

# Diagnosis and Treatment of Patients with early and advanced Breast Cancer



© AGO e. V.  
in the DGGG e.V.  
and  
in the DKG e.V.

Guidelines Breast  
Version 2024.1E

## Health Literacy and Communication

[www.ago-online.de](http://www.ago-online.de)

**FORSCHEN  
LEHREN  
HEILEN**



# Health Literacy

© AGO e. V.  
in the DGGG e.V.  
and  
in the DKG e.V.

Guidelines Breast  
Version 2024.1E

- **Versions 2020-2023:**  
**Bauerfeind / Maass / Rhiem / Schmidt / Schütz**
  
- **Version 2024:**  
**Albert / Ditsch**

**Consulting patient advocates of the AGO-Patient-Taskforce:**

***R. Haidinger, Brustkrebs Deutschland e.V.***

***B. Welter, mamazone e.V.***

www.ago-online.de

**FORSCHEN  
LEHREN  
HEILEN**

# Health Literacy Definition

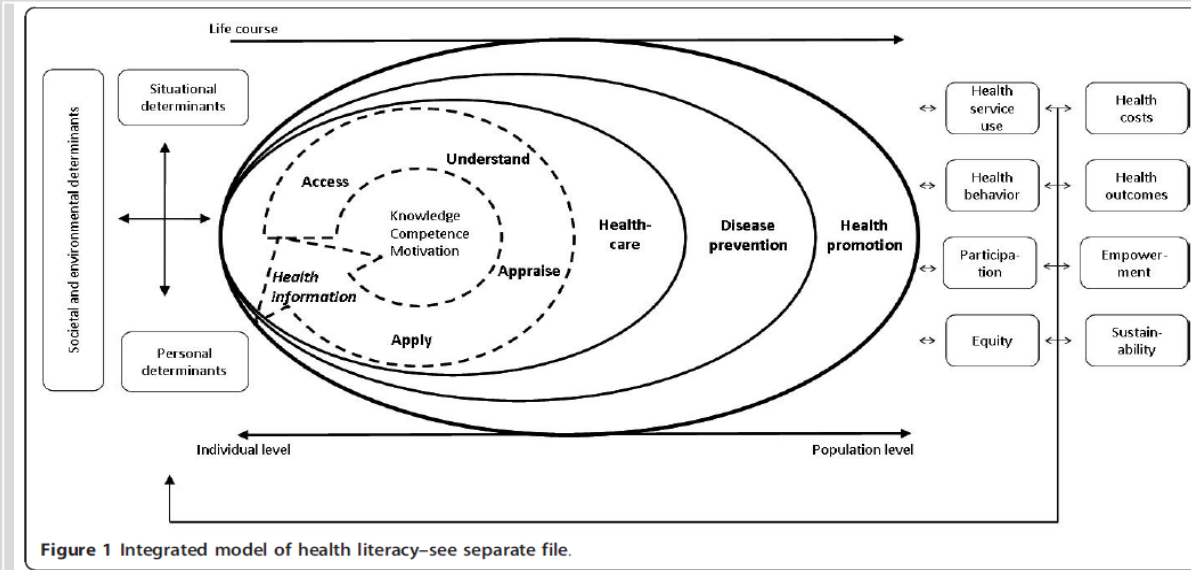
**“Health literacy is linked to literacy and entails people’s knowledge, motivation and competences to access, understand, appraise, and apply health information in order to make judgments and take decisions in everyday life concerning healthcare, disease prevention and health promotion to maintain or improve quality of life during the life course.”**

*Sørensen et al., (2012)*

# Health Literacy Model (according to Sørensen)

© AGO e. V.  
in the DGGG e.V.  
and  
in the DKG e.V.

Guidelines Breast  
Version 2024.1E



## Competencies

**Access:** seek, find, obtain health information.

**Understand:** Understanding the health information received

**Appraise:** Interpret, select, assess, review health information

**Apply:** Use health information to make decisions that support and improve health

# Health Literacy

Health literacy is influenced both by individual abilities and skills ("personal health literacy") and by the demands and complexity of the living environment and systems ("organizational health literacy").

- The more developed health literacy is, the better a person can **inform** himself or herself about health (e.g. prevention, therapy) in everyday life, **form** an **opinion** and **make self-determined decisions** that maintain or improve the quality of life and health throughout the self-determined course of life ("personal health literacy").
- However, the extent of health literacy of a person depends not only on his or her individual prerequisites and acquired competencies, but especially on the **professional quality, appropriateness, comprehensibility, form of communication and availability of the information provided** ("organizational health literacy").



