Received: 5 September 2022 | Accepted: 7 December 2022

DOI: 10.1111/jocn.16603

Journal of Clinical Nursing WILEY

REVIEW

Patients' right to know: A scoping review

Saija Inkeroinen MHSc, BHSc, PHN, RN, Doctoral researcher[1] | **Heli Virtanen PhD, RN, Docent, University Teacher[1]** | **Minna Stolt PhD, BSc (Pod), FEANS, FFPM RCPS(Glasg.), Docent, Professor[1,2]** | **Helena Leino-Kilpi PhD, MEd, RN, FAAN, FEANS, FRCN, MAE, Professor, Nurse director[1,3]**

[1]Department of Nursing Science, University of Turku, Turku, Finland

[2]Department of Nursing Science, University of Eastern Finland, Kuopio, Finland

[3]Turku University Hospital, Turku, Finland

Correspondence
Saija Inkeroinen, Department of Nursing Science, University of Turku, Turku, Finland.
Email: saanin@utu.fi

Funding information
Turun Yliopistollinen Keskussairaala

Abstract

Aims and Objectives: To analyse research-based evidence about patients' right to know from their own perspective to promote ethically high-quality nursing and to identify future research areas.

Background: Patients' right to know is a fundamental right. Although of topical research interest, the current state of scientific evidence on patients' right to know has not been reviewed.

Design: A scoping review according to the methodological framework by Arksey & O'Malley and the Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews.

Methods: In June 2022, a literature search was conducted in the Ovid Medline, CINAHL and Cochrane Library databases. The inclusion criteria were peer-reviewed, empirical studies on the right to know with samples comprising adult patients. Data were analysed with inductive content analysis, and methodological quality was assessed with Mixed Methods Appraisal Tool.

Results: Out of 2658 identified reports, 12 were selected for analysis. Based on the results, the research on patients' right to know can be classified into two main content categories: (1) expectations of the right and (2) realisation of the right. In the quality assessment, most of the reports did not meet all the quality criteria, the most common deficits being related to instrumentation and risk of bias.

Conclusions: Research-based evidence on patients' right to know provided a general insight into expectations and realisation of the right to know and not to know. The results indicate a need for continued efforts for novel approaches with high-quality methodological choices in future studies.

Relevance to Clinical Practice: Nurses make constantly ethical decisions: The findings of this study can be useful for their decision-making and understanding of the patient's perspective on knowledge issues, and therefore, support ethically high-quality patient education.

Patient or Public Contribution: No direct patient or public contribution to the review.

KEYWORDS
patient rights, right to information, right to know, scoping review

1 | INTRODUCTION

The right to know is a human right. The right is stated in numerous international declarations, charters, laws and human rights documents: It serves as a source of protection for people in potentially vulnerable roles, such as workers (Charter of Fundamental Rights of the European Union, 2012), civilians in war, wounded or sick soldiers (International Committee of the Red Cross, 1949), arrested people (European Convention for the Protection of Human Rights and Fundamental Freedoms, 1950; UN General Assembly, 1976) and patients. For patients, the right to know about their own health and care is derived from a central bioethical principle, that is respecting patient autonomy (Beauchamp & Childress, 2013), and therefore, an increasing body of scientific evidence has accumulated on the right to know.

For patients, that is people using health care services or requiring care, the topicality of the right to know is emphasised for several reasons. First, patients' position and circumstances can make them vulnerable due to health deficits and functional abilities potentially affecting their lives (Beauchamp & Childress, 2013; Cohen & Ezer, 2013). Second, the relationship between patients and health care professionals can involve a power imbalance (e.g. informational imbalance) because of patients' dependency on the health care providers (Beauchamp & Childress, 2013; Cohen & Ezer, 2013; Putturaj et al., 2020). Third, the health care context is prone to structural inequities (e.g. lack of resources) and social inequalities (e.g. stigma associated with a health problem) (Beauchamp & Childress, 2013; Cohen & Ezer, 2013; Putturaj et al., 2020). Finally, international health strategies emphasise citizen empowerment as well as patient autonomy in health care (Active Citizenship Network [ACN], 2002; Regulation (EU) 2021/522, 2021; Putturaj et al., 2020). The right to know protects and promotes the good of the patient in all of these issues, creating a need for producing scientific evidence on the right.

Patients' right to know, and the closely related right *not* to know, is defined in various ways. The rights themselves can be defined as justified claims (Beauchamp & Childress, 2013), yet their qualities are complex, involving, for example, the object of the right (what the right relates to, Sim, 2020, e.g. patients have the right to know at minimum the state of their health and condition, ACN, 2002; World Health Organization [WHO], 1994; World Medical Association [WMA], 2015, and the treatment or care, WHO, 1994), duties (Sim, 2020, derived from the right, e.g. health care professionals' duty to realise patient education, ACN, 2002; International Council of Nurses, 2021; WMA, 2015) and power (e.g. to waive a right, Sim, 2020). Patients' right *not* to know cannot be implied simply on the basis of the right to know (McDougall, 2004): however, the right *not* to know is included in many human and patient right documents and laws in relation to the right to know (Council of Europe, 1997; UN Educational, Scientific and Cultural Organisation, 1997; WHO, 1994; WMA, 2015). Thus, the right *not* to know was included in this review. This complexity in defining the right can lead to different approaches for studying the right to know, which can affect the methods, results or methodological quality of the studies. Therefore, there is a need for reviewing the research-based evidence, the research methods used and methodological quality of research.

What does this paper contribute to the wider global community?

- Research-based evidence provides a general insight into the patients' right to know and not to know.
- Research on the right to know can be classified into expectations and realisation of the right.
- In clinical practice, the findings have the potential for contributing to high-quality patient education, and in future research, there is a demand for novel approaches with high-quality methodological choices for research on patients' right to know.

A considerable number of scientific reports have been published about patients' right to know and *not* to know (Hofmann, 2016), yet less attention has been paid to reviewing the current state of research-based evidence. A scoping review is useful for identifying the knowledge gaps in the accumulated evidence and for guiding the directions of future studies. Moreover, a review can contribute to the international health strategies by promoting patients' awareness of the rights and therefore, support citizen empowerment, and even provide background for political decision-making as patient right laws are developed in several countries (PRE-MAX Consortium, 2016). There is a previous review focusing on the perspective of the legal and ethical regulations of patients' right to know (Vall Casas & Rodríguez Parada, 2008), but the patients' voice is lacking. Other reviews that have included patients in their samples have not investigated the right to know specifically, but their main analysis has focused on, for example, disclosure of health information (Bou Khalil, 2013) and all the patients' rights in a certain geographical area (Abedi et al., 2017). Therefore, previous reviews provide limited perspectives on the right to know.

