
Development of patient versions of guidelines in Chinese mainland: a systematic survey of current practices and methods

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Abstract

Objectives: To review current practices and methods underlying the development of patient versions of guidelines (PVGs) in Chinese mainland.

Methods: We systematically searched for PVGs created or published between January 2010 and February 2022. We conducted a framework analysis for the development process and assessed the compliance of PVGs using the Reporting Checklist for Public Versions of Guidelines (RIGHT-PVG).

Results: We identified 26 PVGs developed by 16 PVG-working teams. In accordance with the Guidelines International Network (GIN), only two PVGs were translated using one clinical practice guideline (CPG) provided by the CPG-working group source. Several CPGs and other information sources were integrated and translated into a single PVG by other PVG teams. Moreover, we identified various practices described by different PVG teams that could be structured into six steps. Out of the 17 RIGHT-PVG items, five items were fully reported in all PVGs, while two items (“Provide a summary of the PVG” and “Provide a list of terms and abbreviations”) were not reported in any of the PVGs.

Conclusions and practical implications: A relatively small number of PVGs were developed in Chinese mainland. The development of a PVG requires comprehensive methodological guidance based on several CPGs and other sources of information as opposed to only using one.

Keywords: Clinical practice guidelines; Patient version of guidelines; Patient engagement; Patient involvement; Survey; Chinese mainland

1. Introduction

Clinical practice guidelines (CPGs) are informed by systematic reviews that underscore recommendations intended to optimize patient care [1]. Although CPGs are traditionally developed for health providers, they can provide useful information to patients and their caregivers, as well as other members of the public [2]. In the context of research literature, an increased focus has been placed on creating patient versions of guidelines (PVGs). PVGs refer to “documents that ‘translate’ CPG recommendations and their rationales originally produced for health providers into a form that is more easily understood and used by patients and the public [3].” PVGs provide knowledge that can help to inform patients and the public about a specific health condition. Furthermore, PVGs can enhance inclusion between patients and caregivers in health decision-making processes during clinical encounters with healthcare providers [4]. In 2012, the Guidelines International Network (GIN) published a manual to guide the development of useful CPG-derived materials for the public and patients (hereafter “GIN public guidance”) [5]. International guideline organizations such as the National Institute for Health and Care Excellence (NICE) and the Scottish Intercollegiate Guidelines Network (SIGN) have produced freely accessible patient versions for some of their CPGs [6].

Although PVGs are essentially CPGs in plain language, developing PVGs typically requires careful decisions regarding (1) content, (2) clear communication of the strength of recommendations, (3) options available to patients, and (4) presentation and formatting of the PVG [3]. To promote the development of high-quality, reliable, and publicly available PVGs, the National Health Care Institute of the Netherlands developed a set of minimum criteria for the development process, content, and governance of PVGs (MC-PCG) in 2018 [7]. Thereafter, the Reporting Tool for Practice Guidelines in Health Care (RIGHT) Working Group developed the Reporting Checklist for Public Versions of Guidelines (RIGHT-PVG) in 2021 [8].

According to the GIN public guidance and MC-PCG, PVGs ought to be informed by high-quality CPGs [3]. Furthermore, Graham et al. [3] and van der Weijden et al. [7] indicated that PVGs produced by members of the same CPG groups

could ensure the integrity and accuracy of the content between the CPG and the patient version (hereafter “source CPGs” and “source recommendations,” respectively). Thus, PVGs are often developed by their source CPG organizations (hereafter “source CPG organizations” or “working groups”) such as SIGN and NICE, and subsequently translated from their corresponding CPG versions. However, CPG developers in Chinese mainland often do not develop PVGs [10]. Instead, many PVGs are developed by voluntary groups from hospitals or medical institutions [11, 12] which do not constitute source CPGs. In this case, voluntary groups usually integrate multiple CPGs developed by other organizations into one PVG. The GIN public guidance and MC-PCG comprise the only two public PVG development guidelines which are developed for source CPG developers. However, these guidelines only describe the methodology for PVG development based on one source CPG. As observed by the lack of guidance for PVGs developed by organizations other than the source CPG, existing PVG development guidance may have limited applicability, particularly in the context of insufficient local high-quality CPGs for PVG development [9]. Thus, our objective was to review current practices for the development of PVGs. Specifically, we aimed to understand the overall PVG process, namely, the development, presentation, and dissemination of PVGs. This systematic survey comprised the first study in a series of three articles to inform the process and guiding principles underlying the development of PVG.

2. Methods

We conducted a systematic survey of ongoing and completed PVGs, and purposively sampled protocols (i.e., PVG method reports) published by all PVG teams to describe the development process of PVGs. We focused on identifying the implemented methods and approaches as well as the reporting quality and dissemination of PVGs.

2.1 Inclusion and exclusion criteria

The inclusion of the PVGs was based on the following criteria:

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- 1) The PVG was produced by Chinese organizations.
 - 2) The end-users in the PVG were patients, caregivers, or the public.
 - 3) One of the three items was met:

① The PVG provided recommendations based on existing evidence.

② The PVG was registered in the “Patient version of Guideline” special column on the International Practice Guideline Registry Platform (IPGRP; <http://www.guidelines-registry.cn/>)

③ The PVG followed the GIN definition of PVG or GIN public guidance.

2.2 Retrieval platforms and search strategies

Our preliminary search yielded published protocols or full-texts by many PVG developers in peer-reviewed medical journals. Thus, we systematically searched four Chinese databases (China National Knowledge Infrastructure, China Science and Technology Journal Database, Wanfang Database, SinoMed), three English databases (PubMed, Web of Science, Embase), and the “Patient version of Guideline” special column for PVG registration under the International Practice Guideline Registry Platform (IPGRP) (<http://www.guidelines-registry.cn/>) from January 01, 2015, to February 20, 2022. This study period was used because the first PVG study we identified was published in 2016. Furthermore, we searched for additional references by examining relevant publications (i.e., snowballing) and used the “similar articles” and “citing articles” features from PubMed and Wanfang Database. However, these search features appear only in the two databases. Acknowledging that PVGs likely comprise non-peer-reviewed studies, we searched the “Baidu” website (www.baidu.com) for additional grey literature references for PVGs when the above approaches only identified protocols or registration information. Finally, the first author contacted well-known experts who contributed significantly to the development of PVGs in Chinese mainland to further identify additional relevant articles. Based on these methods employed, we developed a search strategy to identify PVGs in Chinese mainland. The strategy was tailored to the specific requirements of each database as illustrated in the appendix.

2.3 Study selection and data extraction

All identified records were collated and uploaded into EndNote (Clarivate Analytics, PA, US) before removing all duplicates. Thereafter, two independent reviewers (LJY and DY) screened the titles and abstracts to assess their eligibility. Consequently, full-texts of potentially relevant PVG records were retrieved and included depending on the eligibility criteria. Furthermore, this review recorded and reported the reasons for excluding PVGs. Moreover, any discrepancies that emerged during the study selection process were resolved through discussion or final adjudication with a third reviewer (JPL).

