**A Proposal of** **Reporting Items for Patient/Public Version of Guidelines: RIGHT-PVG**

**Abstract**

**Background:** Public (including patients) Versions of Guidelines (PVGs) can help with individual decision making and enhance the patient-clinician relationship by providing friendly and reliable information. An increasing number of guideline organizations are developing the Public (including patients) Versions of Guidelines (PVGs). However, the reporting of PVGs by different groups and organizations varies widely. This study aims to develop reporting checklists for PVGs for healthcare.

**Methods:**

We will develop the PVG reporting checklists as an extension of the Reporting Tool for Practice Guidelines in Health Care (RIGHT) statement. The study design will refer to the methods recommended by the EQUATOR Network, and will be modified as appropriate. We will conduct a literature review, establish an international multidisciplinary team, run a modified Delphi process to identify the reporting items, and pilot test the draft reporting checklists. We plan an update every three years.

**Discussion:**

The RIGHT Working Group has approved the development of the RIGHT-PVGs. The RIGHT for PVGs will directly address what and how information should be reported in PVGs, thus to promote the utility and readability.

**Keywords:** Patient version of guidelines, Reporting, RIGHT

**Background**

Informed by a systematic review of evidence and an assessment of the benefits and harms of alternative care options, clinical practice guidelines (CPGs) include recommendations aimed at optimizing the care[1,2]. These guidelines could support shared decision-making and help patients participate actively in their care. However, CPGs can be challenging for the public (including patients) to understand. Therefore, guideline-derived materials tailored for the public would be essential to inform their health care decisions. Also, patients prefer that health professionals to share written materials with them [3].

Patients are increasingly using the internet for health related information with unclear reliability, and professionals should guide the patient to find reliable and accurate information [4]. Patient version of guidelines (PVGs) are “*documents that ‘translate’ guideline recommendations and their rationales originally produced for health professionals into a form that is more easily understood and used by patients and the public*” [5]. Concise and easy understanding, PVG, on the one hand, is one way to provide reliable information to patients, and can help with individual decision making and enhance patient-clinician relationship. On the other hand, PVG may also help people to be more reassured and confident about their care[5].

Many guideline producing bodies develop PVGs. For example, the National Institute for Health and Care Excellence (NICE), the Scottish Intercollegiate Guidelines Network (SIGN), the American Academy of Neurology (AAN), the National Comprehensive Cancer Network (NCCN), the US Preventive Services Task Force and Netherlands Association of Posttraumatic Dystrophy all produce PVGs which are freely available[6-10]. Whereas, patients also valued the creation of PVGs [11].

From 2011 to 2015, GRADE Working Group in its DECIDE project worked with members of the public, patients, carers, specialists in health information communication, journalists, and guideline developers worked on this topic. The group aimed to identify what the public knew about guidelines, what they were expecting from PVGs, and how information in PVGs should be presented. Most of the work from DECIDE was summarized in the G-I-N Public Toolkit, including the methodological process [12,13], and the European Commission Initiative on Breast Cancer (ECIBC) have already implemented patient versions[14]. In spite of all these initiatives, we could not identify systematic checklists for PVG reporting, and the content, language style and structure of PVGs from different organizations varied remarkably[15]. An interview of guideline developers, shared decision making experts and patient representatives showed a significant concern about the structure and language for PVGs[16], and patients also prefer guidelines with concise content, non-technical language.

The Reporting Tool for Practice Guidelines in Health Care (RIGHT) Working Group recently developed and published its reporting checklists for practice guidelines [17]. Such reporting checklists can promote transparent and rigorous reporting. PVGs would necessitate its own reporting checklists, as they differ from practice guidelines for professionals with respect to target audience, aims, scope, and especially the wording and reporting style[5,18]. Such checklists are particularly needed because PVGs from different groups and organizations vary considerately in terms of style and content [15]. Proper reporting checklists may improve the overall quality of PVGs, thus promote their utility and effectiveness especially for communication between patients and practitioners.

**Aims**

1. To identify and describe currently published literature on the reporting of patient versions of guidelines.
2. To develop essential reporting items for patient versions of guidelines for healthcare.
3. To identify the characteristics of high-quality PVGs.

