

Contrasting Fake News in Oncology: The First Declaration of Good Communication

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PURPOSE Nowadays, websites, online journals, and social media give access to an extraordinary amount of medical information. Misleading news are often disseminated generating false expectations, exaggerated anxiety, and confusion; in oncology setting, disinformation is perhaps more deleterious than in other fields, with a considerable impact on single patients as well as on families and, more in general, on Public Health. We aimed to promote a better interaction between the health care and the world of communication.

MATERIALS AND METHODS A regional technical table was established with the aim of drafting a shared document through the consensus conference method in the RAND/University of California Los Angeles variant, identifying strategies to overcome barriers between communication and health care as well as to propose common criteria for an effective dissemination of medical information.

RESULTS Sixteen articles met the inclusion criteria, from which 72 recommendations were drawn to the communication and health field (40 related to specific issues and 32 transversal to all the specific topics). Following an evaluation of relevance by the panel of experts, it was found that 57 recommendations scored more than 7, 13 between 4 and 6.9, and 2 below 4.

CONCLUSION This consensus and the drawn up document represent a concrete attempt to find a renewed and strategic alliance between key figures in health care and communication operators. As the American Declaration of Independence, our Declaration of Good Communication has identified high-impact recommendations for the best management of patients, providing simple but fundamental concepts and recommendations about effectiveness especially in oncology setting.

JCO Global Oncol 7:740-746. © 2021 by American Society of Clinical Oncology

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INTRODUCTION

In the ongoing fight against diseases, health care professionals ought to make use of any weapon, together with the fundamental and irreplaceable role of scientific research. A true and strong alliance between physician and patient relies on a constant and open dialogue based on humility in the common intent to overcome the disease.¹ Providing appropriate information about diagnosis, prognosis, and treatment is also a fundamental requirement from the ethical and deontological point of view, as well as the indispensable prerequisite for the validity of informed consent. In Europe, patients' right to information has been codified with the European Charter of Patients' Rights presented in Brussels in 2002, which in article three reads literally "Every individual has the right to access to all kind of information regarding their state of health, the health services and how to use them, and all that scientific research and technological innovation makes available."² Furthermore, the Charter of Paris

and the subsequent Joint Declaration of Cancer Patients' Rights constituted a crucial point in the path toward the recognition of appropriate and understandable information as a fundamental patients' right.^{3,4}

Nowadays, in the era of technology, websites, online journals, and social media give access to an extraordinary amount of information. Communication tools play an important role in scientific dissemination, allowing common people to access details about complex topics related to health and to the latest acquisitions in the field of new medical therapies and research.⁵⁻⁷ Moreover, many patients and their family employ websites and social media searching for additional clarifications about their own malignancies and the treatments prescribed.⁸⁻¹¹ However, information available through these channels need to be validated. In some cases, misleading news are disseminated generating false expectations, exaggerated anxiety, and confusion. Even on officially

ASSOCIATED CONTENT

Data Supplement

Author affiliations and support information (if applicable) appear at the end of this article.

Accepted on April 9, 2021 and published at ascopubs.org/journal/go on May 21, 2021; DOI <https://doi.org/10.1200/GO.21.00003>

CONTEXT

Key Objective

To promote the best interaction between health and communication, a permanent round table composed of eminent experts from regional mass media and health care system has been established. A literature research has been conducted with the aim of selecting primary studies related to the best practices applied to health journalism identifying the most representative statements. Through a modified version of Delphi methodology, the panel evaluated the relevance of each statement to support useful strategies for overcoming communication barriers between health care professionals and communication experts.

Knowledge Generated

Our Declaration of Good Communication identified high-impact recommendations for the best management of patients in today's era of technology, in which there is a wide access to information not always coming from health sources.

Relevance

This declaration should be disseminated between health and communication professionals to strengthen that desired TRIPLE ALLIANCE between physicians, patients, and the world of communication.

supported websites, untrained readers could be exposed to ambiguous information that might arouse dangerous misunderstandings.¹² In oncology setting, disinformation is perhaps more deleterious than in other fields, with a considerable impact on single patients as well as on families and, more in general, on public health. In fact, the best use of available resources means not only savings management but also avoiding any waste; more widespread and harmful waste precisely lies in the damage caused by an unclear or deliberately misleading communication.^{13,14} The Bodmer report warned that "Scientists must learn to communicate with the public, be willing to do so, and indeed consider it their duty to do so."¹⁵ On the other hand, experts in communication should have the opportunity to confront with health care professionals to provide the best support to patients.

