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

## Health Literacy and Communication



# Health Literacy

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- **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.*



## 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)*

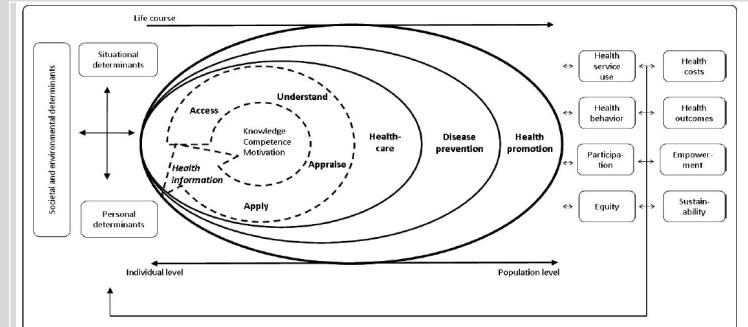
1. Sørensen K, Van den Broucke S, Fullam J, et al. Health literacy and public health: A systematic review and integration of definitions and models. *BMC Public Health*. 2012; 12:80



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# Health Literacy Model (according to Sørensen)



**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

Sørensen K, Van den Broucke S, Fullam J, Doyle G, Pelikan J, Slonska Z, Brand H. Health literacy and public health: A systematic review and integration of definitions and models. BMC Public Health. 2012; 12:80

1. Bruera E, Willey JS, Palmer JL, et al. Treatment decisions for breast carcinoma: patient preferences and physician perceptions. *Cancer*. 2002;94(7):2076–80.
2. Schmid Mast, M., A. Kindlimann, and W. Langewitz, *Recipients' perspective on breaking bad News: how you put it really makes a difference*. Patient Educ Couns, 2005. 58(3): p. 244-51.
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## 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").

1. Jordan S, Töppich J, Hamouda O, et al. Monitoring und Qualitätssicherung von Prävention und Gesundheitsförderung auf Bundesebene [Monitoring and quality assurance of prevention and health promotion at the federal level]. *Bundesgesundheitsblatt Gesundheitsforschung Gesundheitsschutz*. 2011;54(6):745–751. doi:10.1007/s00103-011-1293-2
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4. <https://www.federalregister.gov/documents/2019/06/04/2019-11571/solicitation-for-written-comments-on-an-updated-health-literacy-definition-for-healthy-people-2030>
5. [https://www.rki.de/DE/Content/GesundAZ/G/Gesundheitskompetenz/Gesundheitskompetenz\\_node.html](https://www.rki.de/DE/Content/GesundAZ/G/Gesundheitskompetenz/Gesundheitskompetenz_node.html)
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Gesundheitskompetenz (Teil 1) – Hintergrund, Relevanz, Gegenstand und Fragestellungen in der Versorgungsforschung DNVF  
Memorandum Health Literacy (Part 1) – Background, Relevance, Research Topics and Questions in Health Services Research. Das  
Gesundheitswesen 2020; 82(07): 77 – 93 DOI: 10.1055/a-1191-3689



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# Digital Health Literacy

## Definition

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**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.**

1. Ernstmann N, Bauer U, Berens EM, Bitzer EM, Bollweg TM, Danner M, Dehn-Hindenberg A, Dierks ML, Farin E, Grobosch S, Haarig F, Halbach S, Hollederer A, Icks A, Kowalski C, Kramer U, Neugebauer E, Okan O, Pelikan J, Pfaff H, Sautermeister J, Schaeffer D, Schang L, Schulte H, Siegel A, Sundmacher L, Vogt D, Vollmar HC, Stock S. DNVF Memorandum Gesundheitskompetenz (Teil 1) – Hintergrund, Relevanz, Gegenstand und Fragestellungen in der Versorgungsforschung DNVF Memorandum Health Literacy (Part 1) – Background, Relevance, Research Topics and Questions in Health Services Research. Das Gesundheitswesen 2020; 82(07): 77 – 93 DOI: 10.1055/a-1191-3689
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# Implementation of Health Literacy