**Methods**

We designed our study referred to the methods recommended by the EQUATOR Network, and we will also make some modification as appropriate[19]. Table 1 shows the different tasks with our proposed timeline.

**Table 1 Recommended steps and project timeline**

|  |  |  |  |
| --- | --- | --- | --- |
|  |  Steps | Tasks | Timeline |
| Stage 1 | 1 | Identify the need for guideline  | Apr 2017 |
| 2 | Review the literature  | May 2017 |
| 3 | Obtain funding for the guideline initiative  | May 2017 |
| 4 | Identify the participants  | May to Aug 2017 |
| 5 | Generate a list of items for consideration at Delphi process  | Jul to Oct 2017 |
| 6 | Run a modified Delphi process [20]  | Nov 2017 to Mar 2018 |
| 7 | Present and discuss results of the Delphi process (teleconference)  | Apr 2018 |
| 8 | Draft the checklist  | Apr 2018 |
| 9 | Pilot test the checklist  | May to July 2018 |
| 10 | Develop the guidance statement and publication strategy  | Jul 2018 |
| 11 | Develop an Explanation and Elaboration (E&E) document | Aug 2018 |
| 12 | Seek feedback and revise as appropriate | Sep to Oct 2018 |
| 13 | Work on guideline endorsement and adherence  | Nov to Dec 2018 |
| 14 | Develop a website for the guideline  | Jan to Feb 2019 |
| Stage 2 | 15 | Translate and adapt the guideline | Mar 2019 on |
| 16 | Evaluation of PVGs developed using RIGHT-PVG | From 2020 on |
| 17 | Update the guideline | Every 3 years |

**1. Identify the need for checklists**

We have described the need for the checklists in the Background section. We will also conduct a survey of relevant stakeholders to reflect their recognition and opinions about PVGs.

**2.** **Review the literature**

Aiming at identifying any existing guidance for reporting PVGs, we have conducted a pilot review for literatures on the standards of reporting of guidelines and other related methodological articles, especially in relation to checklist items of standard reporting of PVG. For PVG is really different from clinical guideline, we will refer to “Chapter 7: How to develop patient versions of guidelines” in GIN Public Toolkit as well as RIGHT statement as a framework to collect all the possible items [5]. In addition to searching for existing PVG guidance, we also searched studies on PVG for to identify possible items, including studies of patients’ information needs surrounding guidelines, and any studies that evaluate patients’ perceptions and experiences of PVGs. During the process of collecting evidence and items, we will also consider to come up with the conceptual framework for the reporting checklist.

For studies on PVGs, we searched Medline on 10th Aug. 2017 with following strategy (see box 2): (“shared decision making” [Title/Abstract] AND guideline\*[Title/Abstract] AND Humans[Mesh]) OR (“guide\* for patient”[Title/Abstract] AND Humans[Mesh]) OR (“patient guide\*”[Title/Abstract] AND Humans[Mesh]) OR (“patient version\*”[Title/Abstract] AND “guideline\*”[Title/Abstract] AND Humans[Mesh]). In addition, we searched Google and screened the reference lists of relevant articles to check for possible relevant studies. (see box 2)

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| **Box 2. Search strategy of researches studying PVG** |
| 1. “shared decision making”[Title/Abstract]
2. “patient version\*”[Title/Abstract]
3. “public version\*”[Title/Abstract]
4. “version\* for patient”[Title/Abstract]
5. “version\* for the public”[Title/Abstract]
6. #1 or #2 or #3 or #4 or #5
7. “guideline\*”[Title/Abstract]
8. #6 and #7
9. “guide\* for patient”[Title/Abstract]
10. “guide\* for the public”[Title/Abstract]
11. “patient guide\*”[Title/Abstract]
12. “public guide\*”[Title/Abstract]
13. #8 or #9 or #10 or #11 or #12
14. Humans[Mesh]
15. (#8 or #13) and #14
 |

Our Medline searched identified 432 citations, of which we judged 4 papers as relevant. In addition, we identified another 8 relevant articles through the Google and the screening of the reference lists [3,5,10,16,21-28] (table 2). For there may be researches exploring the reporting of other patient tools which is similar to PVG, we also will conduct further search for them.