In conclusion, the right to know is affirmed in health care (Beauchamp & Childress, 2013), and it has merited research interest (Hofmann, 2016). However, several unanswered knowledge gaps remain. The growing body of evidence (Hofmann, 2016) has not been scoped and previous reviews analysing the right have limitations in terms of the lacking voice of patients, that is samples comprising patients, and the lacking focus on the right to know. Furthermore, the various ways of defining the right can lead to different approaches for operationalising the right in research, justifying the assessment of the methodological quality and reviewing the employed methods.

2 | AIMS

The aim of this study was to analyse research-based evidence about patients' right to know from their own perspective to promote ethically high-quality nursing and to identify future research areas. The following questions are addressed: What are the results and the methodological quality of studies of patients' right to know? What methods have been employed to study the patients' right to know?

3 | METHODS

This scoping review was conducted according to the methodological framework by Arksey & O'Malley (2005). The Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews (File S1) was followed (Tricco et al., 2018). First, a scoping review protocol was developed. Second, relevant reports were identified from the Ovid Medline, CINAHL and Cochrane Library (Cochrane Central Register of Controlled Trials) databases. The search terms were "patient," "right" and "knowledge": for report identification purposes, a positional operator was used for the final search terms "right*" and "know*", and "right*" and "info*" by allowing a maximum of two words between them. In addition, a manual search was conducted on the reference lists of the included reports. The language was limited to English and the publication year from 1994 (when the WHO issued the Declaration on the Promotion of Patients' Rights in Europe, WHO, 1994) to 14 June 2022 (when the search was conducted). Data were transferred to reference management software RefWorks and Zotero for further selection. Reports were assessed against the inclusion and exclusion criteria (Table 1), first on title level, then on abstract level, and finally, on full-text level by two researchers (SI, HV).

Next, the reports, their characteristics and main results were collated and summarised into a table and reviewed by the research team (Table 2). Data were analysed by using NVivo 12 Plus software with inductive content analysis. The unit of analysis was the results of the included studies and the analysis focused on manifest content. The condensed meaning units were abstracted into six sub-content categories and two main content categories (Graneheim & Lundman, 2004). The methodological quality of the studies was assessed with the Mixed Methods Appraisal Tool (MMAT) version 2018 (Hong et al., 2018). Each report was evaluated by at least two researchers, and differences in evaluations were resolved within the research team. The research methods of the reports were collected and described in tables.

4 | RESULTS

The database searches generated 2658 reports, resulting in 11 included reports. Based on the manual citation search, one (1) report was added, yielding 12 reports for the final analysis (Figure 1).

4.1 | Patients' right to know

Based on the analysis, research on patients' right to know was classified into two main content categories (Table 3): (1) expectations of patients' right to know and (2) realisation of patients' right to know.

4.1.1 | Expectations of patients' right to know

Patients' expectations of the right to know consist of three sub-content categories (Table 3): (1) expectations of the right to the content of knowledge, (2) reasoning behind the expectations of the right to know and (3) expectations of the power of the right to know. The expectations included patients' perceptions, preferences, desires, attitudes and views.

Patients' expectations of their right to know were studied regarding the content of knowledge. Patients' expectations of their right to know diagnosis (Erer et al., 2008; Hari et al., 2007), prognosis (Hari et al., 2007) and treatment/care (Erer et al., 2008) were studied

TABLE 1 Inclusion and exclusion criteria (Peters et al., 2020).

	Inclusion criteria	Exclusion criteria
Types of participants	Patients	Children
Concept	Patients' right to know Knowledge or information concerning patient's health, health problem or disease and/or its treatment/care	The focus of the report is on all patients' rights Public health promotion Patients' family members' right to know
Context	Health care	Research Education
Types of sources of evidence	Peer-reviewed, empirical studies	Reviews, theoretical or discussion reports The report's focus is solely on legal aspects Local or organisational recommendations or procedures

TABLE 2 Description of the included reports ($n = 12$, arranged based on main content category and alphabetical order).

Report, year, country	Aim	Research design: Quantitative	Research design: Qualitative	Context: Diagnostics	Context: Hospital care	Results	Quality assessment scores (MMAT, scale 1–7)[a]
Content category: Expectations of patients' right to know							
Bugge et al. (1998) Denmark	To investigate the attitudes of Danish patients regarding information about anaesthesia	x Cross-sectional			x	Danish patients had lower expectations compared to Australian, Canadian and Scottish patients	6
Crawford-Sykes and Hambleton (2001) Jamaica	To assess the peri-operative information needs in Jamaican patients and to compare them to those from other populations	x Cross-sectional			x	Patients did not consider peri-operative information as their right	5
Erer et al. (2008) Turkey	To evaluate the views of cancer patients on patients' rights in the context of the right to information and autonomy	x Cross-sectional			x	Patients perceived having the right to know their diagnosis, disease, treatment and treatment choices. Most of the patients perceived realisation of patients' right to know to be physicians' duty	4
Flatau et al. (2018) Germany	To investigate variations in informational preferences (and the right not to know) in the context of genetic testing	x Explorative, cross-sectional		x		The majority of the participants wanted to know genetic information and incidental findings in genetic testing. Expectations depended on a hypothetical scenario. A minority would want to claim their right not to know	7
Formica et al. (2010) USA	To assess the conflict between kidney transplant recipient's privacy and donor's right to information		x Case study		x	In living kidney transplantation to HIV-positive individuals, the recipient's right to informational privacy outweighs the donor's right to know	6
Hari et al. (2007) Nepal	To ascertain patients' attitudes towards the concept of the right to know about terminal cancer	x Descriptive, cross-sectional			x	Most of the patients wanted to know their diagnosis. A minority wanted to know about prognosis. Patients had various reasons for having the right to know and not to know	4
Lenk et al. (2019) Germany	To assess how patients, physicians and lay persons evaluate genetic knowledge and what rights and duties are assigned in this context to different groups	x Cross-sectional		x		Most of the participants stated that patients have a right to know the disease, genetic information and incidental findings in testing. Expectations depended on a hypothetical scenario	4

TABLE 2 (Continued)