We abstracted key components of the PVGs, including the evaluated condition, year, the guidance followed, the development process, PVG group member composition, and format of the patient versions (e.g., booklet). Finally, we contacted the PVG authors to obtain further data in cases where data were missing or incomplete.

2.4 Data analysis

The current qualitative analysis applied a deductive approach [13]. Two coders (LJY and DY) independently coded the review findings before comparing and discussing the codes. When discrepancies were identified, a third author (JPL) resolved the disagreements. For the deductive approach, we followed the PVG development steps outlined in the MC-PCG in conjunction with the process of adapting the CPGs identified by Yang et al. [14] as a coding framework. Thereafter, we investigated additional concepts using the methodological evidence of the included PVGs. Subsequently, we coded the PVG development process findings against the resulting coding framework and revised and merged codes into themes as new concepts emerged. Finally, we proposed the subthemes using the drafted thematic framework.

For PVGs that provided full-text, two authors (LJY and DY) independently assessed their compliance with RIGHT-PVG. The RIGHT-PVG checklist contains 17

items grouped into four domains, namely, basic information (3 items), background (4 items), recommendations (4 items), and other information (4 items; see Table 3). We rated each of the items in RIGHT-PVG according to four options, namely, “full compliance,” “partial compliance,” “no compliance,” or “not applicable.” The “full compliance” option was used for PVGs comprising the relevant information, “partial compliance” was used if a PVG provided partial relevant information, whereas “no compliance” indicated that the relevant information either could not be found or was unclear. For example, partial compliance can refer to a PVG that provided a partial explanation of cancer epidemiology, explaining only the prevalence and incidence of the disease. Whereas the full explanation included a description of prevalence, incidence, morbidity, mortality, and burden (including financial). Furthermore, “not applicable” referred to PVGs that do not meet the evaluation requirements of an item and cannot be evaluated under “full compliance,” “partial compliance,” and “no compliance” [15, 16]. Moreover, summary statistics (i.e., frequencies and percentages) were provided for each PVG and each RIGHT-PVG item. In case of conflicting opinions, the third author (JPL) was consulted to reach a consensus.

3. Results

3.1 Search result

In total, this review identified and analyzed 26 PVGs developed by 16 PVG-working teams (named by their first affiliation; Figure 1). Six PVG full-texts, including their development process, were obtained from peer-reviewed medical journals [17-22]. Six PVGs were protocols [11, 12, 23-26], while the remaining 14 PVGs comprised PVG IPGRP registration information (including title, organization, year, and authors). Despite attempting to contact all authors for full-texts and other missing information (especially guideline method reports) using the available contact information, namely, by email, telephone, or WeChat (i.e., a multi-purpose social media widely used in the Chinese mainland), we only received 10 responses. Consequently, two full-text PVGs were received [11, 12], while four PVGs were ongoing, three were suspended, and one PVG was completed but not published nor

shared with our team [25]. The status of the remaining PVGs was considered ongoing based on the limited access to further information. Ultimately, 8 full-text PVGs [11, 12, 17-22], 12 PVGs underlying the development process [11, 12, 17-26], and 21 PVGs describing registration information were available. Table 1 summarizes the characteristics of the included PVGs.

Insert Fig 1. Flowchart of including PVGs

3.2 Characteristics of included PVGs

There has been a slight increase in the annual number of PVGs from 2016 to 2021, with a peak of 12 PVGs in 2021. The earliest documented PVGs were traced back to 2016. Particularly, one PVG provided guidance on diagnosing and managing diabetic foot [12] while the other underscored non-drug measures for the secondary prevention of myocardial infarction [25]. The majority of the developed PVGs were for patients with chronic diseases, such as rheumatoid arthritis and stroke. While most of the included PVGs (i.e., 24/34) primarily focused on self-management, several also covered treatment, diagnosis, screening, and prevention.

Table 1 The characteristics of the included PVGs.

Developer (the first author)+ year (the year of the record can be first identified)	Topics	PVG-working team names (named by the first affiliation)	Status of the PVG	Methodologies followed
1. Wang RX 2021 [11]	Secondary prevention of ischemic stroke	Shenzhen Hospital, University of Hong Kong (SH-HK team)	Full text + Protocol (completed)	GIN
2. Liu EM 2021 [22]	Children Cough	Pediatrics Society of Chinese Medical Association (PSCMA team)	Full text* (completed)	
3. Ye CQ 2021 [18]	Exercise for fibromyalgia	Chinese PLA Air Force Special Medical Center (CPAFSMC team)	Full text* Registration (completed)	+ GIN+WHO

4. Xie Y 2020 [21]	Ankylosing spondylitis/spondyloarthritis		Full text* + Registration (completed)	
5. Huang YF 2020 [20]	Hyperuric acidemia gout	Guangdong Immunological Clinical Medical Research Center (GICMRC team)	Full text* + Registration (completed)	GIN+WHO
6. Qiu ML 2020 [19]	Osteoporosis		Full text* + Registration (completed)	
7. Fang LK 2020 [17]	Rheumatoid arthritis		Full text* + Registration (completed)	
8. Jiang JT 2016 [12]	Management of diabetic foot	Evidence-based Nursing Center, Beijing University of Chinese Medicine (BUCM-EBN team)	Full text + Protocol + Registration (completed)	GIN
9. Liu H 2022 [24]	Management of Foreign Body in the Digestive tract of Children	School of Public Health, Lanzhou University (LZU-SPH team)	Protocol + Registration (ongoing)	GIN+WHO
10. Zhou YF 2021 [23]	Non-pharmacological management for gestational diabetes mellitus	JI Evidence-Based Nursing Cooperation Center, Fudan University (FU-EBN team)	Protocol + Registration (ongoing)	GIN+WHO
11. Li Y 2016 [25]	Secondary prevention of myocardial infarction with non-drug treatment	Tianjin University of Chinese Medicine (TUCM team)	Protocol + Registration (completed)	GIN+WHO
12. Nie G 2017 [26]	Management and prevention of chronic HBV infection	Infectious Diseases Branch of National Chinese Association of Integrated Traditional and Western Medicine (NCAITWM-IDB team)	Protocol (suspended)	GIN+WHO
13. Liu H 2021	Novel Coronavirus Vaccination	School of Public Health, Lanzhou University (LZU-SPH team)	Registration (suspended)	Not available
14. Unknown 2021	Neonatal skin management	West China Second Hospital, Sichuan University (SU-WCSH team)	Registration (ongoing)	Not available
15. Li YX 2021	Neonatal feeding	West China Second Hospital, Sichuan University (SU-WCSH team)	Registration (ongoing)	Not available
16. Li YX 2021	Management of neonatal jaundice	West China Second Hospital, Sichuan University (SU-WCSH team)	Registration (ongoing)	Not available