**Table 2 Literatures relevant to PVGs**

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| --- | --- | --- |
| Title | Author, year | Journal |
| 1. Dissemination of clinical practice guidelines: A content analysis of patient versions [21]
 | Santesso N, 2016 | Med Decis Making. |
| 1. What do patients and the public know about clinical practice guidelines and what do they want from them? A qualitative study[22]
 | Fearns NJ, 2016 | BMC Health Serv Res  |
| 1. Improving the user experience of patient versions of clinical guidelines: user testing of a Scottish Intercollegiate Guideline Network (SIGN) patient version. [23]
 | Fearns NJ, 2016 | BMC Health Serv Res  |
| 1. Patients, health information, and guidelines: A focus-group study[3]
 | Liira H, 2015 | Scand J Prim Health Care |
| 1. Trustworthy guidelines–excellent; customized care tools–even better[24]
 | Elwyn G, 2015 | BMC medicine |
| 1. Patients, health information, and guidelines: A focus-group study[25]
 | Liira H, 2015 | Scand J Prim Health Care |
| 1. About the G-I-N PUBLIC Toolkit: Patient and Public Involvement in Guidelines.[5]
 | GIN, 2015 | GIN website  |
| 1. Patient and public attitudes to and awareness of clinical practice guidelines: a systematic review with thematic and narrative syntheses[10]
 | Loudon K, 2014 | BMC Health Serv Res |
| 1. How can clinical practice guidelines be adapted to facilitate shared decision making? A qualitative key-informant study. [16]
 | van der Weijden, 2013 | BMJ Qual Saf |
| 1. Attitudes of women with menstrual disorders to the use of clinical guidelines in their care[26]
 | Sophia Julian, 2010 | Family Practice |
| 1. Communicating evidence for participatory decision making. [27]
 | Epstein RM, 20014 | JAMA |
| 1. Communicating dietary guidelines for Americans: room for improvement [28]
 | Geiger CJ, 2001 | J Am Diet Assoc |

To find out additional items, we will analyze the content and reporting style of the current PVGs. We investigated which organizations are developing patient versions of guidelines through checking their website and from Santesso N et al’ article [21], and reviewed their published guidelines. By April 2017, we had identified 22 organizations or groups (see box 1). If the same organization had developed multiple PVGs using the same methodology and reporting style, we selected two to three of these PVGs to analyze their reporting characteristics.

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| **Box 1. Organizations developed PVGs** |
| 1. American Academy of Neurology (AAN)
2. American College of Physicians (ACP)
3. American Cancer Society (ACS)
4. American Gastroenterological Association (AGA)
5. American College of Gastroenterology (ACG)
6. American Society of Clinical Oncology (ASCO)
7. American Urological Association, Urology Care Foundation
8. Australia and New Zealand Stillbirth Alliance
9. British Columbia Medical Association (BCMA)
10. European Society for Medical Oncology (ESMO)
11. National Comprehensive Cancer Network (NCCN)
12. National Institute for Health and Clinical Excellence (NICE)
13. Queensland Government，
14. Royal College of Obstetricians & Gynaecologists (RCOG)
15. Scottish Intercollegiate Guidelines Network (SIGN)
16. The Endocrine Society
17. US Preventive Services Task Force
18. Association of Breast Surgery (ABS)
19. Cancer Council (CC)
20. European Society of Human Reproduction and Embryology (ESHRE)
21. Urology Care Foundation
22. Canadian Diabetes Association
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**3. Obtain funding**

This project is funded by the Open Fund of Key Laboratory of Evidence Based Medicine and Knowledge Translation of Gansu Province, Lanzhou, China. This project is also supported by two National Natural Science Foundation of China program (The development of evidence grading system for Chinese Integrative Medicine, ID: 81503459; The exploration of critical techniques in guideline development of Chinese Integrative Medicine, ID: 81673825)