In this context, a new pact between health care professionals and experts in communication becomes fundamental. A strategic alliance that aimed to disseminate correct and quality information should not be conditioning, but synonymous of guarantee for the community. In a hybridized information society, news more often arise from the base risking to be faceless and turning information into disinformation. Instead, correct information generates knowledge, and conscious knowledge deeply contributes to prevention and to the effectiveness of the cure.

To promote the best interaction between the world of health and the world of communication, a Regional technical table was established with the aim of drafting a shared document, the first Declaration of the Good Communication in oncology that, likewise the Independence Declaration, provides simple but fundamental concepts and recommendations about effective communication on public health and in oncology setting. This has been done through the consensus conference method. Primary objectives of this consensus were to identify strategies to overcome the barriers between communication and health care and to

propose common criteria for an effective dissemination of medical information.

MATERIALS AND METHODS

A permanent round table composed of eminent experts from Regional mass media and health care system field has been established in January 2018. Since the size of the panel depends more on group dynamics than on statistical power in reaching consensus among experts, 10 participants have been involved. To identify experts in the field of communication, the directors of the major local newspapers were invited. With regard to experts from the field of research and health care, opinion leaders from academic and institutional backgrounds have been involved. More specifically, to form a representative panel, professionals from the universities, from local hospital, and from community services have joined the group. Furthermore, the involvement of general practitioners and professional associations has not been neglected. In the case of professionals who declined the participation, they were asked to suggest the name of a colleague with a similar background who could replace them.

A modified version of Delphi methodology by RAND/University of California Los Angeles (UCLA)¹⁶ developed by the working group has been employed as consensus tool within participants. The original Delphi tool is a quick and structured method for obtaining opinions on a specific topic by a group of experts constituting the evaluation panel. The members of the group then evaluate a matrix containing statements, partly from the scientific literature, partly produced by the experts themselves through several rounds; each round is defined on feedback from the previous evaluation.

Literature Research

A literature research on PubMed has been conducted with the aim of selecting primary studies related to the best practices applied to the health journalism. The search

strategy has been carried out on January and February 2018, developing many strings with specific keywords and MESH terms. Eligibility criteria in studies selections were

1. English or Italian language
2. Papers on healthy adult people (no pediatric issues)
3. Papers regarding patients with cancer
4. Papers conducted from January 2000 to February 2018
5. Relevance of the studies with the reference context (Marche Region, Italy)

Statements Selection

Two different authors (an oncologist MD and a public health professional MD) proceeded to a detailed reading of the papers, independent of each other. They both extracted the best evidences, a series of statements or opinions, from the documents found. Following a comparison of the selected items, a list of statements was structured in an excel format matrix linked to a minimum set of information, as bibliographic references (authors of the paper, title, journal and year of publication, and country where the study has been conducted). The text of the selected statements has been translated in Italian language to facilitate their comprehension among the experts panel. Furthermore, the following topics were identified:

1. Research and communication
2. Outcomes and communication
3. Health technology and communication
4. Care and communication
5. Drugs and communication

Then, the selected statements have been allocated as follows:

1. Recommendations on specific issues (Research and communication, Outcomes and communication, Health Technology and communication, Care and communication, and Drugs and communication)
2. Relevant Recommendations common to all the specific issues

Finally, the panel received the Excel matrix by e-mail.

Relevance Evaluation of the Statements Selected by the Literature, Additional Recommendations, and Case Studies

The members of the panel evaluated the relevance of each statement to support useful strategies for overcoming communication barriers between health professionals and communication professionals. Modified version of Delphi methodology has been used for the evaluation: specifically, the panel members evaluated the relevance of good practices selected as follows:

1. First evaluation of relevance: individual assessment by each group member for each statement proposed within specific subgroups. The judgment was expressed on a scale from 1 to 9, where 1 = certainly irrelevant, 9 = certainly relevant, and 5 = uncertain.

2. Second and third evaluation of relevance (with the possibility of group comparison): evaluation of intermediate judgments (band 4-6.9). Participants displayed a report showing the results of the first evaluation for each recommendation. The discussion then focused on the areas of disagreement that might have emerged.
3. Data analysis: the scenarios were judged in agreement in which, after excluding the two extreme judgments from the analysis, the remaining judgments fell into any of the three regions of the score (1-3, 4-6, and 7-9), corresponding to the three levels of evaluation.

In addition to the compilation of the matrix according to the above criteria, participants were asked to provide additional recommendations to be referred to as Good Practice Points, attributed to five predefined topics (see above), and then submitted to the Panel (Fig 1 and Data Supplement).

