

Consensus Recommendations on Communication between Healthcare Professionals and Patients: Prepare – Ask – Listen – Motivate (PALiMo)

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Abstract

Purpose: A review of medical guidelines on the current standard of care, e.g. the American Society of Clinical Oncology guidelines (ASCO), the 2nd and 3rd ESO-ESMO International Consensus Guidelines for Advanced Breast Cancer (ABC2, ABC3), and guidelines from the European Oncology Nurse Society revealed that though the current guidelines outline the importance of an effective communication between patients and healthcare professionals (HCPs), they do not provide de facto advice on how to achieve that, leaving both HCPs and mBC patients facing difficulties at contributing to meaningful conversations, which can lead to misunderstandings and anxiety on both sides. Open, individual and respectful communication on the other hand can effectuate greater understanding, leading to more efficient therapy decisions.

Methods: An international, multi-disciplinary team of patients, patient advocates, psycho-oncologists, doctors from the fields of gynaecology and oncology as well as oncology nurses from 26 countries worldwide proposed

actions to be taken to make a difference in HCP-patient communication.

Results: Comprehensive recommendations to improve communication between HCPs and patients were developed. The PALiMo Recommendations, which stands for: Prepare – Ask – Listen – Motivate, define a set of suggestions describing specific processes to assist HCPs in conversations with their patients, from the initial diagnosis to finding the appropriate treatment or talking about end-of-life care.

Conclusion: As patients, patient advocates and HCPs have pointed out together, HCP-patient communication needs to be further improved. The results of their discussions will be presented as a series of positions to be introduced to medical associations and other decision-makers within the mBC community and can be used to discuss improvements in HCP-patient communication with stakeholders around the world. The PALiMo Recommendations are an important step towards creating a better environment for mBC patients and supporting HCPs.

Key Recommendations

Prepare the consultation in advance

Patients want HCPs to:

- treat them as equal partners, create trust and empower women with mBC by talking with them, not at them, and including them in decision-making
- communicate respectfully to lay a foundation to accept information provided
- offer follow-up support after the initial, face-to-face consultation
- ask how patients prefer to receive information

Ask the patient if they have understood explanations and whether they agree regarding next steps

Patients want HCPs to:

- focus on empathetic communication
- explain palliative care as a continuous care component of mBC
- receive mandatory communication training

Listen to find out if the patient has any concerns or questions

Motivate and encourage patients for the long patient journey together

Patients want HCPs to:

- find out about the patient preferences
- offer encouragement and support for a long patient journey
- adjust treatment to patients' plans and preferences
- summarise the consultation

1) Introduction

Conversations between healthcare professionals (HCPs) and patients are essential throughout the entire patient journey – not only to convey facts that are necessary to decide upon therapy and care, but also because on the one hand, communicating can help to detect psychosocial distress, and on the other hand to ease the emotional disbalance and the confusion a cancer diagnosis causes patients and their families.

Patients confirm that the quality of information provided at an initial diagnosis of early breast cancer is adequate but do not feel that this is matched at the point of diagnosis of metastatic breast cancer (mBC).⁸ While trying to process the diagnosis and understand potential next steps, they might also be asked to make a decision on treatment options. Feelings of blame and regret along with questioning if their disease has been managed correctly can complicate the sensitive nature of the situation.⁹

Healthcare professionals may have a limit on how much time they can spend with the patient for their appointment, or they may require the patient to make a timely decision on care. They may feel reluctant to deliver the diagnosis or find it challenging to share usually dire facts with the required level of sensitivity. They point out that their communication training needs to be improved to enable them to break bad news or communicate effectively about topics such as end-of-life care.¹⁰

As a result of these challenges - and their combined effects - increased communication difficulties are often experienced between patients and HCPs.⁹ The approach of the PALiMo Recommendations - a series of recommendations for medical guidelines - is to provide suggestions to tackle these difficulties and improve conversations between patients and healthcare professionals, with the aim of making these recommendations an integral part of clinical practice.

What characterises effective HCP-patient communication and why is it important?