**4. Identify participants**

The RIGHT PVG Working Group consist of three subgroups: the reporting items development group (RID group), the Delphi panelists group (DEP group), and the secretariat. Our secretariats now include: Xiaoqin Wang (Lanzhou University), Liang Yao (The People's Hospital of Gansu Province), Long Ge (Lanzhou University), Qi Wang (Macmaster University), Li Jiang (Peking University First Hospital), Xiaojia Ni (Guangdong Provincial Hospital of Traditional Chinese Medicine), and Ružica Tokalić (University of Split School of Medicine), Yanfang Ma (Lanzhou University), Qi Zhou(Lanzhou University), Shujun Xiao (Lanzhou University). The secretariats are in charge of contacting experts, collating documents and email information, arranging teleconference and recording minutes of the meeting.

**4.1 Reporting items development Group (RID group)**

* Role
* To draft the proposal
* To draft the items
* To design questionnaires
* To organize Delphi panels
* To email panelists and collect and analyze the data
* To draft the final report
* RID team members:
* Yaolong Chen, WHO Collaborating Centre for Guideline Implementation and Knowledge Translation；Chinese GRADE Center, Lanzhou, China;
* Xiaoqin Wang, WHO Collaborating Centre for Guideline Implementation and Knowledge Translation；Chinese GRADE Center, Lanzhou, China;
* Kehu Yang, WHO Collaborating Centre for Guideline Implementation and Knowledge Translation；Chinese GRADE Center, Lanzhou, China;
* Liang Yao, WHO Collaborating Centre for Guideline Implementation and Knowledge Translation；Chinese GRADE Center, Lanzhou, China;
* Qi Wang, Health Policy PhD program at McMaster University, Canada;
* Long Ge, WHO Collaborating Centre for Guideline Implementation and Knowledge Translation；Chinese GRADE Center, Lanzhou, China;
* Li Jiang, Peking University First Hospital, Beijing, China.

**4.2 Consensus panelists group (DEP group)**

* Role
* To review the proposal and provide comments
* To contribute to the process of item selection
* To decide the number of items to be included in final guideline
* Panelists: We will invite 16-20 panelists to ensure collective research experience in the following areas: guideline development, PVG, GRADE, knowledge translation, reporting guidelines (including experts of RIGHT statement), and plain language editing. To properly reflect the opinion users of PVGs, representatives of public will also be an important part in this group and we plan to include 3~4 patients in our panel. Literature on what patients want and need from PVG will also be explored as complementary of what patients want. We will consider language, gender equality and wide geographic representation when selecting panelists. The list of the invited experts can be found in appendix.

**5 Generate a list of items for consideration**

We will generate the initial list of items based on the review of literature (see step 2) together with analysis of current patient version of guidelines.

**6 Modified Delphi Consensus**

We will conduct three rounds of modified Delphi survey [20, 29] to achieve consensus and use and use a 7-point scale for expressing agreement for the reporting item (see box 3). We will use SurveyMonkey® (https://www.surveymonkey.com/) as the survey tool. The scale and definitions of agreement and consensus can be found in box 3 and box 4. The process is described below.

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| **Box 3. The 7-point likert scale** |
| 1265437extremely importantnot important at alllow importanceslightly importantneutralmoderately importantvery important  |

Note:

Not important at all: you are confident that the item should be excluded.

Extremely important: you are confident that the item should be included in the final checklist.

1~7: the importance increase in sequence

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| **Box 4. Definition of consensus** |
| Definition of agreement with an item | when 75% or more of participants choose 6-7 |
| Definition of disagreement with an item | when 75% or more of participants choose 1-2 |
| Definition of ambivalence towards an item | when 75% or more of participants choose 3-5 |
| Definition of no consensus within the group | All other types of responses |
| Analysis of responses* Items with agreement are included in the final version and removed from subsequent rounds.
* Items with disagreement are removed.
* Items which are rated as ambivalent or where there is no consensus will be modified to reflect points raised by the Reporting items development Group and included in the next Delphi round.
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| **Box 5. Organizing the Delphi process** |
| **Questionnaire design**To generate a list of items for consideration based on results of the literature review and analysis of current patient version of guidelines.**First round:**The following will be sent by email to the 16-20 panelists:* An introductory letter and background material including current data and research about proposed items
* The link to the online questionnaire
* A reminder letter, and a subsequent telephone call will be made to non-responders after one week.