Report, year, country	Aim	Research design		Context		Results	Quality assessment scores (MMAT, scale 1–7)[a]
		Quantitative	Qualitative	Diagnostics	Hospital care		
Schuurman et al. (2015) Netherlands	To explore the dilemma between patients' right not to know their genetic status and the efficient use of healthcare resources in the form of clinical cancer screening programs		x	x		Patients expected to have a right not to know. They had various reasons for having the right	7
Content category: Realisation of patients' right to know							
Gutman and Gutman (2002) Australia	To discover whether patients undergoing coronary angiography want the cardiologist/ angiographer to inform them of the risks associated with the procedure	x Cross-sectional		x		Most of the patients exercised their right not to know about the risks of the treatment	5
Nyrhinen et al. (2009) Finland	To assess how the patients' right to receive information and the right to self-determination were realised during diagnostic testing	x Cross-sectional		x		Right to know about genetic testing was fairly sufficiently realised	6
Pérez-Cárceles et al. (2007) Spain	To determine the frequency with which 'capable' patients over 65 years of age receive information when admitted to hospital	x Cross-sectional			x	The majority of the patients were less worried and perceived the quality of care to be better after their right to know was realised. The majority of the patients perceived having understood the information	5
Pérez-Cárceles et al. (2010) Spain	To evaluate the extent to which the right to information is fulfilled in the emergency department	x Cross-sectional			x	Right to know the reason for treatment and follow-up care were realised for almost all patients, possible sequelae and side effects for more than a half, and possible complications for a minority of the patients. Realisation increased satisfaction with care. Patients claimed to understand the information	6

[a] Mixed Methods Appraisal Tool version 2018. Higher score indicates higher methodological quality.

among patients in outpatient departments, the right to know perioperative knowledge among elective preoperative patients (Bugge et al., 1998; Crawford-Sykes & Hambleton, 2001), while the studies concerning the right to know genetic knowledge included a variety of patients (Flatau et al., 2018; Lenk et al., 2019). These studies reported distributions of patients' expectations of the right. Based on these distributions, patients expected to have the right to most of the studied knowledge content. However, expectations seemed to vary depending on the country (Bugge et al., 1998; Crawford-Sykes & Hambleton, 2001) and the hypothetical scenarios presented to the patients, such as the health problem in question and its curability (Flatau et al., 2018; Hari et al., 2007; Lenk et al., 2019), severity and inheritability (Flatau et al., 2018; Lenk et al., 2019).

Expectations included patients' reasoning for having the right. The reasoning was studied for both the right to know and the right *not* to know. The reasoning behind the expectations of the right to know was studied in relation to terminal cancer among patients in outpatient departments (Hari et al., 2007) while the right *not* to know was studied among the same patients (Hari et al., 2007) as well as among patients involved in genetic testing (Flatau et al., 2018; Lenk et al., 2019; Schuurman et al., 2015). The reasons for the right to know were a wish to plan one's life, a wish to know the truth, the right to autonomy, religious rituals and patients learning about the health problem anyway sooner or later (Hari et al., 2007). As for patients' right *not* to know, it was expected to protect patients from harmful outcomes and complex, continuous decision-making process, prevent emotional distress to patients and their family members, and support patients' autonomy, hopes, wishes, financial situation and future plans (Flatau et al., 2018; Hari et al., 2007; Lenk et al., 2019; Schuurman et al., 2015).

Patients' expectations of the power of the right to know were related to duties and to other patient rights. As for the duties, patients expected the health care professionals to have a duty to respect the patients' right to know (Erer et al., 2008; Lenk et al., 2019) and right *not* to know (Flatau et al., 2018; Lenk et al., 2019; Schuurman et al., 2015). However, patients expected to waive their right *not* to know in several hypothetical scenarios related to genetic knowledge (Flatau et al., 2018; Lenk et al., 2019). As for the other patient rights, the right to know was argued to be outweighed by another patient right, that is right to privacy, in the case of living organ transplantation (Formica et al., 2010).

4.1.2 | Realisation of patients' right to know

The realisation of patients' right to know consists of three subcontent categories (Table 3): (1) the realisation of the right to the content of knowledge, (2) the outcomes of the realisation for patients and (3) the factors associated with the realisation.

Realisation of the right to know was studied regarding the content of knowledge. These contents included diagnosis, prognosis, treatment/care, the reason for care, possible side effects/complications/sequelae, care instructions, follow-up care and complementary testing studied among hospital patients (Pérez-Cárceles

