 (35)      |
| Short report                  | 2 (2)        |
| Protocol                      | 2 (2)        |
| Review (presenting original results) | 6 (6) |
| Letter to editor/commentary  | 25 (26)      |
| Conference abstract           | 17 (18)      |
| Editorial                     | 7 (7)        |
| Special section dedicated to patients | 3 (3) |

| Study aim                     | N studies (%) |
|-------------------------------|--------------|
| Describe the innovation and/or development of innovation | 23 (24) |
| Describe users and/or how users perceive the innovation | 21 (22) |
| Test effect/impact of innovations | 23 (24) |
| Describe/discuss ethical issues and/or policy change | 8 (8) |
| Test feasibility of innovation | 2 (2) |
| Aim not presented/not relevant | 19 (18) |

(figure 2). A majority (65%) of the studies were published in journals with a scope of general or specialised medicine, with some in journals focused on research or healthcare processes (12%), or journals focused on digital health (10%). One article was published in a journal focused on patients’ health. About half of the studies were classified as peer-reviewed research with 38% original articles, 2% short reports, 2% protocols and 6% reviews that published original results. Remaining articles were published in a peer-reviewed journal but in formats that commonly are not peer-reviewed: 24% Letters to the editor/commentaries, 18% published conference abstracts, 6% editorials and 3% in special sections dedicated to patients. Patient innovators mentioned in articles were listed as authors in most, but not all, publications. The articles seldom described the patient innovator’s role in the research process.

| Study design | N studies (%) |
|--------------|--------------|
| Descriptive | 42 (44)      |
| Observational | 11 (11)    |
| Experimental | 8 (8)        |
| Design not presented | 35 (36) |

| Sample size | N studies (%) |
|-------------|--------------|
| 1           | 8 (8)        |
| 2–100       | 21 (21)      |
| 101–500     | 9 (9)        |
| 501–1000    | 2 (2)        |
| >1000       | 11 (11)      |
| Sample size not presented | 45 (47) |

### Table 4 General characteristics of studies

| Continent (first author affiliation) | N studies (%) |
|--------------------------------------|--------------|
| Europe                               | 35 (36)      |
| North America                        | 54 (56)      |
| South America                        | 0            |
| Asia                                 | 1 (1)        |
| Oceania                              | 4 (6)        |
| Africa                               | 0            |

| Publication year | N studies (%) |
|------------------|--------------|
| 2008             | 3 (3)        |
| 2009             | 2 (2)        |
| 2010             | 3 (3)        |
| 2011             | 4 (4)        |
| 2012             | 2 (2)        |
| 2013             | 2 (2)        |
| 2014             | 5 (5)        |
| 2015             | 6 (6)        |
| 2016             | 10 (10)      |
| 2017             | 10 (10)      |
| 2018             | 15 (16)      |
| 2019             | 19 (20)      |
| 2020             | 15 (16)      |

| Type of journal               | N studies (%) |
|-------------------------------|--------------|
| General medicine              | 20 (21)      |
| Specialised medicine          | 51 (53)      |
| Process related               | 14 (14)      |
| Digital health                | 10 (10)      |
| Patient oriented health       | 1 (4)        |

| Publication type              | N studies (%) |
|-------------------------------|--------------|
| Original research             | 34 (35)      |
| Short report                  | 2 (2)        |
| Protocol                      | 2 (2)        |
| Review (presenting original results) | 6 (6) |
| Letter to editor/commentary  | 25 (26)      |
| Conference abstract           | 17 (18)      |
| Editorial                     | 7 (7)        |
| Special section dedicated to patients | 3 (3) |

| Study aim                     | N studies (%) |
|-------------------------------|--------------|
| Describe the innovation and/or development of innovation | 23 (24) |
| Describe users and/or how users perceive the innovation | 21 (22) |
| Test effect/impact of innovations | 23 (24) |
| Describe/discuss ethical issues and/or policy change | 8 (8) |
| Test feasibility of innovation | 2 (2) |
| Aim not presented/not relevant | 19 (18) |
example, editorials. Sample sizes ranged from one participant (8% of studies) to over 1000 participants (14% of studies). Of the 96 articles included, 77% presented a study aim, and approximately one-third of these had a study aim that focused on describing or testing the innovation: 24% aimed to describe the innovation and/or the development of the innovation, 24% to test the effect and/or impact of the innovation and 2% to test the feasibility of the innovation. Other articles aimed to describe characteristics of users of the innovation and/or describe how users perceived the innovation (22%). A small proportion of the articles described and discussed ethical issues and/or or policy changes relating to patient-driven innovations (8%).