**Second round:**The following will be sent by email to panelists:* Thank you letter and instructions
* Feedback from panelists and the RID group
* The link to the online questionnaire including items on which consensus was not reached
* A reminder letter, and a subsequent telephone call will be made to non-responders after one week.

**Third round:**The following will be sent by email to t panelists:* Thank you letter and instructions
* Feedback from panelists and RID group
* The link of online questionnaire including items on which consensus was not reached
* A reminder letter, and a subsequent telephone call will be made to non-responders after one week.
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Note:

1. Only complete questionnaire would be included in the analysis.
2. The Delphi questionnaire is considered valid if the response rate is over 80% in every round.

During the first round, the panelists have the opportunity to suggest items that were not included in the initial checklist. Panelists will not be asked to comment on the reasons for including or excluding items after the first round process. The responses will be analyzed anonymously by a biostatistician who is not a member of the panel and who will be blinded to the identities of panel members.

**7 Present and discuss results of the Delphi process (teleconference)**We will have an online teleconference including representatives of the RID and DEP groups to present and discuss the results of the Delphi process.

**8 Draft the final checklist**

Based on the results of Delphi surveys and teleconference, we will draft the final checklist, and send it to the representatives of the RID and DEP groups to ensure the accuracy and correctness.

**9 Validation and pilot test**

We will validate the checklist through assessment of the randomly selected one PVG from each organization (i.e. 22 PVGs). Two researchers will apply the checklist to these PVGs to rate how well each item was reported (not reported, partially reported, adequately reported, or not applicable). Researchers will also be asked to provide comments, and feedbacks on the ease of use for each item, the completeness and wording for the whole checklist. In addition, the checklist will be tested in two to four PVGs and feedback of developers’ experience will also be sought. For the further evaluation, the end users (e.g. patients) of these PVGs will also be asked to give their feedbacks through a survey, so that the practicability and rationality could be reflected. The comments and feedbacks will be used to revise the RIGHT-PVG appropriately.

**10 Develop the guidance statement and publication strategy**

Based on the pilot and feedback, we will draft the guidance statement and submit it for publication in a peer-reviewed journal.

**11 Develop an explanatory document (E&E)**

We will develop a detailed justification and explanation document for the essential reporting items of to inform and educate users and facilitate the implementation.

**12 Seek and deal with feedback and revise as appropriate**We will seek feedback from all stakeholders to help guide revision of the next version as appropriate.

**13 Encourage endorsement and adherence**

We will disseminate the statement through the following channels:

* Submit the report and checklist for potential endorsement by EQUATOR, GRADE working group, CONSORT Group, Cochrane Collaboration, International Society for Evidence-Based Health Care, G-I-N and other relevant networks.
* Send the statement to interested guideline developers around world

**14 Develop a website for the checklists**

As a key implementation strategy, we will create a website for RIGHT for PVG. The checklist will be made available at the website. To promote the friendly use, we will also link the web site with the EQUATOR Network [30].

**15 Translate and adapt checklists**

We will translate the checklist and checklists into different languages. We will welcome and collaborate with other guideline developers who want to translate or adapt this tool to other types of guidelines.

**16 Evaluation of PVGs developed using RIGHT-PVG**

After releasing this reporting checklists, the use and effect of RIGHT-PVG will be monitored and evaluated continuously in stage 2. The reporting quality of PVGs will be assessed with RIGHT-PVG, and a formal user testing of PVGs will be conducted through surveys or trials, which both will help to find out the gap between the current reporting items and practice, thus help with the update of the next version.

**17 Update checklists**

We will review the reporting checklists every 3 years, revising it as indicated, taking into account feedback on the checklist as well as new information and publications in the scientific literature.