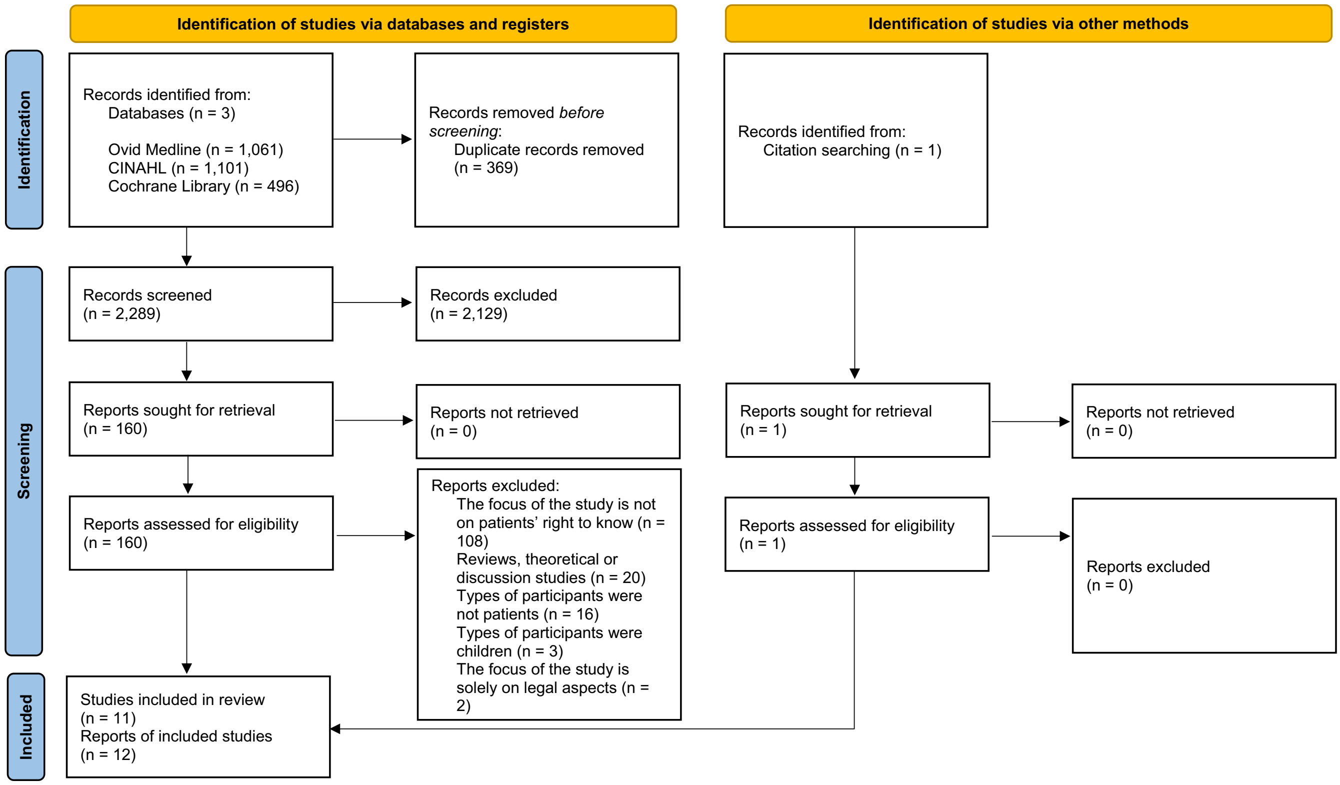

FIGURE 1 Flow diagram (Page et al., 2021).

TABLE 3 Contents and evidence sources of the main and sub-content categories.

Main content category	Sub-content category	Contents	Evidence source
Expectations of patients' right to know	Expectations of the right to content of knowledge	Diagnosis	Erer et al. (2008), Hari et al. (2007)
		Prognosis	Hari et al. (2007)
		Treatment/care	Erer et al. (2008)
		Perioperative knowledge	Bugge et al. (1998), Crawford-Sykes and Hambleton (2001)
		Genetic knowledge	Flatau et al. (2018), Lenk et al. (2019)
	Reasoning behind the expectations of the right to know	Reasons for the right to know	Hari et al. (2007)
		Reasons for the right *not* to know	Flatau et al. (2018), Hari et al. (2007), Lenk et al. (2019), Schuurman et al. (2015)
	Expectations of the power of the right to know	In relation to the health care professionals' duties	Erer et al. (2008), Flatau et al. (2018), Lenk et al. (2019), Schuurman et al. (2015)
		In relation to the other patients' right to privacy	Formica et al. (2010)
Realisation of patients' right to know	Realisation of the content of knowledge	Diagnosis	Pérez-Cárceles et al. (2007, 2010)
		Prognosis	Pérez-Cárceles et al. (2007, 2010)
		Treatment/care	Pérez-Cárceles et al. (2007, 2010)
		Reason for care	Pérez-Cárceles et al. (2010)
		Risks of an intervention	Gutman & Gutman (2002)
		Possible side effects/complications/sequelae	Pérez-Cárceles et al. (2010)
		Complementary testing	Pérez-Cárceles et al. (2007, 2010)
		Genetic testing	Nyrhinen et al. (2009)
		Care instructions	Pérez-Cárceles et al. (2010)
		The follow-up care	Pérez-Cárceles et al. (2010)
	The outcomes of the realisation for patients	Experiential-related outcomes	Pérez-Cárceles et al. (2007, 2010)
		Cognitive-related outcomes	Pérez-Cárceles et al. (2007, 2010)
	The factors associated with the realisation	Gender	Pérez-Cárceles et al. (2010)
		Educational level	Nyrhinen et al. (2009), Pérez-Cárceles et al. (2010)
		Age	Pérez-Cárceles et al. (2007, 2010)
		Seriousness of emergency	Pérez-Cárceles et al. (2010)
		Information providers' specialisation	Nyrhinen et al. (2009)

et al., 2007, 2010), risks of treatment studied among patients undergoing coronary angiography (Gutman & Gutman, 2002), and genetic testing studied among patients and parents of children undergoing genetic testing (Nyrhinen et al., 2009). In the studies, patients evaluated the realisation of the right to these knowledge contents. There was variation in realisation regarding the content of knowledge and patients' evaluations, but in general, the right to most of the content seemed to be realised.

For patients, the realisation of the right to know was related to experiential and cognitive outcomes, as indicated in cross-sectional study designs (without interventions) in Spain. Experiential-related outcomes were a decrease in patients' worry and an increase in satisfaction with care and perceived higher quality of care (Pérez-Cárceles et al., 2007, 2010). Upon more detailed examination, a majority of older patients were less worried when their right to know was realised, albeit some were more worried (Pérez-Cárceles et al., 2007). Patients in emergency care were more satisfied with care if their right to know various aspects of their care was realised (Pérez-Cárceles et al., 2010). Among older patients, those whose right was realised perceived the quality of care as better (Pérez-Cárceles et al., 2007). As for cognitive-related outcomes, they concerned understanding the information: the majority of the patients felt that they had understood the information (Pérez-Cárceles et al., 2007) and that their right to understand the diagnosis was realised (Pérez-Cárceles et al., 2007, 2010). However, some of these patients did not identify the diagnosis that was in their medical records (Pérez-Cárceles et al., 2007, 2010) and were not able to read or understand physicians' written instructions (Pérez-Cárceles et al., 2010).

The factors associated statistically with the realisation of the right to know were patients' gender, educational level, age, the

TABLE 4 Samples and sampling of the included reports ($n = 12$, arranged based on main content category and alphabetical order).

	Sample						Sampling				
Report	Patients with short-term treatment/ care	Patients with a long-term health problem	Unspecified patients	Laypeople	Family members	Health care professionals	Consecutive	Convenience	Purposive	Random selection	Stratified
Content category: Expectations of patients' right to know											
Bugge et al. (1998)	x						x				
Crawford-Sykes and Hambleton (2001)	x						x				
Erer et al. (2008)		x								x	
Flatau et al. (2018)	x	x	x	x	x	x		x			
Formica et al. (2010)	x	x									
Hari et al. (2007)			x							x	
Lenk et al. (2019)	x	x	x	x	x	x		x			
Schuurman et al. (2015)	x					x			x		
Content category: Realisation of patients' right to know											
Gutman and Gutman (2002)	x						x				
Nyrhinen et al. (2009)	x	x			x	x	x				
Pérez-Cárceles et al. (2007)			x		x						x
Pérez-Cárceles et al. (2010)			x		x		x				

seriousness of the emergency and information providers' specialisation. However, no generalisations can be made as these associations were found in single descriptive studies. Realisation had a positive association with the male gender in terms of the right to understandable information in emergency care (Pérez-Cárceles et al., 2010) and with lower educational level in terms of the right to genetic knowledge (Nyrhinen et al., 2009), although no statistically significant association was found between realisation and educational level in emergency care (Pérez-Cárceles et al., 2010). Realisation had a negative association with older age (Pérez-Cárceles et al., 2007, 2010). The more serious the patients' emergency was classified by health care professionals in the emergency department, the better the right to know seemed to be realised (Pérez-Cárceles et al., 2010). When physicians or nurses providing the information were from the genetic department, there was a positive association with the right to genetic knowledge compared to general ward staff (Nyrhinen et al., 2009).