17. Yang T 2021	Pulmonary arterial hypertension	National Professional Council on Cardiovascular Diseases (NPCCD team)	Registration (ongoing)	Not available
18. Fang JX 2021	Etogenic diet in children with refractory epilepsy	Evidence-based Nursing Center, Beijing University of Chinese Medicine (BUCM-EBN team)	Registration (ongoing)	Not available
19. Li XH 2021	Elderly people with chronic pain	School of Nursing, Sichuan University (SU-SN team)	Registration (ongoing)	Not available
20. Wang Y 2021	Stroke	Dongzhimen Hospital of Beijing University of Chinese Medicine (BUCM-DH team)	Registration (ongoing)	Not available
21. Yang D 2020	Stroke limb dysfunction rehabilitation care	Evidence-based Nursing Center, Beijing University of Chinese Medicine (BUCM-EBN team)	Registration (ongoing)	GIN
22. Ni XJ 2020	Non-motor symptoms after stroke	Guangdong provincial hospital of Chinese medicine (GPHCM team)	Registration (ongoing)	Not available
23. Yan R 2020	Health education for cancer patients	Cancer Nursing Professional Committee of Shandong Nursing Society (CNPCSNS team)	Registration (ongoing)	Not available
24. Xie Y 2020	Evaluation and management of antinuclear antibodies	Guangdong Immunological Clinical Medical Research Center (GICMRC team)	Registration (ongoing)	Not available
25. Yang ZY 2017	Treatment of knee osteoarthritis in patients based on joint decision-making between doctors and patients	Institute of Arthropathy, Peking University (PU-IA team)	Registration (ongoing)	Not available
26. Liu XJ 2016	Constipation after stroke	Evidence-based Nursing Center, Beijing University of Chinese Medicine (BUCM-EBN team)	Registration (suspended)	Not available

* PVG full texts, including their development process

3.3 Current practice

Twelve PVGs developed by nine PVG-working teams reported the methods used for PVG development. The authors of these PVGs reported following the GIN public guidance to produce PVGs. Among the PVGs, seven followed the World Health Organization (WHO) handbook for PVG development (hereafter, “WHO handbook”) [27]. Notably, we found that the processes for developing PVGs were not uniform.

Thus, we identified various practices described by different PVG teams. For example, some PVG teams stated that they used seven steps [17, 19-21] while others required nine steps to develop PVGs [12]. Furthermore, some teams identified patients' needs and formulated key questions before searching for evidence [17, 19-21, 25]. In contrast, some teams explored the patients' needs to determine whether the selected recommendations were relevant to them only after the selection of source CPG(s) and recommendations [12]. Based on the framework analysis, we structured the six main steps involved in developing PVGs (Tables 2 and 3).

3.3.1 Team

Reportedly, all PVGs were developed by a multidisciplinary expert group (including experts that assess evidence and develop guidelines informed by existing research and healthcare professionals) [11, 12, 17, 19, 20, 22, 24, 25]. The development of some PVGs involved editors with experience in writing to individuals who were not in healthcare (i.e., kindergarten teachers or journalists) [11, 24], while the development of one PVG included legal experts and experts from the National Centers for Disease Control to ensure its rigorousness [24]. Two PVGs were developed by the source CPG-working group [12, 22]. Furthermore, all developed PVGs reportedly involved patient representatives at particular stages of the process including the scope selection stage [11, 17-21, 23-26], the content and format stage [24], and the optimization of PVG [11, 12, 22-24] as presented in Table 2.

3.3.2 Selection of the scope and source CPG(s)

The PVG development teams defined or identified PVG topics and key questions before the selection of source CPGs. Two PVGs were based on priority topics of the previously adapted or developed CPG [12, 22]. One team reported the topics were predefined based on patient information needs interviews [11]. In contrast, the remaining teams identified the topic before formulating key questions based on existing CPGs, empirical research, and interviews with both patients and health professionals [17-21, 23-26]. Thereafter, the teams searched for relevant existing

CPGs. Particularly, most teams conducted a comprehensive search for CPGs after defining or identifying the topics and key questions. Furthermore, two PVGs were translated from one corresponding CPG, which was adapted and developed by the working groups [12, 22]. Moreover, one PVG was developed immediately after source CPG development [22], while another PVG [12] was developed two years after the source CPG adaptation. Thus, this PVG [12] updated the source CPG with a comprehensive search for related evidence before assessment of source materials (Table 3).

3.3.3 Assessment of source materials

The PVG development teams reviewed and assessed the obtained source CPGs. This step was stratified into three levels based on the reported practice. However, not all teams completed all three assessment levels for the source materials (Table 3).

► **Guideline level:** PVG developers selected CPGs for further appraisal based on the following criteria: relevance to the topic; key questions; publishing time; comprehensiveness of information; writing language; and version of revised CPGs [11, 12, 23]. Thereafter, source CPGs were assessed using the AGREE II instrument [11, 12, 18, 23-26] and the CPGs of high quality were included. Furthermore, seven PVG teams started *de novo* development (i.e. conducting a comprehensive search for SRs [17-21, 24-26] and primary evidence [17-21, 24]) after the assessment of the CPGs. One PVG cited the low quality of CPGs as a reason for starting *de novo* development [25]. However, the other PVGs did not provide any reason.

► **Recommendation level:** The recommendations of the included CPGs were assessed and selected based on the following criteria: relevance to the topics [11, 12, 23], acceptability and applicability for patients [11, 12], context [12], clinical significance [12], the potential impact on patient care [11], accuracy [12], and clarity [12]. When there is no recommendation for answering specific questions, *de novo* development begins with a comprehensive search for SRs [25].

► **Evidence level:** The evidence of the source recommendations [23] and newly included studies [12, 17-21, 24-26] were reviewed using corresponding assessment

tools. When required, the original search was conducted and supplemented with new evidence [23]. The reasons for updating and supplementing source evidence were because the source CPG (1) did not clearly answer all the key questions; (2) was not adequately searched or appraised; and (3) was considered outdated (e.g., more than two years since the last search).

3.3.4 Decision-making process

During the development process, PVG developers had to decide whether to adopt (without modifications) the source recommendations and how to address the recommendations on the same clinical questions from different CPGs. Consequently, the developers would adapt (with modifications in the expression of the recommendation) the items on the condition that the recommendations were considered vague or ambiguous [11]. Furthermore, recommendations can be tailored when applied in different contexts [12]. Some PVGs teams have integrated recommendations from different CPGs based on individually developed principles [12]. Additionally, some PVG teams formulated new recommendations through consensus decision-making or voting, using only the source recommendations as a reference [23]. Because the researchers found that the process of forming new recommendations was more time-efficient, in contrast, to determining the appropriate and before translating them to patients. However, it remains unclear how other PVG teams mitigate this situation (i.e., adapted, adopted, or merely as a reference), although some have stated including CPGs [24-26]. Moreover, PVG developers used the GRADE approach to formulate the recommendation in the context of *de novo* development [17-21, 26].