The presentations and the matrices filled in were sent to the working group 3 days before the event so that the proposed recommendations could be included in the matrix related to the second round. Finally, in support of each specific topic addressed, the group deemed appropriate to present some successful case studies. On the basis of the average evaluation of the various recommendations, these were then included in the final document.

RESULTS

After the analysis of the abstracts, the articles that met the inclusion criteria were found to be 16,¹⁷⁻³² from which 72 recommendations were drawn to the communication and health field (40 related to the specific issues identified and 32 transversal to all the specific topics) (Fig 2).

Following an evaluation of relevance by the panel of experts, it was found that 57 recommendations scored more than 7, 13 between 4 and 6.9, and 2 below 4. Considering all the recommendations related to the identified specific issues (40), the ones that obtained the highest score are shown in Table 1. Considering all the 32 recommendations relevant for all the specific issues, the ones that obtained the highest score are shown in Table 2.

DISCUSSION

In today's era of technology, the widespread dissemination of new communication tools makes it more than necessary to reiterate the importance of a correct way of communication that should be direct and understandable as well as faithful to the truth, avoiding distorting messages. This is more important in the medical field, where a correct communication could have a significant impact on people's health. Moreover, in the oncology setting, a considerable number of patients together with their families keep looking for information and clarifications regarding their diagnoses and prescribed treatments. This practice exposes users to a real risk of encountering incomplete, inaccurate, and, in some cases, misleading information, commonly referred to as *fake news*; a peculiar feature of this information is exactly

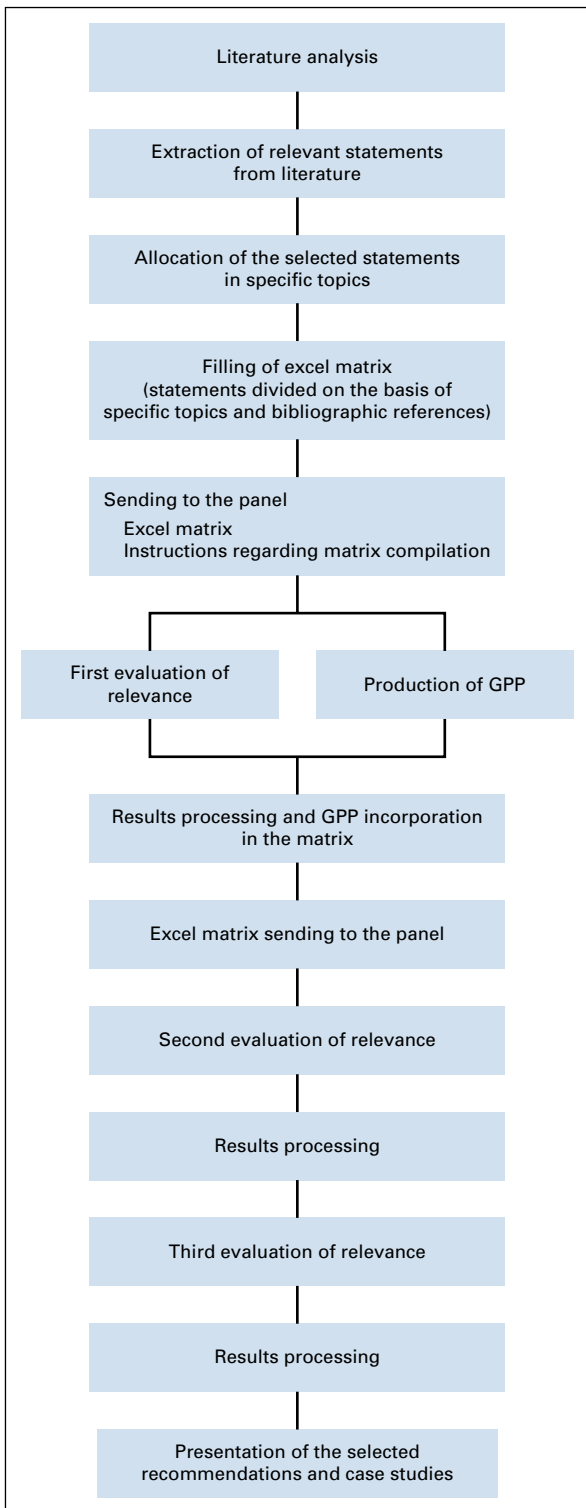


FIG 1. The modified version of Delphi methodology by RAND UCLA developed by the working group. GPP, Good Practice Points; UCLA, University of California Los Angeles.