4.2 | Methodological quality of the reports

The methodological quality of the reports varied (Table 2). All quality criteria were met by the report by Flatau et al. (2018), assessed with the quantitative descriptive study design criteria of MMAT, as well as the report by Schuurman et al. (2015), which was assessed with the qualitative study design criteria of MMAT. Most commonly, reports did not meet the criteria related to measurements (Bugge et al., 1998; Crawford-Sykes & Hambleton, 2001; Erer et al., 2008; Gutman & Gutman, 2002; Hari et al., 2007; Pérez-Cárceles et al., 2007) or the risk of nonresponse bias (Erer et al., 2008; Hari et al., 2007; Lenk et al., 2019; Nyrhinen et al., 2009; Pérez-Cárceles et al., 2007): due to limited reporting, they could not be scored. Limitations or unclarities were also identified in reporting research questions or aims (Lenk et al., 2019), sampling strategy (Crawford-Sykes & Hambleton, 2001), representativeness of the sample (Gutman & Gutman, 2002; Hari et al., 2007; Lenk et al., 2019) and data analysis (Erer et al., 2008; Formica et al., 2010; Pérez-Cárceles et al., 2010).

4.3 | Methods employed to study patients' right to know

4.3.1 | Research design and context

Most of the included reports (*n* = 10) reported cross-sectional studies (Table 2), the exception being one case study (Formica et al., 2010) and one focus group study (Schuurman et al., 2015). The contexts of the studies were medical diagnostics (genetic testing, Flatau et al., 2018; Lenk et al., 2019; Nyrhinen et al., 2009; Schuurman et al., 2015, and coronary angiography, Gutman & Gutman, 2002) and hospital care (surgical care, Bugge et al., 1998; Crawford-Sykes & Hambleton, 2001, outpatient clinics, Erer et al., 2008; Hari et al., 2007, emergency care, Pérez-Cárceles et al., 2010, organ transplantation, Formica et al., 2010), and hospital care without specification (Pérez-Cárceles et al., 2007).

4.3.2 | Sample and sampling

Sample sizes ranged from 2–518 and included a variety of patients (Table 4): patients for short-term treatment/care, patients with a

TABLE 5 Data collection and analysis of the included reports (*n* = 12, arranged based on main content category and alphabetical order).

	Data collection					Data analysis	
Report	Questionnaire	Case	Interview	Focus group	Analysis of medical records	Statistical methods	Qualitative analysis
Content category: Expectations of patients' right to know							
Bugge et al. (1998)	x					x	
Crawford-Sykes and Hambleton (2001)	x					x	
Erer et al. (2008)	x					x	
Flatau et al. (2018)	x					x	
Formica et al. (2010)		x					
Hari et al. (2007)	x		x			x	
Lenk et al. (2019)	x					x	
Schuurman et al. (2015)				x			x
Content category: Realisation of patients' right to know							
Gutman and Gutman (2002)	x					x	
Nyrhinen et al. (2009)	x					x	
Pérez-Cárceles et al. (2007)	x					x	
Pérez-Cárceles et al. (2010)	x				x	x	

TABLE 6 Research ethics and limitations of the included reports ($n = 12$, arranged based on main content category and alphabetical order).

	Research ethics						Limitations							
Report	Ethical committee approval	Declaration of Helsinki followed	Research permission	Informed consent	Voluntary participation	Anonymity secured	Psychometric properties of the questionnaire	Interviewer bias	Sampling bias	Small sample size	Confounding	Non-response	Internal validity	External validity
Content category: Expectations of patients' right to know														
Bugge et al. (1998)	x			x										
Crawford-Sykes and Hambleton (2001)							x	x						
Erer et al. (2008)	x		x	x										
Flatau et al. (2018)	x				x	x			x		x		x	
Formica et al. (2010)														
Hari et al. (2007)	x							x	x	x				
Lenk et al. (2019)	x	x				x			x				x	
Schuurman et al. (2015)	x									x				
Content category: Realisation of patients' right to know														
Gutman and Gutman (2002)	x			x				x		x	x			x
Nyrhinen et al. (2009)	x			x						x		x		
Pérez-Cárceles et al. (2007)	x			x										
Pérez-Cárceles et al. (2010)	x			x										

long-term health problem and unspecified patients whose reason for care was not reported. Patients for short-term treatment/care included preoperative surgical patients (Bugge et al., 1998; Crawford-Sykes & Hambleton, 2001), coronary angiography patients (Gutman & Gutman, 2002), a kidney donor (Formica et al., 2010) and individuals seeking for genetic counselling or testing (Flatau et al., 2018; Lenk et al., 2019; Nyrhinen et al., 2009; Schuurman et al., 2015). Patients with a long-term health problem included patients with cancer (Erer et al., 2008) or with a genetic/hereditary health problem (Flatau et al., 2018; Lenk et al., 2019; Nyrhinen et al., 2009), and a kidney transplant recipient (Formica et al., 2010). Unspecified patients whose reason for care was not reported included older hospital patients (Pérez-Cárceles et al., 2007), patients with a nonhereditary health problem (Flatau et al., 2018; Lenk et al., 2019), and patients in emergency (Pérez-Cárceles et al., 2010) and outpatient departments (Hari et al., 2007). Two reports were based on the same study (Flatau et al., 2018; Lenk et al., 2019); the results of these reports were analysed separately in this review. The samples also included health care professionals, patients' family members and laypeople; if their results were reported separately in the included reports, they were excluded from the analysis of this study, and if they were reported together, they were included in the analysis. Nonprobability sampling was the most commonly used sampling method (n = 8).

4.3.3 | Data collection and analysis

The most common data collection method was questionnaire (*n* = 10, Table 5). They seemed to be developed for the study, except for two studies using the same previously developed structured questionnaire (Bugge et al., 1998; Crawford-Sykes & Hambleton, 2001). The questionnaires were reported to measure patients' desire or wish for knowledge, perspectives on the provided information and its sufficiency, and patients' opinions and attitudes towards knowledge and towards the right to know or *not* to know. Most commonly, data were analysed statistically (*n* = 10).

4.3.4 | Research ethics and limitations

Research ethics was described in 10 reports (Table 6). In all these reports, ethical approval was given by ethics committee.

Limitations were discussed in seven reports. Limitations were most commonly related to small sample size (*n* = 4), sampling bias (*n* = 3) and interviewer bias (*n* = 3).