The decision-making process occurred through panel discussions, voting, or using the Delphi method. To ensure that the recommendations included in PVGs were appropriate, some teams conducted patient interviews before consensus was reached to determine the patients' needs for the selected recommendations [23] (Table 3).

3.3.5 The content and format

Following the decision-making process, the developers drafted the PVGs based on the recommendations. In support of the drafting process, some developers involved fine arts professionals [11] and editors with experience writing copies for a non-expert audience (i.e., kindergarten teachers, journalists, or literary professionals) [26]. To guide patients with the implementation and practice of these recommendations, several PVG developers detailed the recommendations by including other information with the guidance of three principle [12]. The detailed information can be stemming from the source evidence or from new searching evidence [11, 12]. For example, in the context of blood glucose control, stroke-related guidelines were not as detailed or as updated as those for diabetes. As a result, they consulted the diabetes-related guidelines for clarification [11]. To ensure the relevance and accessibility of the recommendations to patients, developers assessed patients' needs, preferences [12], and understandability [24] of the included recommendations through interviews with patients. Accordingly, the PVGs were drafted based on the patients' feedback (Table 3).

3.3.6 PVG optimization and follow-up

After drafting PVGs, either an external review, user testing, or a peer review process was conducted to ensure the understandability of PVGs among patients; either process assessed the reliability and accuracy of the categorization and recommendation integration process [12]. In addition, the feasibility, appropriateness, meaningfulness, and effectiveness of the recommendations [11, 12], as well as the rationality of structure [12], understandability and accuracy of the content, and normalization of reports [12] were analyzed. Some studies have also conducted PVG quality appraisals using AGREE II [11, 12, 23]. Moreover, a follow-up process, including a plan for dissemination, monitoring, and updating, was scheduled. These processes are similar to CPG development processes and are outlined in Table 3.

3.4 RIGHT-PVG reporting checklist domains

Eight PVGs [11, 12, 17-22] were available for compliance assessment using the

RIGHT-PVG. Five of the 17 RIGHT-PVG items were fully reported in all PVGs, while two items (“Provide a summary of the PVG, including the main recommendations” and “Provide a list of terms and abbreviations used in the PVG.”) were not reported in any of the PVGs. Furthermore, one item (“Suggest a list of questions for patients to ask their healthcare providers”) was reported in only 25% PVGs. On average, PVGs fully reported nine of 17 (59%) items (ranging from 7 to 13 items). Table 4 shows their compliance with all the RIGHT-PVG items.

Among the eight full-text PVGs, six [17-22] were presented as published articles comprising 3 to 5 pages. Furthermore, two PVGs [11, 12] were presented as booklets consisting of more than 15 pages, combined with the format of calendars and web pages. Moreover, two [11, 12] were presented using colors, icons, and graphics. Six [17-22] presented all recommendations using the question and answer format. For example, *“Question: Are gout patients susceptible to diabetes? Recommendation 5: Patients with gout and diabetes choose hypoglycemic drugs that do not increase insulin levels (1 B).”*

3.4.1 Basic information

Only three PVGs could be identified as guidelines for patients and the public from the title. The remaining five used “Practice guideline for/of (health condition/disease)” in the title, which can be easily recognized as a CPG for health professionals [17-21]. Furthermore, all studies reported the topic and publication year. However, none of the studies specified the version of the PVG in the title, cover page, or copyright statement. In addition, six PVGs provided the contact information of their developers (including affiliations, addresses, and email addresses). The contact information comprised only the affiliations as no phone numbers nor email addresses were provided in one PVG [12]. While one PVG did not provide any contact information at all [11]. Moreover, none of the PVGs provided a summary of the main recommendations.

3.4.2 Background

All PVGs introduced the target condition, informed by the definition, risk factors, signs, subtypes, complications, staging (progress), and epidemiology. Furthermore, each PVG introduced management, preventive, and diagnostic options, among others. However, six PVGs presented a proportion of the background information as recommendations [17-22] (e.g., in the PVG for patients with hyperuricemia/gout, the risk factors of hyperuricemia/gout were introduced. For example, *“Hyperuricemia and gout are complicated diseases in which genetic and environmental factors work collectively (1B)”*). Moreover, seven PVGs described their scope, purpose, intended use, and users. Only one PVG did not provide any information about its scope, purpose, intended use, and users [19]. Except for one [12], all PVGs provided a reference to the source guideline or other types of evidence.

3.4.3 Recommendations

All except one PVG [11] provided recommendations. Recommendations included background information, diagnosis, prevention, treatment, and self-management. Furthermore, all PVGs included the target populations or conditions for each recommendation. Each PVG presented the potential benefits and harms of the diagnoses, treatments, or self-management options that were relevant to the patients as well as the specific settings in which the options were recommended to be implemented. These PVGs also described available options for mitigating undesirable outcomes. One of the seven PVGs that provided recommendations did not provide quality of the evidence [12]. Two PVGs [12, 22] presented the strength of recommendations using symbols such as a smiling face [22], which indicated a stronger recommendation.

3.4.4 Other information

Except one [12], all developers reported conflicts of interest in terms of contributors to PVG and stated no conflicts of interest. Only one [11] developers suggested a list of questions for patients to ask their healthcare providers. Only three [11,18,22] developers described the funding source(s) of the PVG, without providing

their any influencing role in the PVG and guideline development processes. None of the developers provided a list of terms and abbreviations used in the PVG despite the difficulty associated with understanding the terms in PVG, such as “Allele,” and “Wagner classification.”