**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.

SVR - Council of Experts for the Assessment of Developments in the Health Care System

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4. <https://www.svr-gesundheit.de/gutachten/gutachten-2021/>



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# 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

1. Søndergaard SM, The impact of shared decision making on time consumption and clinical decisions. A prospective cohort study. Patient Education and Counseling, Volume 104, 2021.
2. Maes-Carballo M, Shared decision making in breast cancer screening guidelines: a systematic review of their quality and reporting. European Journal of Public Health, Volume 31, August 2021.
3. Pfob A, Towards Patient-Centered Decision-Making in Breast Cancer Surgery - Machine Learning to Predict Individual Patient-Reported Outcomes at 1-Year Follow-up. Annals of Surgery, March 18, 2021.
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5. Institut für Qualität und Wirtschaftlichkeit im Gesundheitswesen (IQWiG) HTA-Bericht Behandlungsgespräche: Führt eine gemeinsame Entscheidungsfindung von Arzt und Patient bei der Therapiewahl zu besseren Ergebnissen? Projekt: HT22-01 Version: 1.0 Stand: 04.09.2023 [https://www.iqwig.de/presse/pressemittelungen/pressemittelungen-detailseite\\_100418.html](https://www.iqwig.de/presse/pressemittelungen/pressemittelungen-detailseite_100418.html) Abruf 03012024



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# Health Literacy

## Basic Principles of Patient-centered Communication

- Communicate information truthfully and empathetically
- Impart medical evidence-based knowledge in lay language
- Critical debate of pseudo-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)

1. Leitlinienprogramm Onkologie (Deutsche Krebsgesellschaft, Deutsche Krebshilfe, AWMF): Psychoonkologische Diagnostik, Beratung und Behandlung von erwachsenen Krebspatient\*innen, Langversion 2.1, 2023, AWMF-Registernummer: 032-051OL <https://www.leitlinienprogramm-onkologie.de/leitlinien/psychoonkologie/>; Zugriff am [03.01.2024]



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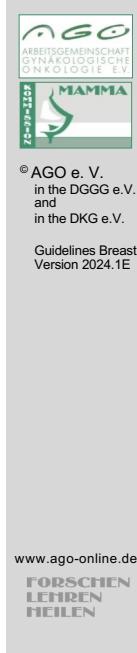
## Evidence-based Information

**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.

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2. Ärztliches Zentrum für Qualität in der Medizin (ÄZQ). Handbuch Patientenbeteiligung. <https://www.aezq.de/mdb/edocs/pdf/schriftenreihe/schriftenreihe33.pdf>. Zugriff 20.01.2020
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# 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.**

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

1. Littell RD, Kumar A, Einstein MH, et al.: Advanced communication: A critical component of high quality gynecologic cancer care: A Society of Gynecologic Oncology evidence based review and guide. *Gynecol Oncol.* 2019;155(1):161–169. doi:10.1016/j.ygyno.2019.07.026

### Trust and Fear

1. Zwingmann J, Baile WF, Schmier JW, et al. Effects of patient-centered communication on anxiety, negative affect, and trust in physician in delivering a cancer diagnosis: A randomized, experimental study. *Cancer* 2017;123:3167-3175.
2. Elsner, K., Naehrig, D., Halkett, G., & Dhillon, H. M. (2017). Reduced patient anxiety as a result of radiation therapist-led psychosocial support: a systematic review. *Journal of medical radiation sciences*, 64(3), 220–231. doi:10.1002/jmrs.208
3. Curtis J, Back A, Ford D, et al. Effect of communication skills training for residents and nurse practitioners on quality of communication with patients with serious illness: a randomized trial. *JAMA*.2013;310:2271-2281
4. O. Husson, F. Mols, L.V. van de Poll-Franse The relation between information provision and health-related quality of life, anxiety and depression among cancer survivors: a systematic reviewAnn Oncol, 22 (2011), pp. 761-772
5. Tulsky, J.A., et al., Enhancing communication between oncologists and patients with a computer-based training program: a

randomized trial. Ann Intern Med, 2011. 155(9): p. 593-601.