the difficulty to identify them as fake.³³ In this regard, it would be desirable for the two parties involved in this process, the medical world and the communication world,

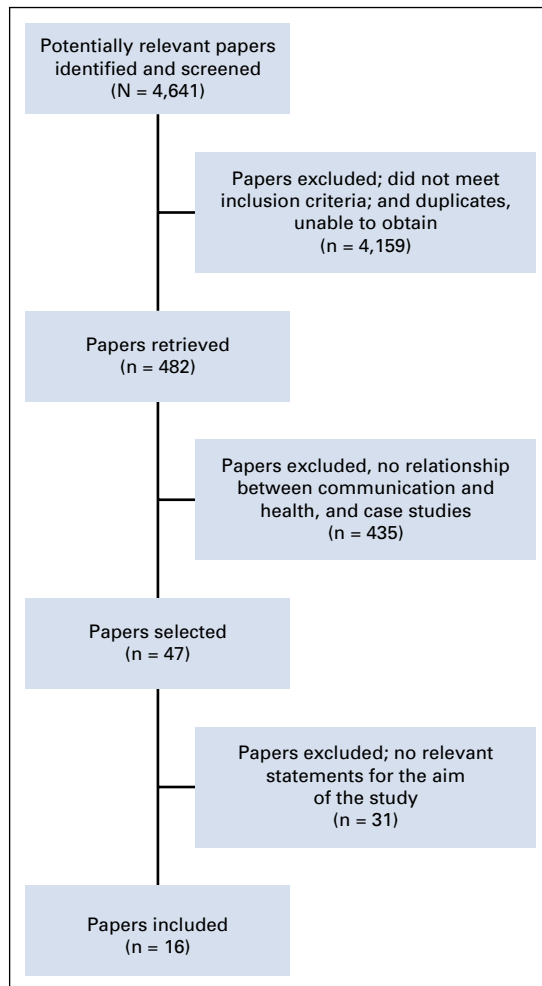


FIG 2. Algorithm of selected papers and recommendations.

to be in some way aligned, sharing a common search for the truth and a correct way for communication.

This thorny issue sheds light on the existing gap between these two distinctive worlds that has been already extensively treated in the literature. Numerous attempts to fill the gap between communication experts and health experts have been realized mostly through questionnaires focusing on the main difficulties in their interaction, showing that the expectations of both worlds of experts concern the behavior of the others in the field of communication, leading to communication failure. The most significant detected problems were the lack of adequate medical training for journalists, the lack of time, space and knowledge, problems regarding sources, and problems relating to publishers and marketing.^{20,22,25}

The present work is part of this setting, with the aim of identifying specific guidelines that could help to reduce disinformation traps and their potentially serious effects on public health and on single patient outcome. More in detail, the purposes of our work were to identify the potential strategies to overcome barriers between the world of

communication and world of health care and, then, propose some specific and shared criteria for a correct dissemination of medical information. To our knowledge, this represents the first document realized through the consensus conference method, providing recommendations about effective communication in public health and in oncology setting. These recommendations, shared and produced by communication experts and experts in the medical area, might represent a common basis and good standards that might be used in daily practice to improve the quality of communication in oncology setting.

Obviously, this method might be applicable to all areas of medicine, replicating our methodology and involving specific experts. An integrated and interdisciplinary approach represents an increasing need to counteract and reduce the damage caused by unclear or deliberately mendacious communication, especially in the medical field.³⁴ Considering the plurality of stakeholders involved, the elaboration of a shared set of best practices could represent a fundamental starting point to improve communication on behalf of patients or users and everyone involved in this process.

Nevertheless, this work presents some limitations. First of all, the panel selection was absolutely subjective even if realized searching and maintaining a high quality of the individual components in terms of training with the aim of selecting them especially on the basis of their complementarity. Furthermore, the selection of papers from literature and the identification of the statements from the articles have been inevitably affected by the subjectivity of those who dealt with the selection; the heterogeneity of the

papers found in the literature is another limitation. Moreover, the bibliographic research considered exclusively scientific publications in the medical field, excluding those coming from marketing and communication setting. However, this choice was made on the basis of the technical nature of the addressed issues: the idea was to start from indications coming from experts of the specific context of application.

Considering the multiplicity of stakeholders involved and the need for an integrated and multidisciplinary approach to the investigated topic, the chosen method has been the Consensus Conference (Consensus Conference), in the RAND/University of California Los Angeles variant, which is widely used in the medical field. This methodology has never been used in studies related to social sciences; then, our work might be considered the first application in this field leading to interesting results.