Table 2 Team composition

Team Name	Members	N	Main task
SH-HK team [11]	Neurology nurses	4	Interviewing with patients, guideline searching, source CPG quality assessment using AGREE II, translating recommendations in an easy-to-understand manner for patients, drafting PVGs, preparing external review with a questionnaire
	Neurology medical specialists	2	Providing advice and guidance to drafting PVGs
	Patients	2	Participating in translating recommendations in an easy-to-understand manner for patients
	Kindergarten teacher	1	
	illustrator	1	
BUCM-EBN team [12]	Guideline Development Working Group (including Patients)	30	Drafting the scope of the guideline, preparing the planning proposal, establishing expert consensus group and external review group, managing any COIs among potential members, updating, retrieval, <u>evaluating</u> , synthesis and <u>transforming</u> of evidence, monitoring and documenting the entire guideline development process; coordinating the development of guidelines; monitoring and updating guidelines
	Guideline consensus expert group (including Patients)		Determining the target population, involved interventions and outcomes; providing guidance of evidence generation to guideline Development Working Group; Reviewing the draft guidelines to ensure their accuracy, completeness and applicability; dealing with the opinions of external review
	Guideline external review group (including Patients)		Reviewing the scope <u>and</u> topic of patient guidelines; reviewing the final patient guidelines to ensure its clarity and transparency; evaluating the possible impact of these patient guidelines and giving feedback and suggestions for modification and improvement; identifying major problems existing in the patient guidelines and proposing to the Guideline Development Working Group to solve
TUCM team [25]	Expert steering Committee	10-15	Establishing Guideline Development Working Group; <u>managing</u> any COIs among potential members; guiding preparing the planning proposal, determining the target population, scope of the guideline, methods and process of guideline development, evidence retrieval, evaluation and the formation of evidence to decision matrix; reviewing and revising the recommendations and the full text of the guidelines, and reaching consensus on the recommendations; handling the opinions of external review

	Guideline Development Working Group(including Patients and journalists)	10-15	Collection, refinement and prioritization of questions, preparing the planning proposal, evidence retrieval, evaluation and the formation of evidence to decision matrix, conducting external peer review, coordinating the development of guidelines
FU-EBN team [23]	Clinical professional Expert in evidence-based nursing methodology	10-15	Formulating questions; Formulating recommendations; reviewing the PVG draft Evidence retrieval, evaluation and the formation of evidence to decision matrix, drafting PVGs
GICMRC team [17, 19-21]	Patients Expert steering Committee Guideline consensus expert group Guideline secretarial group Guideline evidence evaluation group Guideline external review group Member of the patients' association		Reviewing the readability and feasibility for patients
LZU-SPH team [24]	Chief Expert Expert Committee(including legal experts, Newsman, and experts from the national CDC) Secretarial group Evidence Evaluation Team	2-4 10-20 3-5 3-10	Quality control of development process, managing any COIs among potential members Approval for planning proposal, forming the guideline development working group; guiding determining the target population, scope of the guideline, methods and process of guideline development, evidence retrieval, evaluation and the formation of evidence to decision matrix; reviewing and revising the recommendations and the full text of the guidelines; handling the opinions of external review; approval for publish of PVG Preparing the planning proposal and registration; collection, refinement and prioritization of questions; evidence retrieval, evaluation and the formation of evidence to decision matrix; Organizing related meetings; coordinating external review; documentation of the entire guideline development process; coordinating works between each group Evidence retrieval, evaluation, and grading; formation of evidence to decision matrix; assisting the secretarial team to deal with evidence-related issues

	Patient and Public Team	20-30	Participating in determining the scope of the guidelines, dissemination, and implementation methods of the PVG; participating in the collection and selection of clinical questions; conducting surveys on <u>the</u> values and preferences of patients and the public; evaluating the understandability of recommendations
	Consensus team (including patients)	19-29	Reaching consensus and voting <u>on</u> the recommendations; evaluating the understandability of recommendations
	External Review team	3-5	Reviewing the PVG draft, and giving feedback to a secretarial group
PSCMA team [22]	Source guideline working group		
CPAFSMC team [18]	Rehabilitation physicians, rheumatology physicians, physical therapists, evidence-based medicine professionals		
NCAITWM-IDB team [26]	Expert steering committee		
	Guideline consensus expert group		
	Guideline secretarial group		
	Guideline evidence evaluation group		
	Patient and Public group		

N: number of team members CPGs: clinical practice guidelines PVG: Patient version of guideline COI: Conflict of interest

Table 3 Main steps of the development of PVGs

Team Name	Selection of the scope and source CPG(s)	Assessment of source materials	Decision-making process	The content and format	Optimization of PVG and follow-up
SH-HK team [11]	<ul style="list-style-type: none"> ➤ Identifying topics based on patient information needs interviews ➤ Comprehensive searching <u>for the best available topics related CPGs</u> 	<ul style="list-style-type: none"> ➤ Selection of source CPGs matched by criteria ^a ➤ Source CPG quality assessment using AGREE II ➤ Identifying relevant recommendations from source CPG(s) based on acceptability, and applicability for patients and potential impact on patient care through group meeting 	<ul style="list-style-type: none"> ➤ Decision making as adoption or modifications of recommendations according to their readability to patients through group meeting ➤ Modifying the vague or ambiguous recommendations based on additional review of other literature 	<ul style="list-style-type: none"> ➤ Translation of recommendations in an easy-to-understand manner for patients (with patient-friendly format and language) through group meetings (including one kindergarten teacher and one illustrator), making it easier for the public to understand and accept ➤ Detailing the recommendations by supplementing with additional review of other literature 	<ul style="list-style-type: none"> ➤ External review (by professionals and patients) with a questionnaire developed based on the FAME framework (feasibility; appropriateness; meaningfulness; effectiveness) ➤ Quality appraisal using AGREE II
BUCM -EBN team [12]	<ul style="list-style-type: none"> ➤ Based on the previous adapted CPG's priority topics ➤ Updating the adapted CPG by comprehensive searching for new potential CPGs/ TCM related SRs 	<ul style="list-style-type: none"> ➤ Selection of source CPGs matched by criteria ^b ➤ New included CPG quality assessment using AGREE II ➤ SRs appraisal using JBI Checklist for Systematic Reviews ➤ Identifying relevant recommendations from new 	<ul style="list-style-type: none"> ➤ Categorization of all identified recommendations combined with the recommendations from the source adapted CPG, based on the hierarchical and logical relationships between them ➤ Recommendation integration: 	<ul style="list-style-type: none"> ➤ Identifying patients' preferences for the selected recommendations through interviews with patients ➤ Translation of recommendations in an easy-to-understand manner for patients based on patients' 	<ul style="list-style-type: none"> ➤ External review (by professionals and patients) of the scientificity and accuracy of the categorization and recommendation integration; feasibility; appropriateness;