5 | DISCUSSION

The aim of this study was to analyse research-based evidence about patients' right to know (including the right *not* to know) from their own perspective. The right to know about one's own health and care, which is a human right recognised by several laws and human rights documents, has generated a growing body of literature (Hofmann, 2016). The primary findings of this scoping review were the division of research on the right into two main content categories, the expectations and the realisation of the right, and the assessment of the methodological quality and analysing the methods of the studies.

The two main content categories of the results, that is the expectations and the realisation of the right, emphasised the biophysiological content of knowledge, such as knowledge about disease and its treatment (Leino-Kilpi et al., 1998). This finding is consistent with the descriptions of the content in many patient rights documents (ACN, 2002; WHO, 1994; WMA, 2015). The biophysiological knowledge is indeed vital, for example, for informed consent, so that patients can understand diagnoses, prognoses, the nature and purpose of the treatment, and the risks and benefits (Beauchamp & Childress, 2013). Patients seem to expect biophysiological knowledge even beyond the informed consent for treatment, as indicated in the literature of empowering patient education (Anderson & Funnell, 2010; Klemetti et al., 2015). However, studying the right solely from the perspective of biophysiological knowledge may appear limited. Multidimensional knowledge is assumed to be essential for patient empowerment (Klemetti et al., 2015; Leino-Kilpi et al., 1998), highlighting the importance of identifying and meeting patients' multidimensional expectations for knowledge. Taken together, one possible implication is that patients could have a right to multidimensional and individually tailored knowledge that is meaningful for them: this implication could be considered in clinical practice (e.g. in patient education). Therefore, in future research, adding multidimensionality to the content of knowledge (such as functional, social or emotional knowledge, Klemetti et al., 2015; Leino-Kilpi et al., 1998) could advance the field of patients' rights and support patient empowerment.

The factors associated with the realisation of the right were not systematic. The contradictions can be due to heterogeneity of the studies in terms of their contexts, data collection methods, cultures and knowledge content. Therefore, no clear conclusions for clinical practice can be drawn, and more research on the role of patients' sociodemographic factors in their right to know is warranted. Moreover, the perspective of health equity was not represented in the reports. Earlier studies have suggested that exercising patients' rights may be problematic among minority communities, such as deaf people (Haricharan et al., 2013; Rodríguez-Martín et al., 2018). Furthermore, to develop a broader picture of the factors associated with the right, further research is required for studying novel characteristics related to patients (e.g. health literacy), health care professionals (e.g. education and competence) or health care organisations (e.g. ethical climate).

From the perspective of findings' relevance to clinical practice, unanticipated limitations emerged from the methodological quality and methods of the included reports: It was not possible to score every criterion of the MMAT due to limited reporting. Furthermore, it was unclear what the measured variable was and how it informed about the right. The questionnaires were often stated to measure received knowledge rather than the right to know: They aimed to measure, for example, wishes and perceptions of the received knowledge. This applied especially in the second main content category, that is the realisation of the right to know. Similar methodological choices can be seen in previous patient-right literature: Instruments have measured patients' evaluations or views on the observance of information provision (Dehghan et al., 2020; Mohammed et al., 2018; Parsapoor et al., 2012). Patients' right to know can be a complex concept to measure, which highlights the importance of identifying and expounding the theoretical background of the instruments. Moreover, many of the instruments employed in the included reports seemed to have been used for the first time and description of their psychometrics was lacking. These observations could suggest a need for profound operationalisation of the right to know and the development of validated instruments for future research.

The contexts of the included reports demonstrated a growing interest in genetics in the field of patients' right to know. Rapid development in the field has prompted ethical discussion around the right (Brownsword & Wale, 2017; Christenhusz et al., 2013; Hofmann, 2016). In addition to the contexts of the included reports, that is diagnostics and hospital care, patients' right to know about their health and care is fundamental in all fields of health care. For example, primary health care was not represented in the results of this review, although its importance in research of patients' right to know is evident: Primary health care is vital in reaching all people, providing information and educating patients (WHO, 2018). The unbalanced representation of different fields of health care can be due to our search strategy or cultural differences in definitions (e.g. primary health care).

5.1 | Limitations and strengths

The limitations of this study concern defining the search terms, search strategy, report selection, data analysis and relevance of findings to clinical practice. In defining the search terms, limitations stemmed from the fact that the right is rather a complex concept and studying the right to know is challenging, which can lead to numerous possible search terms. Regarding the search strategy, a positional operator was used to identify the relevant reports, but at the same time, it can limit the search results. As for the report selection, the reports did not always state clearly whether the focus was on patients' knowledge or patients' right to know, which left room for interpretation in the report selection phase. In data analysis, a few included reports did not report patients' perspective separately, and therefore, the results may include the perspective of health care professionals, patients' family members and laypeople. As for the relevance to clinical practice, evidence-based clinical practice implications were not possible due to limitations in the methodological quality and methods of the included reports: a need for novel approaches with high-quality methodological choices in future research is evident.

The strength of this study is that the guideline specifically developed for scoping reviews was systematically followed (Tricco et al., 2018). In the building of the search strategy, we tested search term options and search strategies in cooperation with an information specialist. A manual search was also conducted to strengthen the review.

6 | CONCLUSION

Research-based evidence on patients' right to know about their own health and care is focused on the expectations and realisation of the right. These findings provide insight into patients' perspectives of their right to know and *not* to know, yet the number of studies was scarce and the methods had limitations. A demand for a diverse and broad approach to the research about the right was identified. In future studies, analysing facilitators and barriers to the right to multidimensional knowledge content with clearly defined methodologies and diverse research methods (i.e. contexts, samples and data collections) could advance the field of patients' rights.

7 | RELEVANCE TO CLINICAL PRACTICE

Patients' expectations of the right to know and their observance of its realisation highlight the importance of health care professionals' duties related to the right. In health care practice, professionals, managers and organisations could advance equity in realisation of the right: efforts for ethically high-quality patient education are needed. There seem to be several factors associated with realisation of the right that could be advantageous to consider in practice, but further evidence is still needed.

ACKNOWLEDGEMENTS

The authors would like to thank MHSc Silja-Elisa Eskolin and MSc Sasu Muje for their contributions to the assessment of the methodological quality of the reports.

FUNDING INFORMATION

This work was supported by the Turku University Hospital, Turku, Finland with governmental funding for research in health sciences (Project 13762).

CONFLICT OF INTEREST

No conflict of interest to declare.

DATA AVAILABILITY STATEMENT

Data sharing is not applicable to this article as no new data were created or analysed in this study.