#### Patient satisfaction

1. A. Boissy, A.K. Windover, D. Bokar, M. et al. Communication skills training for physicians improves patient satisfaction. J. Gen. Intern. Med., 31 (7) (2016), pp. 755-761
2. Venetis MK, Robinson JD, Turkiewicz KL, Allen M. An evidence base for patient-centered cancer care: a meta-analysis of studies of observed communication between cancer specialists and their patients. Patient Educ Couns. Dezember 2009;77(3):379–83.
3. J.B. Mallinger, J.J. Griggs, C.G. Shields. Patient-centered care and breast cancer survivors' satisfaction with information. Patient Educ Couns, 57 (2005), pp. 342-349
4. Zachariae R, Pedersen CG, Jensen AB, et al.: Association of perceived physician communication style with patient satisfaction, distress, cancer-related self-efficacy, and perceived control over the disease. Br J Cancer. 2003;88:658–65 (personal contact, medical aspects)
5. Arora, N.K., Interacting with cancer patients: the significance of physicians' communication behavior. Soc Sci Med, 2003. 57(5): p. 791-806.

#### Adherence

1. Miller TA. Health literacy and adherence to medical treatment in chronic and acute illness: A meta-analysis. Patient Educ Couns. 2016;99(7):1079–1086. doi:10.1016/j.pec.2016.01.020
2. Zolnierek, K.B. and M.R. Dimatteo, Physician communication and patient adherence to treatment: a meta-analysis. Med Care, 2009. 47(8): p. 826-34.
3. Kahn, K.L., et al., Patient centered experiences in breast cancer: predicting long-term adherence to tamoxifen use. Med Care, 2007. 45(5): p. 431-9.

#### Decision making

1. Edwards AG, Naik G, Ahmed H, et al. Personalised risk communication for informed decision making about taking screening tests. Cochrane Database Syst Rev. 2013;2013(2):CD001865. Published 2013 Feb 28. doi:10.1002/14651858.CD001865.pub3

#### Communication problems

1. Nicolaije KA, Husson O, Ezendam NP, et al. Endometrial cancer survivors are unsatisfied with received information about diagnosis, treatment and follow-up: a study from the population-based PROFILES registry. Patient Educ Couns. 2012;88(3):427–435. doi:10.1016/j.pec.2012.05.002



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## Communication Training

Oxford	LoE	AGO
		+

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

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

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

### Promotion of communicative skills

1. Barth J, Lannen P. Efficacy of communication skills training courses in oncology: a systematic review and meta-analysis. *Ann Oncol*. 2011;22(5):1030–1040. doi:10.1093/annonc/mdq441
2. Bos-van den Hoek DW, Visser LNC, Brown RF, Smets EMA, Henselmans I. Communication skills training for healthcare professionals in oncology over the past decade: a systematic review of reviews. *Curr Opin Support Palliat Care*. 2019;13(1):33-45. doi:10.1097/SPC.0000000000000409

### Patienten Satisfaction

1. Uitterhoeve, R.J., et al., The effect of communication skills training on patient outcomes in cancer care: a systematic review of the literature. *Eur J Cancer Care (Engl)*, 2010. 19(4): p. 442-57.

### Empathy

1. Moore PM, Rivera S, Bravo-Soto GA, Olivares C, Lawrie TA. Communication skills training for healthcare professionals working

with people who have cancer. Cochrane Database Syst Rev. 2018;7(7):CD003751. Published 2018 Jul 24.  
doi:10.1002/14651858.CD003751.pub4

Training, coaching, OPL

1. A. Boissy, A.K. Windover, D. Bokar, M. et al. Communication skills training for physicians improves patient satisfaction. J. Gen. Intern. Med., 31 (7) (2016), pp. 755-761



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## 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.

1. Rimer BK, Briss PA, Zeller PK, Chan EC, Woolf SH. Informed decision making: what is its role in cancer screening? *Cancer*. 2004 Sep 1;101(5 Suppl):1214-28. doi: 10.1002/cncr.20512.