**DISCUSSION**

This article reports a scoping review of publications about patient-driven innovations in peer-reviewed journals. The review identified 96 articles published from year 2008 to 2020, reporting 20 different patient-driven innovations and the number of publications increased in the later years. Among the 20 innovations reported, ‘DIYAPS’ and the online health network ‘PatientsLikeMe’ accounted for half of the articles. Considering that over 1200 patient-driven innovations are listed on www.patient-innovation.com, the number of 20 patient-driven innovations published in peer-reviewed journals is remarkably small.

Canhao et al. point out that the lack of patients scaling up and spreading their innovations to others may be an example of market failure. Based on the potential benefits of patient-driven innovations, actors such as medical product and service producers and government regulators could support patient innovators in the development and diffusion of their innovations. We suggest that the lack of patient-driven innovations reported in peer-reviewed journals may also be seen as an academic failure as scientific peer-reviewed journals are important arenas for disseminating, evaluating, improving and discussing ideas in healthcare. The research community has an important part to play in complementing other ways of support for the creative contributions of the patients by using the systematic methods of research to evaluate, develop, and integrate these solutions into patients’ daily lives and healthcare systems. According to Canhao et al. there are several barriers for patient innovators that prevent them from sharing their innovations, including lack of resources, skills or access to the process of approval and commercialisation. In this review, only a minor portion of the studies had an observational or experimental design, and it is possible that similar barriers that prevent patient innovators from sharing their innovations apply to research and scientific writing.

**Strengths and limitations**

The strengths of the study include the broad scope of the review. We followed the process outlined in Arksey and O’Malley and the review was guided by a predetermined strategy for data collection and analysis. Methodological strengths lie in this systematic approach to searching the four large databases, complemented by snowball sampling. Earlier research has reviewed specific patient-driven innovations, for example, a review of ‘DIYAPS’ by Kesavadev et al. or investigated characteristics of patient innovators. This is the first review undertaken of patient-driven innovations, according to a broad and comprehensive definition, and one of the very few undertaken of innovations in which patients have played a significant role in development of the innovation. This builds on Oliveira et al.’s definition of patient innovations where innovation is limited to ‘a treatment, a technical aid product, or a medical device’. We co-created a broader definition together with patient innovators in order to include social innovations such as collaborative or social networks. Thus, this broader scope and definition of patient-driven innovations was able to capture more innovations in which patients have played a significant role in the development.

The limitations of the study include the choice to only select peer-reviewed articles, but this was motivated by our aim to explore the proliferation of patient-driven innovations within the scientific literature. If the purpose had been to create an inventory of patient-driven innovations, the inclusion of grey literature would have yielded more results. Furthermore, the source of information was restricted to the included articles and in some cases the webpage www.patient-innovation.com. Patient-driven innovations are not always labelled as such in the publications. Therefore, despite the broader definition and the use of snowball sampling and online searches to identify the drivers of innovations, our results are likely an under-representation of research on patient-driven innovations. Also, as patient-driven innovations may initially go through commercialisation processes with a shift of ‘drivers’, it is possible that we would relabel some innovations as not being patient driven if we had access to more information.

**Unanswered questions and future research**

As this field of research is relatively new, there are several unanswered questions for future research. Considering the potential benefits that patient-driven innovations can have if they become widely used, it will be important to understand factors that may facilitate or hinder implementation, spread and scale-up of patient-driven innovations; none of the included articles in this review systematically examined these questions. It may also be important to gain deeper understanding of patient-driven innovations in general, what unmet user need they address, how they are used and by whom and what outcomes they have for patients and healthcare systems. A further unanswered question is what determines whether patient innovators decide to publish their results and if so, in which journal(s). Patient innovators were often listed as coauthors in publications related to their innovations, there was a broad variation in type of publication, and it was common...
CONCLUSIONS

Peer-reviewed publications on patient-driven innovations are increasing and peer-reviewed journals constitute an arena where patient-driven innovations can be evaluated, discussed and developed further. We see an important opportunity for researchers and clinicians to support patient innovators’ research and publication while being mindful about not taking over the work of the innovators themselves.

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Contributors MR, AB, JØ, SR, CS, CW and HH conceived and planned the review and defined central concepts; MR designed the search strategy in collaboration with Magdalena Svanberg & Emma-Lotta Säätelä at the Karolinska Institute University Library; MR, AB, HJ, SH, CW and HH identified relevant studies; MR, AB, HJ, SR, HH, CW, CS, JB charted the data; MR, AB, HJ, SR, HH, CW, CS, JB collated and summarized results; MR, PM and HH drafted the first version of the paper. CW generated figure 1. HH was responsible for the overall content as the guarantor. All authors revised or critically reviewed the paper and read and approved the final draft.

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Data availability statement All data relevant to the study are included in the article or uploaded as online supplemental information. Online Supplemental files with the complete search strategy, extracted data by article and an explanation of how extracted data was categorised is available in online supplemental appendices 1–4.

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