ORCID

Saija Inkeroinen https://orcid.org/0000-0001-5989-9442
Heli Virtanen https://orcid.org/0000-0003-1801-549X
Minna Stolt https://orcid.org/0000-0002-1845-9800
Helena Leino-Kilpi https://orcid.org/0000-0003-2477-971X

REFERENCES

Abedi, G., Shojaee, J., Moosazadeh, M., Rostami, F., Nadi, A., Abedini, E., Palenik, C. J., & Askarian, M. (2017). Awareness and observance of patient rights from the perspective of iranian patients: A systematic review and meta-analysis. *Iranian Journal of Medical Sciences*, *42*(3), 227–234.

Active Citizenship Network. (2002). European Charter of Patients' Rights.

Anderson, R. M., & Funnell, M. M. (2010). Patient empowerment: Myths and misconceptions. *Patient Education and Counseling*, *79*(3), 277–282. https://doi.org/10.1016/j.pec.2009.07.025

Arksey, H., & O'Malley, L. (2005). Scoping studies: Towards a methodological framework. *International Journal of Social Research Methodology*, *8*(1), 19–32. https://doi.org/10.1080/1364557032000119616

Beauchamp, T. L., & Childress, J. F. (2013). *Principles of biomedical ethics* (7th ed.). Oxford University Press.

Bou Khalil, R. (2013). Attitudes, beliefs and perceptions regarding truth disclosure of cancer-related information in the Middle East: A review. *Palliative & Supportive Care*, *11*(1), 69–78. https://doi.org/10.1017/S1478951512000107

Brownsword, R., & Wale, J. (2017). The right to know and the right not to know revisited: Part one. *Asian Bioethics Review*, *9*(1), 3–18. https://doi.org/10.1007/s41649-017-0012-1

Bugge, K., Bertelsen, F., & Bendtsen, A. (1998). Patients' desire for information about anaesthesia: Danish attitudes. *Acta Anaesthesiologica Scandinavica*, *42*(1), 91–96. https://doi.org/10.1111/j.1399-6576.1998.tb05086.x

Charter of Fundamental Rights of the European Union, 2012/C 326/02. (2012). http://data.europa.eu/eli/treaty/char_2012/oj

Christenhusz, G. M., Devriendt, K., & Dierickx, K. (2013). To tell or not to tell? A systematic review of ethical reflections on incidental findings arising in genetics contexts. *European Journal of Human Genetics*, *21*(3), 248–255. https://doi.org/10.1038/ejhg.2012.130

Cohen, J., & Ezer, T. (2013). Human rights in patient care: A theoretical and practical framework. *Health and Human Rights*, *15*(2), 7–19.

Council of Europe. (1997). Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine.

Crawford-Sykes, A. M., & Hambleton, I. R. (2001). Patients' desire for peri-operative information: Jamaican attitudes. *The West Indian Medical Journal*, *50*(2), 159–163.

Dehghan, M., Mehdipour-Rabori, R., Rayani, M., Zakeri, M. A., Mobasher, M., Iranmanesh, M., & Rezai, N. (2020). Comparison of the importance and observance of the patient's bill of rights from the perspectives of patients and personnel of hospitals in Kerman. *Journal of Medical Ethics and History of Medicine*, *13*, 5. https://doi.org/10.18502/jmehm.v13i5.4070

Erer, S., Atici, E., & Erdemir, A. D. (2008). The views of cancer patients on patient rights in the context of information and autonomy. *Journal of Medical Ethics*, *34*(5), 384–388. https://doi.org/10.1136/jme.2007.020750

European Convention for the Protection of Human Rights and Fundamental Freedoms. (1950). As amended by Protocols Nos. 11, 14 and 15, supplemented by Protocols Nos. 1, 4, 6, 7, 12, 13 and 16, ETS 5.

Flatau, L., Reitt, M., Duttge, G., Lenk, C., Zoll, B., Poser, W., Weber, A., Heilbronner, U., Rietschel, M., Strohmaier, J., Kesberg, R., Nagel, J., & Schulze, T. G. (2018). Genomic information and a person's right not to know: A closer look at variations in hypothetical informational preferences in a German sample. *PLoS One*, *13*(6), e0198249. https://doi.org/10.1371/journal.pone.0198249

Formica, R. N., Asch, W. S., Wagner, K. R., & Kulkarni, S. (2010). Kidney transplantation and HIV: Does recipient privacy outweigh the donor's right to information? *Clinical Journal of the American Society of Nephrology*, *5*(5), 924–928. https://doi.org/10.2215/CJN.06820909

Graneheim, U. H., & Lundman, B. (2004). Qualitative content analysis in nursing research: Concepts, procedures and measures to achieve trustworthiness. *Nurse Education Today*, *24*(2), 105–112. https://doi.org/10.1016/j.nedt.2003.10.001

Gutman, J., & Gutman, J. (2002). The right not to know and coronary angiography: Is the common law of Australia consistent with patients' wishes? *Journal of Law and Medicine*, *10*(2), 168–173.

Hari, D., Mark, Z., Bharati, D., & Khadka, P. (2007). Patients' attitude towards concept of right to know. *Kathmandu University Medical Journal (KUMJ)*, *5*(4), 591–595.

Haricharan, H. J., Heap, M., Coomans, F., & London, L. (2013). Can we talk about the right to healthcare without language? A critique of key international human rights law, drawing on the experiences of a deaf woman in Cape Town, South Africa. *Disability & Society*, *28*(1), 54–66. https://doi.org/10.1080/09687599.2012.699277

Hofmann, B. (2016). Incidental findings of uncertain significance: To know or not to know—that is not the question. *BMC Medical Ethics*, *17*, 13. https://doi.org/10.1186/s12910-016-0096-2

Hong, Q. N., Fàbregues, S., Bartlett, G., Boardman, F., Cargo, M., Dagenais, P., Gagnon, M.-P., Griffiths, F., Nicolau, B., O'Cathain, A., Rousseau, M.-C., Vedel, I., & Pluye, P. (2018). The mixed methods appraisal tool (MMAT) version 2018 for information professionals and researchers. *Education for Information*, *34*(4), 285–291. https://doi.org/10.3233/EFI-180221

International Committee of the Red Cross. (1949). The Geneva Conventions of 12 August 1949.

International Council of Nurses. (2021). ICN Code of Ethics for Nurses.