Clear and compassionate communication between HCPs, patients and families is a critical aspect of psychosocial care in any supportive or palliative care setting.¹¹ There remains a need for greater sensitivity and transparency from HCPs and for better information and proactive communication to patients about diagnosis and treatment options.⁸ Communication about prognosis and anticipated treatment benefits, which is delivered with empathy and compassion by healthcare professionals, is anticipated to allow a patient to maintain hope while also being realistic about the likely outcome.¹²

The 3rd ESO-ESMO international consensus guidelines for advanced breast cancer (ABC3) define that every mBC patient must have access to optimal cancer treatment and support according to the highest standards of patient-centred care, i.e. open communication, educating patients about treatment options in a clear, culturally appropriate form, encouraging patients to be proactive in their care and empowering patients to improve their own quality of life.³ Effective communication can have benefits such as reducing patients' insecurities or avoiding misunderstandings, enabling patients to make better and more efficient therapy decisions, which saves valuable time for both sides, and even helping HCPs feel more confident and less anxious about breaking bad news. Nevertheless, international consensus guidelines for advanced breast cancer, such as the 3rd ESCO-ESMO, do not provide recommendations on how to achieve such communication.

Background: What is metastatic breast cancer (mBC)?

Breast cancer (BC) is still the most common cancer for women in 183 countries worldwide.¹ Breast cancer can be categorised in stages from 0 to IV.² A patient's stage at diagnosis has a significant impact on the long-term prognosis and treatment choice.² Stage IV breast cancer indicates that the cancer has spread to distant organs.² This advanced stage of breast cancer is known as metastatic breast cancer (mBC).² MBC is an incurable condition, and the median overall survival of patients is 2–4 years.^{3,4} Approximately one third of women diagnosed and treated for early breast cancer will go on to develop mBC.⁵ Women with mBC report significant distress, feelings of fear, anxiety, isolation, and depression as a result of their diagnosis, as well as uncertainty regarding the future and fear of dying.⁶ In the absence of a cure, the goal of treatment is to extend life, delay progression of the disease and help each person maintain the best quality of life for as long as possible.⁵

Over the next 15 years, the number of deaths due to breast cancer is expected to nearly double, underscoring the urgent need to address gaps in the current standard of care.⁷

2) The roles of patients, nurses, doctors and multidisciplinary care teams

The management of mBC is complex, and therefore involvement of all appropriate specialties in a multidisciplinary team is crucial (including, but not restricted to, medical, radiation, and surgical oncologists,

imaging experts, pathologists, gynaecologists, psycho-oncologists, social workers, oncology nurses and palliative care specialists).³ From early on in the patient journey, the approach to care should encompass not only physical but also functional, social, psychological and spiritual domains.

Healthcare professional⁸ - An individual who provides health services to healthcare consumers.

Medical oncologist⁸ - A doctor who specialises in diagnosing and treating cancer. They are often the main healthcare professional in the case of a patient with cancer and may coordinate the treatment given by other specialists.

Oncology nurse⁸ - A nurse in the field of oncology who provides care for patients with cancer. Nurses monitor patients' physical conditions, offer communicative support and education to patients and their families, may prescribe medication and administer chemotherapy while coordinating with the treating oncologist. They also conduct research, provide psycho-oncological support and act as patient advocates.

Psycho-oncologist^{14,15} - Professionals with expertise in psycho-oncology or psycho-social cancer care in the multidisciplinary treatment team (MDT), mostly clinical and health psychologists or psychiatrists and psychotherapists. They screen for distress and psychosocial needs of the cancer patients and their families, and provide psychosocial interventions in a wide range of methods, such as psycho-educational and psychological support interventions, counselling, coping skills and psychotherapy (individual, group or family) accordingly.

3) Background – Need for HCP-patient communication established

The idea for the development of the HCP-patient recommendations started with a multidisciplinary team of 50 mBC patients, patient advocates, oncologists and nurses from 22 countries worldwide. They discussed how to close gaps in the support of women with mBC and what could be done to improve it at the 1st MBC Summit in 2016. The multidisciplinary team determined that a stronger focus on more specific standards in HCP-patient communication was needed and concluded that developing suggestions for the improvement of said communication was their first priority; an endeavour they summarised in the MBC Summit Position Paper.¹⁶ One year later, the 2nd MBC Summit offered a platform to bring together an interdisciplinary team from over 26 countries worldwide, which developed HCP-patient communication recommendations for medical guidelines:

the PALiMo Recommendations.

Definition of HCP-patient communication

Communication between healthcare professionals (HCPs) and a patient with metastatic breast cancer (mBC) is to be understood as HCP-patient communication. In these recommendations, HCPs comprise oncologists, psycho-oncologists, gynaecologists, other involved physicians as well as oncology nurses and other healthcare practitioners. The communication between patients and HCPs can happen anytime along the treatment journey from diagnosis to palliative care setting and can take place during visits in the hospital, in breast cancer centres or in the outpatient setting. It includes face-to-face communication, as well as communication via phone or digital tools.