# Digital Health Literacy

## Definition

© AGO e. V.  
in the DGGG e.V.  
and  
in the DKG e.V.

Guidelines Breast  
Version 2024.1E

**Digital health literacy is the ability to search for, find, understand and evaluate health-related information in relation to digital applications and digital information services and to apply the acquired knowledge to solve a health problem.**

[www.ago-online.de](http://www.ago-online.de)

FORSCHEN  
LEHREN  
HEILEN

# Implementation of Health Literacy

© AGO e. V.  
in the DGGG e.V.  
and  
in the DKG e.V.

Guidelines Breast  
Version 2024.1E

**Reasons cited for overuse, underuse and misuse in the health care system include the weak position of patients (SVR 2001).**

In the context of health literacy, the patient is

- more autonomous **actor and co-designer**
- the one who takes **responsibility** and an **active role** in medical decisions
- the person who extracts the **individually relevant meaning** from professionally offered information and **behaves in accordance with individual ideas about** certain health situations
- the one whose **digital health literacy** (e.g. media literacy, critical judgement) – as well as that of health professionals – should be supported.

# Health Literacy

## Patient-centered Communication

Oxford

LoE	AGO
3a	+

Aim of a physician-patient communication: enable a self-determined decision based on sufficient health competence (Shared Decision Making)

**Doctor-patient communication is key for acquiring health competence. It is the basis for successful oncological treatment and support. Core elements are, for example:**

- **Non-directive communication** - i.e. those seeking advice have the right to choose their own goals in life, even if they contradict generally accepted, even evidence-based, recommendations after well-founded consideration.
- **Comprehensible communication** - i.e. geared to the level of knowledge, reception habits, competence requirements and preferences of the different patients





# Health Literacy

## Basic Principles of Patient-centered Communication

- **Communicate information truthfully and empathetically**
- **Impart medical evidence-based knowledge in lay language**
- **Critical debate of pseude-scientific recommendations**
- **Active listening**
- **Showing empathy**
- **actively listening and expressing empathy**
- **Find out if and how the patient wants to be informed about his / her situation**
- **use understandable language avoiding or explaining technical terms**
- **Continuously improve understanding through e.g. repetitions, breaks, summary, comprehensible information material**
- **Encourage asking questions and expressing feelings**
- **Identifying individual stresses, problems and needs**
- **Motivating self-determination and personal activities ("empowerment")**
- **Giving hope for healing and relief**
- **Offer further assistance (e.g. psycho-oncology, self-help)**

© AGO e. V.  
in the DGGG e.V.  
and  
in the DKG e.V.

Guidelines Breast  
Version 2024.1E

[www.ago-online.de](http://www.ago-online.de)

**FORSCHEN  
LEHREN  
HEILEN**



# Health Literacy

## Evidence-based Information

**Evidence-based information in health care should be used to answer patients' questions in an understandable way. They are based on the current state of knowledge and are free from influence:**

**requirement for evidence-based health information as a discrimination against pseudo-scientific recommendations:**

- The information on services or products may not be used directly or indirectly for marketing purposes.
- The systematic search corresponds to the questions relevant to the target group.
- The selection of evidence suitable for the research question is justified.
- An undistorted presentation of the results relevant to the patients (e.g. side-effects, mortality, complaints, complications, health-related QoL) is available.
- The presentation of uncertainties is appropriate in terms of content and language.
- The presentation of results is clearly separated from the derivation of recommendations.
- Consideration of current evidence to communicate figures, risk information and probabilities.
- there must be sufficient time for the decision.
- The possibility that the measure may be refused must not be a reason for withholding information.

© AGO e. V.  
in the DGGG e.V.  
and  
in the DKG e.V.

Guidelines Breast  
Version 2024.1E

www.ago-online.de

FORSCHEN  
LEHREN  
HEILEN

# Health Literacy

## Communication

**Non-directive and evidence-based doctor-patient communication geared to the current needs, values, problems, resources and preferences of patients has beneficial effects.**

	<u>Oxford</u>
	LoE
■ Reduction of fear	2b
■ Trust in treating oncologists is increased	2b
■ Treatment satisfaction is increased	2a
■ Therapy adherence is increased	2a
■ Decision making is improved	2a
■ Mental complaints are improved	2a

# Health Literacy

## Communication Training

© AGO e. V.  
in the DGGG e.V.  
and  
in the DKG e.V.