		included CPG(s) relevant to the topics, acceptability and applicability for patients and local context clinical significance, accuracy, clarity	dealing with two or more relevant recommendations ^d	preferences	meaningfulness; effectiveness of the recommendations; the rationality of structure, readability, the accuracy of content, normalization of reports;
			<ul style="list-style-type: none"> ➤ Preparing recommendation summary tables containing source recommendations and the result of recommendation categorization and integration ➤ Reaching consensus through a panel discussion, and a further selection of recommendations based on its appropriateness to be presented to a patient 	<ul style="list-style-type: none"> ➤ Detailing the recommendations by including other information stemming from the source evidence or from new searching evidence, with the guidance of three principles ^e ➤ Reaching consensus through a panel discussion 	<ul style="list-style-type: none"> ➤ Quality appraisal using AGREE II
TUCM team [25]	<ul style="list-style-type: none"> ➤ Identifying questions based on interviews with patients; ➤ Questions prioritization by stakeholders; ➤ Comprehensive searching for CPGs; 	<ul style="list-style-type: none"> ➤ Source CPG quality assessment using AGREE II, then a <i>de novo</i> development started if the GPG is of low quality, with comprehensive searching for SRs ➤ Assessment of recommendations, and a <i>de novo</i> development started when the existing recommendations can't answer some questions, with comprehensive searching for SRs ➤ SRs appraisal using AMSTAR 	<ul style="list-style-type: none"> ➤ Summarize the recommendations from source CPGs and prepare a matrix containing question, recommendations, and supporting evidence ➤ Reaching consensus of the recommendations by the panel 	<ul style="list-style-type: none"> ➤ Drafting PVGs 	<ul style="list-style-type: none"> ➤ External review ➤ Publishing the full-text of PVG in relevant professional journals, scientific journals, popular journals and other relevant mass media
FU-EB N team	<ul style="list-style-type: none"> ➤ Identifying questions based on an interview 	<ul style="list-style-type: none"> ➤ Selection of source CPGs matched by criteria ^c 	<ul style="list-style-type: none"> ➤ Recommendation integration: dealing with two or more 	<ul style="list-style-type: none"> ➤ Drafting PVGs based on the readability of the content, 	<ul style="list-style-type: none"> ➤ Reviewing the readability and feasibility for patients;

[23]	<p>with patients and health professionals;</p> <ul style="list-style-type: none"> ➤ Questions prioritization by stakeholders using modern multidimensional scaling; ➤ Comprehensive searching of CPGs 	<ul style="list-style-type: none"> ➤ Source CPG quality assessment using AGREE II ➤ Selection of recommendations relevant to the questions ➤ Source evidence review and searching for new SRs (e.g., when the evidence base is outdated. ➤ SRs appraisal using AMSTAR ➤ Preparing a matrix containing recommendations, and supporting evidence 	<p>relevant recommendations</p> <ul style="list-style-type: none"> ➤ Identifying patients' needs for the selected recommendations ➤ Preparing health questions-source recommendation (strength) - sources of evidence(quality)- patients' acceptance frameworks ➤ Formulating recommendations through consensus or voting 	<p>actionability of the practices, understandability with graphics in format</p>	<ul style="list-style-type: none"> ➤ External review with AGREE II ➤ Finalizing and dissemination through professional journals, WeChat platforms, websites, maternity brochures ➤ Updating
GICM RC team [17, 19-21]	<ul style="list-style-type: none"> ➤ Identifying questions based on existing CPGs, empirical research, interview with patients and health professionals ➤ Questions prioritization by the survey on patients ➤ Comprehensive searching for CPGs 	<ul style="list-style-type: none"> ➤ Assessment of CPGs (then a <i>de novo</i> development started without providing reasons, with comprehensive searching for SRs and primary evidence) ➤ SRs appraisal using AMSTAR ➤ RCT appraisal using ROB ➤ Observational studies appraisal using NOS ➤ Diagnostic studies appraisal using QUADAS-2 	<ul style="list-style-type: none"> ➤ Preparing GRADE Evidence to Decisions frameworks ➤ Reviewing GRADE Evidence to Decisions frameworks by the expert panel ➤ Formulating recommendations by evidence evaluation and synthesis group 	<ul style="list-style-type: none"> ➤ Drafting PVGs 	<ul style="list-style-type: none"> ➤ Reviewing the recommendations by experts using Delphi method
LZU team [24]	<ul style="list-style-type: none"> ➤ Identifying questions based on existing CPGs, empirical research, 	<ul style="list-style-type: none"> ➤ Source CPG quality assessment using AGREE II (then a <i>de novo</i> development started without 	<ul style="list-style-type: none"> ➤ Preparing evidence summary tables for each question containing the type of study 	<ul style="list-style-type: none"> ➤ Users (patients) test of the understandability of recommendations 	<ul style="list-style-type: none"> ➤ External review ➤ Reviewing and approval by the expert committee

	<p>interviewing with patients and health professionals</p> <ul style="list-style-type: none"> ➤ Questions prioritization by the patient and public group ➤ Turning all the questions into PICO format ➤ Comprehensive searching for CPGs, SRs and primary evidence based on the PICO questions 	<p>giving reasons, comprehensive searching for SRs and primary evidence)</p> <ul style="list-style-type: none"> ➤ SRs appraisal using AMSTAR ➤ RCT appraisal using ROB ➤ Cohort and case-control studies appraisal using NOS ➤ Case series and case reports appraisal using IHE ➤ Evidence quality grading using GRADE 	<p>and quality of evidence</p> <ul style="list-style-type: none"> ➤ Formulating recommendations based on GRADE approach ➤ Reaching consensus by experts using Delphi method 	<ul style="list-style-type: none"> ➤ Drafting PVGs 	<ul style="list-style-type: none"> ➤ Finalizing and dissemination through academic conferences, professional journals, Medical websites, popular science platforms, websites, brochures ➤ Updating
PSCM A team [22]	<ul style="list-style-type: none"> ➤ Based on the previous developed CPG's priority topics ➤ Translation of the previous developed CPG to PVG 	<ul style="list-style-type: none"> ➤ No assessment of source materials 	<ul style="list-style-type: none"> ➤ Not available 	<ul style="list-style-type: none"> ➤ Drafting PVGs with guiding principle of understandability and scientificity 	<ul style="list-style-type: none"> ➤ User-testing PVG to ensure its understandability through focus group ➤ Revision of the PVG according to users' comments and suggestions
CPAFS MC team [18]	<ul style="list-style-type: none"> ➤ Identifying questions based on empirical research, interview with health professionals ➤ Questions prioritization by the survey on 	<ul style="list-style-type: none"> ➤ Source CPG quality assessment using AGREE II, and a <i>de novo</i> development started without giving reasons, comprehensive searching for SRs and primary evidence) 	<ul style="list-style-type: none"> ➤ Preparing evidence summary tables based on GRADE Evidence to Decisions frameworks ➤ Formulating recommendations based on GRADE approach 	<ul style="list-style-type: none"> ➤ Drafting PVGs 	<ul style="list-style-type: none"> ➤ Updating

	patients	➤ SRs appraisal using AMSTAR	➤ Reaching consensus by experts using delphi method		
	➤ Comprehensive searching for CPGs	➤ RCT appraisal using ROB			
		➤ Cohort and case-control studies appraisal using NOS			
		➤ Case series and case reports appraisal using IHE			
NCAIT WM-ID B team [26]	➤ Identifying questions based on interviews with patients and health professionals	➤ Assessment of CPGs, and a <i>de novo</i> development started without giving reasons, with comprehensive searching for SRs	➤ Preparing evidence summary tables based on GRADE Evidence to Decisions frameworks	➤ Drafting PVGs by including Literary and Fine Arts professionals	➤ Approval
	➤ Comprehensive searching for CPG;	➤ Assessment of SRs using AMSTAR and updating SRs (eg, when the existing SRs is not within 2 years)	➤ Formulating recommendations based on GRADE approach		➤ Publishing
			➤ Reaching consensus by experts using delphi method		➤ Dissemination and evaluation
					➤ Updating