In conclusion, the importance of a collaboration between health care professionals and experts in communication represents an increasing need to curb and reduce the damage caused by an unclear or intentionally misleading communication. This consensus and the drawn up document represent a concrete attempt to find a renewed and strategic alliance between key figures in health and communication operators to produce useful and reproducible indications for an effective dissemination of medical information. As the American Declaration of Independence sanctioned simple but fundamental statements, among these Life, Liberty, and the Pursuit of Happiness, in the same way, our Declaration of Good Communication has identified high-impact recommendations for the best

TABLE 1. Recommendations Related to the Identified Specific Issues (40) With the Highest Scores

Recommendation	Valuation
Research and communication	
Assess clinical relevance and use of study results ¹⁷	8.3
Assess accuracy of the research protocol ¹⁷	8.2
Treatment outcome and communication	
Health information in the media cannot substitute for personal medical advice. It is important that the public understands this ¹⁸	8.5
In health reporting, context is crucial. Research advances to be reported need to be placed in context ¹⁸	8.2
Technology and communication	
The results indicate a strong belief of respondents that greater knowledge on the part of the public leads to more positive attitudes toward science and technology and that public visibility of science helps to secure political support ¹⁹	8.6
The intricacy of technical terminology and preponderance of jargon made it difficult to decipher the real substance of the research ¹⁹	7.9
Care and communication	
Very few news reports about cancer discuss death and dying, and even those that do generally do not mention palliative and hospice care ¹⁹	8.5
Do not restrict information to sensationalism facts; follow up its evolution in time ¹⁷	8.2
Drugs and communication	
Be cautious with off-label indications of drugs ¹⁷	8.2
Provide complete information on drugs (not only indications but also contraindication frequency and severity of adverse effects); consider a drug as innovative only if it defines a new class II or III in ATC ¹⁷	7.8

Abbreviation: ATC, Anatomical Therapeutic Chemical classification system.

TABLE 2. Recommendations Relevant for All Specific Issues (32) With the Highest Scores

Recommendation	Valuation
Editors, reporters, and writers need to scrutinize the terminology used in health news. Vague, sensational terms (such as cure, miracle, and breakthrough) may harm news consumers by misleading and misinforming. At the core of journalism's values, such terms should not be used because they are meaningless ¹⁸	8.6
Coverage of cancer-related issues and scientific advances requires greater collaboration between the press and cancer health care community to provide both credibility and accountability for the health information disseminated ²⁰	8.6
Assess reliability and authoritativeness of sources even of institutional ones (universities and agencies) ¹⁷	8.5
Most journalists reported aiming to develop clear and concise messages in an effort to ease comprehension and understanding for their viewers ²²	8.5
Avoid any form of sensationalism in terms and graphics ¹⁷	8.5
Journalists stated that increased collaborations with public health practitioners would improve their own understanding of health and medical information and allow them to develop health news content that was more appropriate for their target communities ²²	8.4
Consider relation between source (peer reviewed papers, media releases, gray literature, systematic revisions, and congress presentations) ¹⁷	8.3
Give to retractions the same space and emphasis of the rectified news item ¹⁷	8.2
Appeal to ethical values: they (journalists) are also sensitive about the potential negative impacts of media coverage of public health issues ²³	8.2
Be transparent at all levels of reporting; reveal funding and other conflicts of interest that may influence physicians and scientists in academics and elsewhere, patients who might have organizational or industry ties, journalists, and publishers of news ²⁴	8.1

management of patients in today's era of technology, in which there is a wide access to information not always coming from health sources. This declaration should be

disseminated between health and communication professionals to strengthen that desired TRIPLE ALLIANCE between physicians, patients, and the world of communication.

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PRIOR PRESENTATION

Presented as abstract at ASCO 2020 (abst e19231) and as poster at AIOM 2020 (poster TO3) October 30-November 1, 2020, Rome, Italy.

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Financial support: All authors

Administrative support: All authors

Provision of study materials or patients: All authors

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Manuscript writing: All authors

Final approval of manuscript: All authors

Accountable for all aspects of the work: All authors

AUTHORS' DISCLOSURES OF POTENTIAL CONFLICTS OF INTEREST

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Open Payments is a public database containing information reported by companies about payments made to US-licensed physicians (Open Payments).

Rossana Berardi

Consulting or Advisory Role: Lilly, Boehringer Ingelheim, Amgen, AstraZeneca, Novartis, Roche, GlaxoSmithKline, Eisai, MSD Oncology

Massimiliano Marinelli

Honoraria: Apoteca Farmacie

No other potential conflicts of interest were reported.

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