4) Objective

The PALiMo Recommendations provide concrete and practical recommendations for possible inclusion in existing medical and scientific guidelines. They incorporate not only factual information on *what* could change in HCP-patient communication, but also focus on describing *how* appropriate HCP-patient communication should take place.

These recommendations for guidelines have been developed to help patients with mBC enhance their communication and relationship with HCPs throughout their journey. The PALiMo Recommendations encourage change across the mBC community and can be used to drive best practices in care and communication, including a basis for continuous training. The goal for these concrete recommendations is to remove communication barriers between patients and their care teams and thus pave the way for a better environment for both.

How to define guidelines

Medical and clinical guidelines exist in various formats; they are issued by different medical and healthcare professional associations worldwide. Generally, guidelines “are designed to support the decision-making processes in patient care. The content of a guideline is based on a systematic review of clinical evidence - the main source for evidence-based care.”¹⁷

The purpose of guidelines can vary according to the areas of expertise, but commonly they:

- describe appropriate care based on the best available scientific evidence and broad consensus

- reduce inappropriate variation in practice
- provide a focus for continuing education
- promote efficient use of resources
- act as focus for quality control.¹⁷

For the PALiMo recommendations, the following definition for the term “guidelines” will be applicable throughout this document: “A multidisciplinary metastatic breast cancer guideline with a focus on HCP-patient communication is defined as a guideline developed by representatives from the mBC community, i.e. mBC patients, patient advocates, oncologists, psycho-oncologists and oncology nurses. The aim of the guidelines is to give recommendations for HCP-patient communication for the involved stakeholders.”¹⁸

5) Review of current guidelines

Prior to the Consensus Meeting, a review of current medical guidelines has been performed in order to find out how medical guidelines today describe HCP-patient communication in breast cancer. The guidelines examined represent the highest level of guidelines formed at conferences and congresses in the field of oncology; they set the current standard of care.

- ESO-ESMO (European School of Oncology-European Society of Medical Oncology) 2nd international consensus guidelines for advanced breast cancer¹³ (ABC2)
 - “For active and informed participation, all ABC patients should be offered comprehensive, culturally sensitive, up-to-date and easy to understand information about their disease and its management.”¹³
- ESO-ESMO 3rd international consensus guidelines for Advanced Breast Cancer³ (ABC3)
 - “The importance of providing patients with full information in appropriate, understandable and culturally sensitive way, as well as involving them in sharing the decision-making regarding all aspects of their management has been repeatedly stressed in all ABC guidelines.”³
- EONS (European Oncology Nursing Society) Breakthrough Cancer Pain Guidelines¹⁹
 - “Moreover, good collaboration between health professionals, patients, and carers represents an essential component for the provision of optimal care for cancer patients.”¹⁹
- ASCO (American Society of Clinical Oncology): Assessing Patient-Centered Communication in Cancer Care²⁰

- “Patient-centered communication is defined as healthcare that establishes a partnership among practitioners, patients, and their families (when appropriate) to ensure that decisions respect patients’ wants, needs, and preferences and that patients have the education and support they need to make decisions and participate in their own care.”²⁰

6) Findings in the reviewed guidelines

The detail and depth of recommendations for HCP-patient communication differ between the reviewed guidelines. Many guidelines, while pointing out the importance of a patient-centred, effective communication, remain vague regarding concrete advice on how to achieve that.

Three overarching topics stood out as being important for good HCP-patient communication:

- Information and understanding
- Effective, open communication
- Patient values, needs and preferences

These topics form the basic structure and guided the development of the PALiMo Recommendations.

7) Methodology

Selection of Participants

The 2nd MBC Summit (Vienna, October 2017) included 50 mBC patients and patient advocates, 1 oncologist, 2 psycho-oncologists, 1 gynaecologist, and 4 oncology-nurses from 26 different countries worldwide. Patient advocates and patients were selected based on their experience with or representation of mBC in their respective countries.

Work Process

To be able to determine recommendations for guidelines, all participants needed to be up to date with current medical guidelines and unmet needs in HCP-patient communication. During joint panel discussions, current guidelines were reviewed and their advice on HCP-patient communication summarised.

Following this, two workshops were conducted. During the first, 3 separate groups brainstormed on each topic (Information and understanding; Effective, open communication; Patient values, needs and preferences).

All three groups were assembled randomly and multi-disciplinarily, so that each group consisted of representatives of each profession. All ideas were collated and afterwards each of the participants ordered them by importance and priority level.