**Discussion**

RIGHT for PVGs will directly address what and how the information should be reported in PVGs. Problems of reporting can be identified through the analysis of existing PVGs from different organizations or groups. Then, combined with the literature review and feedback from stakeholders, we will collect all the items of interest. The Delphi process and direct discussion will help finalize items of most importance for reporting PVGs.

The methodology of RIGHT for PVGs will build on the experience and knowledge of the RIGHT Working Group, that has so far focused on the development and implementation of reporting in practice guidelines. RIGHT for PVGs is one of extensions of the RIGHT checklist [17] and is approved by the RIGHT Working Group.

Based on the work above, we will cooperate with guideline developers to implement RIGHT for PVGs, to evaluate the utility and to obtain feedback so that we can keep it up-to-date. Several groups of people will be able to benefit from RIGHT for PVGs, including the guideline developers, patients and the public, the journal editors, and practitioners.

**List of abbreviations**

RIGHT: Reporting Items for practice Guidelines in HealThcare

PVGs: patient version of guidelines

NICE: National Institute for Health and Care Excellence

SIGN: the Scottish Intercollegiate Guidelines Network

AAN: the American Academy of Neurology

NCCN: the National Comprehensive Cancer Network

G-I-N: Guideline International Network

E&E: Explanation and Elaboration

EQUATOR: Enhancing the QUAlity and Transparency Of health Research

GRADE: The Grading of Recommendations Assessment, Development and Evaluation

CONSORT: Consolidated Standards of Reporting Trials

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

AMSTAR: a measurement tool to assess systematic reviews

RID group: reporting items development group

DEP: Delphi panelists group

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**Appendix**

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| Name | Institution  | Research interest  |
| Amir Qaseem | American College of Physicians, USA | RIGHT, Clinical Practice Guideline Development |
| Yngve Falck-Ytter | University Hospitals Case Medical Center, USA | RIGHT, GRADE, Gastroenterology |
| Faruque Ahmed | Centers for Disease Control and Prevention, USA | RIGHT, Clinical Practice Guideline Development |
| Madelin Siedler | American Gastroenterology Association, USA | Health communication (act as public representative) |
| Holger Schunemann | Department of Health Research Methods, Evidence and Impact, Canada | RIGHT, Practice Guideline Development, GRADE |
| Nancy Santesso | Department of Health Research Methods, Evidence and Impact, Canada | Patient Version of Guideline Development, GRADE |
| Ana Marušić  | University of Split School of Medicine, Croatia EQUATOR Network, Croatia | RIGHT, Clinical Practice Guideline Development |
| Susan Norris | WHO Guidelines Review Committee, Switzerland | RIGHT, Practice Guideline Development and Review |
| Janne Estill  | Institute of Global Health, University of Geneva, Switzerland | Epidemiology, mathematical models for disease progression and transmission |
| Elie Akl | American University of Beirut Medical Centre, Lebanon | RIGHT, Public health and health policy |
| Edwin Chan Shih-Yen  | Office of Clinical Sciences, Duke-NUS Graduate Medical School, Singapore | RIGHT, Clinical decision-making |
| Claire Glenton | Cochrane Norway, Norwegian Institute of Public Health, Norway | Implementation research and systematic review |
| Joey Kwong | National Center for Child Health and Development; Cochrane Gynaecological Cancer Review Group, China | Cochrane Systematic Review  |
| Sarah Louise Barber | WHO Kobe Centre, Japan | RIGHT, economic evaluation, quality of care assessments |
| Akiko Okumura | Medical Information Network Distribution Service (MINDS) Guideline Centre, Japan | Practice guideline development |
| MYEONG SOO Lee | Korea Institute of Oriental Medicine, Korea | Systematic reviews and clinical trials |
| Suodi Zhai  | Peking University Third Hospital, China | Pharmacy Department and Clinical Practice Guideline Development |
| Hongcai Shang  | Tianjin University of Traditional Chinese Medicine, China | RIGHT, Evidence-based Chinese Medicine and PVG Development |
| Mingming Zhang | Chinese Cochrane Centre, China | Patient involvement and patient safety (act as public representative) |
| Yuanyuan Zhang | Lanzhou University, China | Humanities & social sciences, education (act as public representative) |