Guidelines Breast  
Version 2024.1E

**Oxford**

**LoE**

**AGO**

**+**

**Qualified training measures can help to promote communicative skills.**

**communication training for doctors can e.g.**

- |                                                                                   |           |
|-----------------------------------------------------------------------------------|-----------|
| ▪ Enhance empathy                                                                 | <b>2a</b> |
| ▪ Extend and enrich communication skills                                          | <b>2a</b> |
| ▪ Increase patient satisfaction (information, support, consideration of concerns) | <b>2b</b> |
| ▪ Improve transmission of information                                             | <b>2b</b> |



# Informed Decision Making

## An informed decision is made when an individual

- understands the disease referred to
- understands what the medical management involves
- including the benefits, risks, limitations, alternatives and uncertainties;
- has considered his/her preferences and
- makes the decision in accordance with these,
- is of the opinion that one has participated in the decision to the desired extent and
- made the decision voluntarily and with the highest degree of personal autonomy.

© AGO e. V.  
in the DGGG e.V.  
and  
in the DKG e.V.

Guidelines Breast  
Version 2024.1E

[www.ago-online.de](http://www.ago-online.de)

FORSCHEN  
LEHREN  
HEILEN

# Health Literacy

## Shared Decision Making - Participatory Decision

### Oxford

LoE	GR	AGO
-----	----	-----

- **Patients want to be integrated actively involved into decision making at an early stage and open discussions about prognosis, treatment options, and quality of life**
- **Doctors should motivate patients to ask questions, demand clarification, express emotions, opinions, and preferences**
- **Active involvement of caregivers/trusted persons**

<b>1b</b>	<b>A</b>	
<b>3b</b>	<b>C</b>	<b>+</b>
<b>4</b>	<b>C</b>	<b>+</b>

# Shared Decision – Meta-analysis of Frequency and Influencing Factors



© AGO e. V.  
in the DGGG e.V.  
and  
in the DKG e.V.

Guidelines Breast  
Version 2024.1E

## Method:

- 8 databases for studies about breast cancer patients' surgical decisional control preferences and shared decision making preference
- Meta-analysis of the frequency of preferred and actual shared decision making and decision congruence was performed (descriptive analysis)
- Fourteen original studies were included

## Results:

- overall pooled frequency of the preferred shared decision making: 48.1% (95%CI 33.5%, 62.6%)
- the actual shared decision making 38.1% (95%CI 33.9%, 42.2%)
- pooled frequency of the decision congruence between preferred and actual decision styles was 61.7% (95%CI 54.6%, 68.8%).

Descriptive analysis findings indicated that the influencing factors of shared decision making included individual factors, surgeon-patient communication factors, and health setting factors.

www.ago-online.de

FORSCHEN  
LEHREN  
HEILEN

# Decision Aids

## Decision aids address

- a wide range of preventive, diagnostic and therapeutic applications
- are offered as brochures, decision charts, videos or computer programs
- contain information on advantages and disadvantages, available options and instructions for individualized decision-making
- are used individually or as components of structured counseling or training.

The minimum quality standards are evidence-based, complete, unbiased and comprehensible.

**Medical decision aids do not replace medical advice.**

© AGO e. V.  
in the DGGG e.V.  
and  
in the DKG e.V.

Guidelines Breast  
Version 2024.1E

[www.ago-online.de](http://www.ago-online.de)



# Health Literacy

## Decision Aids for Patients

Oxford

LoE

AGO

+

### The use of decision support in the physician-patient communication

- improves knowledge about treatment options 1a
- reduces the decision conflict 1a
- improves the level of information 1a
- increases the feeling about the clarity of personal values 1a
- encourages a more active role in decision-making 2b
- improves risk perception 2b
- improves the match between the chosen option and the patient's values 3a



# Health Literacy

## Decision coaching

Oxford		
LoE	GR	AGO
		+

**The use of decision coaching by health professionals based on evidence-based patient information can improve the decision-making process of patients.**

**Decision coaching is able to improve**

- **the knowledge of patients**
- **the active role of patients in the process of decision making**

<b>2a</b>	<b>B</b>
<b>2b</b>	<b>B</b>

© AGO e. V.  
in the DGGG e.V.  
and  
in the DKG e.V.

Guidelines Breast  
Version 2024.1E

[www.ago-online.de](http://www.ago-online.de)

**FORSCHEN  
LEHREN  
HEILEN**

# Use of eHealth (DiGA)

© AGO e. V.  
in the DGGG e.V.  
and  
in the DKG e.V.

Guidelines Breast  
Version 2024.1E

- **Use of DiGA to improve quality of life during and after breast cancer therapy**
- **Use of PROs for improved collection of therapy-associated side effects and quality of life**

Oxford		
LoE	GR	AGO
2b	B	+/-
2b	B	+/-

\* See current DiGA status / reimbursement