For the 2nd workshop, each group discussed one of the topics with the aim of determining five to seven suggestions most suited to improving communication in the respective area. After establishing an overview of the most prominent suggestions, the groups' results were presented to and discussed with all MBC Summit attendees.

8) Outcomes

The Consensus Recommendations on Communication between Healthcare Professionals and Patients: Prepare – Ask – Listen – Motivate (PALiMo) were agreed on by all participants and reviewed by all HCPs who were present at the 2nd MBC Summit. The findings are presented according to the three core themes. They summarise all proposals that emerged during the workshops and include opinions from experts in the field of oncology and psycho-oncology.

PALiMo

The recommendations for guidelines follow a usual pattern along the patient's journey to accompany the patient and HCP during their joint conversations. The acronym symbolises the overall, overarching themes that should guide HCP and patient consultations:

- P** – Prepare the consultation in advance
- A** – Ask the patient if they have understood explanations and whether they agree regarding next steps
- Li** – Listen to find out if the patient has any concerns or questions
- Mo** – Motivate and encourage patients for the long patient journey together

9) Guideline statements / General recommendations

Topic 1: Information and understanding

“All ABC patients should be offered comprehensive, culturally sensitive, up-to-date and easy to understand information about their disease and its management.”³
(ABC3)

The topic “Information and understanding” balances the need for patients to receive information they can understand and information that enables them to make treatment decisions as equal partners. For the HCPs, it is vital to know *how* to explain the diagnosis and different therapy options. Educating patients about treatment options and supportive care should be done by conveying factual information in a clear, culturally appropriate form.³

1	Recommendations for guidelines:
<p>1A</p> <p>Patients want HCPs to treat them as equal partners, create trust and empower women with mBC by talking with them, not at them, and including them in decision-making</p>	<ul style="list-style-type: none"> • Encourage patients to continuously ask questions • Emphasise that it is fine to have questions • Regularly ask patients if they understand explanations and next steps • Ask patients if they agree with next steps • Give patients space for questions and remain silent for a while after asking questions • Be sure to include patients in care discussions with other HCPs when conversations take place in front of them
<p>1B</p> <p>Patients want HCPs to communicate respectfully to lay a foundation to accept information provided</p>	<ul style="list-style-type: none"> • If possible, designate a fixed contact person patients can talk to about challenging topics • Introduce all HCPs who will have contact with patients and explain their responsibilities
<p>1C</p> <p>Patients want HCPs to offer follow-up support after the initial, face-to-face consultation</p>	<ul style="list-style-type: none"> • The first consultation disclosing the diagnosis should always be a personal appointment with the doctor • Offer follow-up conversations e.g. by telephone or Skype • Respect patients’ wishes should they decline to receive further information • Offer patients the opportunity to speak with peers and/or participate in support groups • Offer for the oncology nurse to conduct psychosocial distress screening and monitor each patient visit
<p>1D</p> <p>Patients want HCPs to ask how patients prefer to receive information</p>	<ul style="list-style-type: none"> • Offer different formats, e.g. printed information, face-to-face conversation, digital materials etc. • Ensure personal, individual explanations of disease and disease management in lay terms • Individualise information according to each patient and their situation, including taking into account the state of the disease and its characteristics

Topic 2: Effective and open communication

“Open communication between patients and their cancer care teams as a primary goal”.³ (ABC3)

Every mBC patient must have access to optimal cancer treatment and supportive care according to the highest standards of patient-centred care, with open

communication between patients and their cancer care teams as the starting point for effective HCP-patient communication. Effective communication can help patients and family members cope with their disease, make informed decisions, and effectively manage their care.²⁰

2	Recommendations for guidelines
<p>2A</p> <p>Patients want HCPs to focus on empathetic communication</p>	<ul style="list-style-type: none"> • Prepare ahead of consultations, e.g. review each patient’s case and personal situation • Create a safe space and comfortable atmosphere and suggest patients be accompanied by a family member or friend • Close the door and windows • Offer the patient a seat close to you • Make sure there will be no interruptions, e.g. telephone calls, beeper, other people entering the room • Have a tissue box nearby • When delivering bad news, always be sure to incorporate options and provide a positive perspective so patients leave with a feeling of hope • Understand and respect patients’ priorities so they feel optimistic – e.g. the ability to maintain quality of life through individual therapy options
<p>2B</p> <p>Patients want HCPs to explain palliative care as a continuous care component of mBC</p>	<ul style="list-style-type: none"> • Explain palliative care as a means of helping patients to live with the disease while maintaining quality of life • Be sensitive to lessen the shock while introducing the topic of palliative care to patients • Start the conversation about palliative care early on, but try to determine when each patient is ready • Use conditional verbs like ‘could be’, ‘would’, ‘might be’
<p>2C</p> <p>Patients want HCPs to receive mandatory communication training</p>	<ul style="list-style-type: none"> • Mandatory communication training for HCPs early on in their studies and throughout their career • Ongoing communication training for all relevant HCPs • Trainings should be held in cooperation with patient advocates – as patients are experts in living with their disease