CPGs, clinical practice guidelines; AGREE II, Appraisal of Guidelines for Research & Evaluation II; GRADE, Grading of Recommendations, Assessment, Development and Evaluations; SR, systematic review; ROB: Risk of Bias NOS: Newcastle-Ottawa Scale IHE: Institute of Health Economics PICO: population, intervention, comparison, outcome QUADAS-2: Quality Assessment of Diagnostic Accuracy Studies

^a Selection criteria for source CPGs: 1.relevance to the topics; 2.published within ten years;3. information is complete, including name, table of contents, introduction, content, recommendation; 4. writing in Chinese and English; 5.the latest version for revised guidelines

^b Selection criteria for source CPGs: 1. relevance to the topics; 2.published since the last search of the adapted CPG; 3.information is complete, including name, table of contents, introduction, content, recommendation; 4.writing in Chinese and English; 5.the latest version for revised guidelines

^c Selection criteria for source CPGs: 1. relevance to the topics; 2.published within five years; 3. information is complete, including development process, recommendation, the strength of recommendation and references

^d Principle of recommendation integration: 1. Consistency of recommendations: for the same recommendation, the most concise statement is used to summarize the

recommendation, followed by the source of the guideline, quality of evidence rating, and/or strength of recommendation for all recommendations.

2. Complementary recommendations: if the recommendations are complementary to each other for the same intervention or care, they are combined into a single recommendation based on logical linguistic relationships and followed by the guideline source, quality of evidence rating, and/or strength of recommendation.

3. Conflicting recommendations: retain the original recommendation, trace the source of evidence of the corresponding recommendation, explore the reasons for conflicting recommendations, and present the source of the guideline, year of publication, source of original evidence, quality rating of evidence and/or strength of recommendation to the panel.

° Principle of detailing the recommendations: 1. The chapters are set up reasonably: ① the detailed content is well-defined and clearly thought out; ② the detailed content is rigorous and complete, The sequence is properly arranged; ③ the transition of the detailed chapters is natural and well-connected.

2. Clinical significance: ①The refined guideline content can improve the topic-related knowledge of patients; ②The refined guideline content will not lead to adverse experiences of patients.

Table 4 Reporting of the patient version of guidelines

	Huang YF	Qiu ML	Fang LK	Xie 2020	YMa 2016	JY Wang RX	Liu EM	Y e 2021	CQ 2021
RIGHT for PVG checklist	[20]	[19]	2020	[21]	[12]	[11]	[22]	[18]	
			[17]						
1.1 Identify the document as a guideline version for patients and the public.	P	P	P	P	F	F	F	P	
1.2 Specify the topic (e.g., condition, technique, or medication) addressed in the PVG.	F	F	F	F	F	F	F	F	
1.3 Specify the publication year and the version (if applicable) (e.g., first version, second version) of the PVG in the title, cover page, or copyright statement.	P	P	P	P	P	P	P	P	

2.1 Provide contact information of the developers of the PVG (e.g., affiliations, website, or address, phone number, or email address).	F	F	F	F	P	N	F	F
3.1 Provide a summary of the PVG, including the main recommendations.	N	N	N	N	N	NA	N	N
4.1 Introduce the target condition, including (as relevant) the definition, risk factors, signs, subtypes, complications, staging (progress), and epidemiology.	F	F	F	F	F	F	F	F
4.2 Introduce the management, preventive, diagnostic, and other options.	F	F	F	F	F	F	F	F
5.1 Describe the scope, purpose, intended use, and users of the PVG.	F	N	F	F	F	F	F	F
6.1 Provide a reference or link to the source evidence, e.g., source guideline of the PVG, where the methods of the source guideline (e.g., the evidence review and recommendation development process) can be found. ^a	F	F	F	F	N	F	F	F
7.1 Include for each recommendation: a) the target populations or conditions, b) the recommended treatment or management option (e.g., prevention plan, diagnostic strategy, or rehabilitation), c) potential benefits and harms, especially those that are patients important, and d) the specific settings where the options are recommended to be implemented	F	F	F	F	P	NA	F	F
7.2 Describe what options, if any, are available to deal with undesirable outcomes.	F	F	F	F	F	F	F	F
7.3 Describe the self-management options if any are reported in the source guideline ^b .	F	F	F	F	F	F	F	F
8.1 Provide a clear and simple explanation of the meaning of terms related to the strength of recommendations and quality of the evidence (e.g., by using commonly understood symbols).	P	N	P	P	N	NA	F	P
9.1 Suggest a list of questions for patients to ask their healthcare providers if relevant.	N	N	N	N	N	F	N	N
10.1 Provide a list of terms and abbreviations used in the PVG.	N	N	N	N	N	N	N	N
11.1 Describe the funding source(s) of the PVG and the source guideline and their roles or any influences, in the PVG or guideline development processes, respectively.	N	N	N	N	N	P	P	P

12.1 Report the conflicts of interests of contributors to the PVG and the source guideline in a format that the patients and the public can understand, and how they were managed.

F F F N F F F

PVG: Patient versions of guidelines; F: Full compliance; N: No compliance; P: Partial compliance; NA: Not applicable

^a: We modified the item “6.1 Provide a reference or link to source guideline of the PVG, where the methods of the source guideline (e.g., the evidence review and recommendation development process) can be found,” as many PVGs are develop from *de novo* development, so we changed “the source guideline of the PVG” to “ the source evidence, e.g., source guideline of the PVG”

^b: We modified the item “7.3 Describe the self-management options if any are reported in the source guideline.” As it is difficult to identify if the source guideline reported self-management options, we deleted the condition “if any are reported in the source guideline.”

4. Discussion and Conclusion

4.1 Discussion

4.1.1 Summary of the main findings

This study identified 26 PVGs developed by 16 PVG-working teams. In total, nine PVGs were completed, of which eight had full-texts available. Furthermore, four PVGs were protocols while 14 PVGs only consisted of registration information. We underscored current practices for PVG development and the reporting of PVGs produced by diverse groups in Chinese mainland. Furthermore, we identified various practices described by PVG teams and structured these into six steps, namely, (1) team, (2) selection of the scope and source CPG(s), (3) assessment of source materials (i.e., an assessment at the guideline, recommendation, and evidence levels), (4) decision-making process, (5) content and format, and (6) optimization of PVG and follow-up. Most PVGs teams that did not include source CPG members conducted a comprehensive search after defining or identifying the topic, scope, and key questions. To ensure the quality of PVGs and the integrity and accuracy of the content between the CPG and PVG, PVG developers included a rigorous decision-making process for PVG recommendations.