# Health Literacy

Shared Decision Making - Participatory Decision

Oxford		
LoE	GR	AGO
1b	A	
3b	C	+
4	C	+

- 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

## Definition

1. Beauchamp, T.L. and J.F. Childress, Principles of biomedical ethics. 2001: Oxford University Press, USA.
2. Sieber, W.J. and R.M. Kaplan, Informed adherence: the need for shared medical decision making. *Control Clin Trials*, 2000. 21(5 Suppl): p. 233s-40s.
3. Weinstein, J.N., Editorial: The missing piece: Embracing shared decision making to reform health care. 2000, LWW.

## Prognosis, Treatment, QoL

1. Hagerty RG, Butow PN, Ellis PM, Dimitry S, Tattersall MH. Communicating prognosis in cancer care: a systematic review of the literature. *Ann Oncol*. 2005; 16(7):1005–1053. [PubMed: 15939716]
2. Hagerty RG, Butow PN, Ellis PM, et al. Communicating with realism and hope: incurable cancer patients' views on the disclosure of prognosis. *J Clin Oncol*. 2005; 23(6):1278–1288. [PubMed: 15718326]
3. Wright AA, Zhang B, Ray A, et al. Associations between end-of-life discussions, patient mental health, medical care near death, and caregiver bereavement adjustment. *JAMA*. 2008; 300(14):1665–1673. [PubMed: 18840840]

4. A Vodermaier 1, C Caspari, J Koehm, S Kahlert, N Ditsch, M Untch: Contextual factors in shared decision making: a randomised controlled trial in women with a strong suspicion of breast cancer. *Randomized Controlled Trial Br J Cancer*. 2009 Feb 24;100(4):590-7. doi: 10.1038/sj.bjc.6604916. Epub 2009 Feb 10.
5. Oprea N, Ardito V, Ciani O: Implementing shared decision-making interventions in breast cancer clinical practice: a scoping review. *BMC Med Inform Decis Mak*. 2023 Aug 23;23(1):164. doi: 10.1186/s12911-023-02263-8.

Hesitation etc.

1. Frosch DL, May SG, Rendle KA, et al.: Authoritarian physicians and patients' fear of being labeled "difficult" among key obstacles to shared decision making. *Health Aff (Millwood)*. 2012; 31(5):1030–1038. [PubMed: 22566443]

Caregivers:

1. Cincidda C, Pizzoli SFM, Ongaro G, Oliveri S, Pravettoni G. Caregiving and Shared Decision Making in Breast and Prostate Cancer Patients: A Systematic Review. *Curr Oncol*. 2023 Jan 6;30(1):803-823. doi: 10.3390/curroncol30010061.
2. Recommendation ABC7, Lisbon, Portugal, Nov 2023



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

### 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.

1. Zheng H, Yang L, Hu J, Yang Y. Frequency and Influencing Factors of Shared Decision Making Among Breast Cancer Patients Receiving Surgery: A Systematic Review and Meta-Analysis. Clin Breast Cancer. 2023 Jan;23(1):e20-e31.



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## 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.**

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# Health Literacy

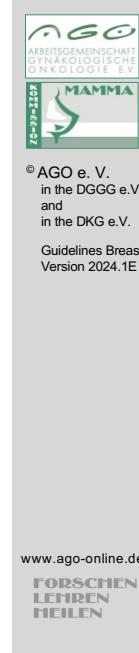
## Decision Aids for Patients

	Oxford	AGO
	LoE	AGO
<b>The use of decision support in the physician-patient communication</b>		
▪ 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	

### Decision Aids

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## 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 2a B
- the active role of patients in the process of decision making 2b B

#### Active Role:

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## Use of eHealth (DiGA)

Oxford		
LoE	GR	AGO
2b	B	+/-

- 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

2b      B      +/-

\* See current DiGA status / reimbursement

DiGA aktuell: [diga.bfarm.de](http://diga.bfarm.de)

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