Topic 3: Patient preferences, values and needs

“Patient preferences, values and needs should always be taken into account for optimal cancer care. Patients should be encouraged to be proactive in their care and to share decision-making with their healthcare providers.”^{3,20} (ASCO, ABC3)

From the time of diagnosis, mBC patients should be offered a personalised approach to meet the needs of the individual as a routine part of their care.¹³ This could include the HCPs being ready to change and adapt treatment strategies to disease status, adverse effects and

quality of life, patients’ priorities and life plans.³ Patients are called upon to proactively share their personal needs and preferences with HCPs, progressing efficiently and effectively in their patient journey.³

Moreover, good collaboration between HCPs and mBC patients represents an essential component for the provision of optimal care for mBC patients. HCPs are then able to advise on different disease management strategies and tailor treatments to the patient’s specific needs.¹⁹

3	Recommendations for guidelines
<p>3A</p> <p>Patients want HCPs to find out about the patient preferences</p>	<ul style="list-style-type: none"> • Ask questions such as e.g. <ul style="list-style-type: none"> - How do you feel? - What is bothering you (today)? - What works for you/what makes you happy? - How can I help you? - Would you like to further talk about this topic? • Try to understand patients’ daily routines and what is important to them, e.g. activities and hobbies, and integrate this knowledge in shared decision making
<p>3B</p> <p>Patients want HCPs to offer encouragement and support for a long patient journey</p>	<ul style="list-style-type: none"> • Express commitment to a continuous patient journey together, as a team and partners • Ask patients about their plans like upcoming events in order to adjust e.g. medical appointments accordingly • Ask patients what they hope for • Give guidance on how to live with disease, e.g. managing side effects, and ask patients how they would like to be supported
<p>3C</p> <p>Patients want HCPs to adjust treatment to patients’ plans and preferences</p>	<ul style="list-style-type: none"> • Regularly check-in with patients on their preferences to see if they have changed
<p>3D</p> <p>Patients want HCPs to summarise the consultation</p>	<ul style="list-style-type: none"> • Encourage patients to make notes during consultations • Describe what has been discussed • State what has been agreed • Ask if they have any remaining questions, doubts or concerns

10) Conclusion

As patients, patient advocates and HCPs have pointed out together, HCP-patient communication needs to be further improved.

Research into current medical care guidelines revealed that, while they outline the importance of effective HCP-patient communication, they do not provide concrete advice on how to achieve that. Three topics were obtained from this review of selected relevant guidelines.

A multidisciplinary team from over 26 countries worldwide was able to define comprehensive recommendations to improve communication between HCPs and patients at the 2nd MBC Summit. The Consensus Recommendations on Communication between Healthcare Professionals and Patients: Prepare – Ask – Listen – Motivate (PALiMo) propose a set of ideas to close gaps in HCP-patient communication from the initial diagnosis to finding the appropriate treatment or talking about end-of-life care.

The PALiMo Recommendations are supplied in digital and printed versions and will be provided to patient organisations and medical associations. They will also be distributed to HCPs and patients to support their communication throughout consultations by describing specific processes for the improvement of HCP-patient communication. The steps described in this document may also be developed further as stand-alone guidelines for HCP-patient communication.

The PALiMo Recommendations are an important step towards creating a better environment for mBC patients and supporting HCPs while breaking bad news and finding the best and personalised treatment approach possible for a long patient journey together.

11) Participants

The 2nd MBC Summit included 52 participants from 26 different countries in total:

- 44 mBC patients and patient advocates from Austria, Belgium, Croatia, Czech Republic, Denmark, Egypt, Finland, France, Germany, Greece, Hungary, Ireland, Israel, Italy, Macedonia, Norway, Poland, Portugal, Romania, Russia, Spain, Sweden, Turkey, United Arab Emirates, USA
- 1 oncologist from Spain
- 2 psycho-oncologists from Austria and Portugal
- 1 gynaecologist from Germany
- 4 oncology-nurses from Ireland, Israel and the United Kingdom

The participants were invited to join the 2nd MBC Summit due to their expertise in the dedicated oncology fields and because of their reoccurring presence from the 1st MBC Summit.

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