4.1.2 Comparison with previous studies

The findings suggest that most PVG developers in Chinese mainland formulated PVGs by translating them from both CPGs and *de novo* development. However, according to GIN public guidance and MC-PCG, PVGs are translated versions of CPGs. Thus, PVGs derived from *de novo* development may constitute a CPG as opposed to a PVG. In addition, one PVG [11] was defined as a PVG that included the GIN definition for it, despite not providing any recommendations in the PVG full-text. However, a PVG without any recommendations is considered a general health document rather than a PVG according to the conceptual framework for patient-directed knowledge tools developed by Dunja et al. [28]. Therefore, this result indicates a lack of PVG knowledge among developers as there may be

misunderstandings about the concept of PVGs owing to its early development in Chinese mainland and other countries, such as the Netherlands [29]. Fortunately, the conceptual framework for patient-directed knowledge tools [28] can be used to enhance the understanding of the PVG criteria, its purpose, and core elements among developers and users to facilitate the appropriate development and application of PVGs.

The GIN public guidance which was followed for the development of all the Chinese PVGs, provided a process for developing a PVG from one CPG. However, using only one CPG as a basis for PVG may be limited in addressing patients' needs, particularly because CPGs are primarily developed for health professionals. Therefore, van der Weijden [7] suggested that the content of PVGs should combine the subject of CPGs with the patients' information needs. Ultimately, multiple CPGs or other sources of information ought to be integrated and translated into a single PVG, as this process will address the desires and perceptions of target users more effectively. Thus, this could explain why only two PVGs [12, 22] were developed based on the CPG previously developed by the source CPG-working group, as GIN suggested. Furthermore, all the other teams conducted a comprehensive search for CPGs after defining or identifying the scope. Thereafter, they supplemented the CPGs with new evidence after assessing the source CPG. Thus, this indicates that more development processes are required for PVGs, such as addressing two or more relevant recommendations. However, there is currently a lack of guidance regarding developing PVGs based on multiple guidelines. Consequently, various practices have been described by different PVG teams. For example, some PVG development teams adapt (with modifications in the recommendation) or adopt (without modifications) source recommendations. However, some PVG teams formulated new recommendations based on the source recommendations. Moreover, the current review also highlighted that some PVGs used AGREE-II as a quality criterion. However, the process of defining the quality of PVGs differs from that of CPGs based on their varying target audiences and development processes. Therefore, a comprehensive methodological guide is required for the development of PVG.

The appraisal of these PVGs with the RIGHT-PVG tool revealed that the reporting of PVGs developed in Chinese mainland requires significant improvement. Specifically, several items were poorly reported (e.g., a summary of the PVG, including the main recommendations, a list of terms and abbreviations used in the PVG, funding source(s) and role(s) of the funder, and explanations of the meaning of terms related to the strength of recommendations and quality of the evidence). These factors help people to assess the trustworthiness of a PVG. Furthermore, the factors comprise important facilitators to enable PVG uptake and implementation. As this is a guideline for patients, a “friendly” clear tone should be presented, which can be achieved using color, quotes, icons, simple language, charts, and brief chunked text [30]. However, this was only implemented by two PVGs. Therefore, an increased focus should be placed on these aspects in future PVG reports. Furthermore, most (6/8, 75%) PVGs were published in professional journals. Thus, it was difficult to identify the guideline document for patients and the public. Consequently, this may be difficult for users to find and might hinder the uptake and implementation of PVGs. Two PVGs underscored the process of dissemination. However, the full-text will only be accessible after 5 to 6 years, which indicates their poor dissemination [25, 26].

4.1.3 Strength and limitations

To the best of our knowledge, this is the first review of PVGs developed in Chinese mainland. Our study summarizes the current practices in PVG development applied by various teams nationwide. We structured the development process into six steps, including a three-level source material assessment (i.e., guideline, recommendation, and evidence level). Thereafter, we compared PVGs with RIGHT-PVG tools and extended the evidence on how to formulate PVGs as well as the gaps that need to be bridged to develop better PVGs in the Chinese mainland. However, this review has several limitations which have been acknowledged. First, despite searching multiple databases and platforms for PVGs, we experienced several challenges finding every PVG on the Chinese mainland. For instance, potentially

eligible PVGs might have been overlooked for inclusion because some PVGs were only developed for patients in a specific hospital rather than for the public. Second, documentation and dissemination plans were required to provide a larger publicly accessible database of Chinese PVGs. Consequently, certain crucial PVG development processes could not be extracted and summarized because of incomplete reporting. For example, we could not find information on whether and where the patients were trained or educated when PVG teams started *de novo* development of PVG as well as how some PVG teams addressed the source recommendations. Finally, the RIGHT-PVG tool consists of a broad range of assessments for the individual PVG components without detailed assessment guidelines. Thus, this might have led to subjective estimation during the assessment process.

4.2 Conclusions

PVG is still in its early stages of development in Chinese mainland with a relatively small number of PVGs developed. Seemingly, the understanding of PVG, CPG, and health education materials is limited among PVG developers. Furthermore, the processes used to develop PVGs were not uniform. Instead, various development practices and methods were described by different PVG teams across the Chinese mainland. Moreover, the PVGs provided adequate reporting of several RIGHT-PVG items. However, significant improvement is required for insufficiently reported areas to help people assess the reliability of a PVG and facilitate its uptake and implementation as the dissemination of PVGs is poor in Chinese mainland.

4.3 Practical implications

To facilitate the development and uptake of PVGs that can address the needs and perceptions of the target users, comprehensive methodological guidance is pertinent to enhance PVG development based on one or multiple CPGs and other source information. The findings of this review also emphasize the need for documentation and dissemination plans to provide a larger database of PVGs that is publicly accessible. Moreover, a clear and robust distinction should be made between PVGs,

CPGs, and general health materials.

Abbreviations

CNKI: China National Knowledge Infrastructure; VIP: China Science Technology Journal Database; GRADE: Grading of Recommendations Assessment, Development and Evaluation criteria; GIN: Guidelines International Network; CPG: Clinical practice guidelines; PVG: Patient versions of guideline; MC-PCG: Minimum criteria for the development process, content, and governance of PVGs; RIGHT-PVG: Reporting Checklist for Public Versions of Guidelines; SR: Systematic Review; NICE: National Institute for Health and Care Excellence; SIGN: Scottish Intercollegiate Guidelines Network

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Availability of data and materials

All data generated or analyzed during this study are included in this published article.

Ethics approval and consent to participate

Not applicable.

Consent for publication

Not applicable.

Competing interests

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest

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