Klemetti, S., Leino-Kilpi, H., Cabrera, E., Copanitsanou, P., Ingadottir, B., Istomina, N., Katajisto, J., Papastavrou, E., Unosson, M., & Valkeapää, K. (2015). Difference between received and expected knowledge of patients undergoing knee or hip replacement in seven European countries. *Clinical Nursing Research*, *24*(6), 624–643. https://doi.org/10.1177/1054773814549992

Leino-Kilpi, H., Luoto, E., & Katajisto, J. (1998). Elements of empowerment and MS patients. *The Journal of Neuroscience Nursing*, *30*(2), 116–123. https://doi.org/10.1097/01376517-199804000-00005

Lenk, C., Duttge, G., Flatau, L., Frommeld, D., Poser, W., Reitt, M., Schulze, T., Weber, A., & Zoll, B. (2019). A look into the future? Patients' and health care staff's perception and evaluation of genetic information and the right not to know. *American Journal of Medical Genetics. Part B, Neuropsychiatric Genetics*, *180*(8), 576–588. https://doi.org/10.1002/ajmg.b.32751

McDougall, R. (2004). Rethinking the "right not to know.". *Monash Bioethics Review*, *23*(1), 22–36. https://doi.org/10.1007/BF03351407

Mohammed, E. S., Seedhom, A. E., & Ghazawy, E. R. (2018). Awareness and practice of patient rights from a patient perspective: An insight from upper Egypt. *International Journal for Quality in Health Care*, *30*(2), 145–151. https://doi.org/10.1093/intqhc/mzx182

Nyrhinen, T., Hietala, M., Puukka, P., & Leino-Kilpi, H. (2009). Are patient rights to information and self-determination in diagnostic genetic testing upheld? A comparison of patients' and providers' perceptions. *Journal of Genetic Counseling*, *18*(1), 72–81. https://doi.org/10.1007/s10897-008-9190-z

Page, M. J., McKenzie, J. E., Bossuyt, P. M., Boutron, I., Hoffmann, T. C., Mulrow, C. D., Shamseer, L., Tetzlaff, J. M., Akl, E. A., Brennan, S. E., Chou, R., Glanville, J., Grimshaw, J. M., Hróbjartsson, A., Lalu, M. M., Li, T., Loder, E. W., Mayo-Wilson, E., McDonald, S., … Moher, D. (2021). The PRISMA 2020 statement: An updated guideline for reporting systematic reviews. *PLoS Medicine*, *18*(3), e1003583. https://doi.org/10.1371/journal.pmed.1003583

Parsapoor, A., Mohammad, K., Malek Afzali, H., Ala'eddini, F., & Larijani, B. (2012). Observance of Patient's rights: A survey on the views of patients, nurses, and physicians. *Journal of Medical Ethics and History of Medicine*, *5*, 5.

Pérez-Cárceles, M. D., Gironda, J. L., Osuna, E., Falcon, M., & Luna, A. (2010). Is the right to information fulfilled in an emergency department? Patients' perceptions of the care provided. *Journal of Evaluation in Clinical Practice*, *16*(3), 456–463. https://doi.org/10.1111/j.1365-2753.2009.01142.x

Pérez-Cárceles, M. D., Lorenzo, M. D., Luna, A., & Osuna, E. (2007). Elderly patients also have rights. *Journal of Medical Ethics*, *33*(12), 712–716. https://doi.org/10.1136/jme.2006.018598

Peters, M. D. J., Godfrey, C., McInerney, P., Munn, Z., Tricco, A. C., & Khalil, H. (2020). Chapter 11: Scoping reviews. In E. Aromataris & Z. Munn (Eds.), *JBI manual for evidence synthesis*. JBI.

PRE-MAX Consortium. (2016). *Patients' rights in the European Union—Mapping eXercise*. European Commission.

Putturaj, M., Belle, S. V., Criel, B., Engel, N., Krumeich, A., Nagendrappa, P. B., & Prashanth, N. S. (2020). Towards a multilevel governance framework on the implementation of patient rights in health facilities: A protocol for a systematic scoping review. *BMJ Open*, *10*(10), e038927. https://doi.org/10.1136/bmjopen-2020-038927

Regulation (EU) 2021/522, 2020/0102/COD. (2021). http://data.europa.eu/eli/reg/2021/522/oj

Rodríguez-Martín, D., Rodríguez-García, C., & Falcó-Pegueroles, A. (2018). Ethnographic analysis of communication and the deaf community's rights in the clinical context. *Contemporary Nurse*, *54*(2), 126–138. https://doi.org/10.1080/10376178.2018.1441731

Schuurman, A. G., van der Kolk, D. M., Verkerk, M. A., Birnie, E., Ranchor, A. V., Plantinga, M., & van Langen, I. M. (2015). Maximising the efficiency of clinical screening programmes: Balancing predictive genetic testing with a right not to know. *European Journal of Human Genetics: EJHG*, *23*(9), 1124–1128. https://doi.org/10.1038/ejhg.2014.269

Sim, J. (2020). Do we need rights in bioethics discourse? *The Journal of Medicine and Philosophy*, *45*(3), 312–331. https://doi.org/10.1093/jmp/jhaa004

Tricco, A. C., Lillie, E., Zarin, W., O'Brien, K. K., Colquhoun, H., Levac, D., Moher, D., Peters, M. D. J., Horsley, T., Weeks, L., Hempel, S., Akl, E. A., Chang, C., McGowan, J., Stewart, L., Hartling, L., Aldcroft, A., Wilson, M. G., Garritty, C., … Straus, S. E. (2018). PRISMA extension for scoping reviews (PRISMA-ScR): Checklist and explanation. *Annals of Internal Medicine*, *169*(7), 467–473. https://doi.org/10.7326/M18-0850

UN Educational, Scientific and Cultural Organisation. (1997). Universal Declaration on the Human Genome and Human Rights.

UN General Assembly. (1976). International Covenant on Civil and Political Rights.

Vall Casas, A., & Rodríguez Parada, C. (2008). Patients' right to information: A review of the regulatory and ethical framework. *Textos Universitaris de Biblioteconomia i Documentació*, *21*. https://doi.org/10.1344/105.000000325

World Health Organization. (1994). *A declaration on the promotion of Patients' rights in Europe*. World Health Organization.

World Health Organization. (2018). A vision for primary health care in the 21st century. https://www.who.int/publications-detail-redirect/WHO-HIS-SDS-2018.15

World Medical Association. (2015). WMA Declaration of Lisbon on the rights of the patient.

SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

How to cite this article: Inkeroinen, S., Virtanen, H., Stolt, M., & Leino-Kilpi, H. (2022). Patients' right to know: A scoping review. *Journal of Clinical Nursing*, *00*, 1–14. https://doi.org/10.1111/jocn.16603