

Online Appendix A. Questionnaires including at least five items assessing empowerment related manifestations.

Measurement Tool and Authors	Target population and Country	Number of items	Description of focus	Description of subscales	Reason for inclusion – what makes it a measure of empowerment
Primary focus on the INTRAPERSONAL COMPONENT of PE How people think about themselves and includes domain-specific perceived control and self-efficacy, motivation to control, perceived competence, and mastery One's perception of one's ability is important. If the patients don't believe they know the relevant questions, dare to ask them or think they can get or understand information from the doctor they are unlikely to act actively to achieve these results.					
The Communication and Attitudinal Self-efficacy scale for cancer (CASE-cancer) [1]	Developed for cancer patients In the development the scale was interviewer-administered, but it is also appropriate to be self-administered USA	12 About 6-8 empowerment related items	Examine perceived control related to important roles patients are expected to fulfill in cancer care.	Subscales: 1) Understand and participate in care 2) Maintain a positive attitude 3) Seek and obtain information “Items are constructed with simple stems designed to gauge confidence (e.g. It is easy for me to...; I know I will be able to...; I am confident that I can...). The patients were asked to state if they ‘very strongly disagree’ to ‘very strongly agree’ with the different statements.	Measures mainly the intrapersonal component e.g., beliefs and self-efficacy in patients ability to - seek and obtain information - understand an participate in care - ask questions (etc.)
The Perceived Efficacy in Patient-Physician Interactions Questionnaire (PEPPI) [2]	Developed for older patients Used among patients with prostate cancer USA In the development study the questionnaire was	10 About 9 empowerment related items	To measure patients self-efficacy in obtaining medical information and attention to their medical concerns from physicians. To measure patients' confidence in their ability to elicit and understand	Subscales not mentioned. Each item begins with: “how confident are you in your ability to...” Response format ‘Very confident’ to ‘not at all confident’.	Measures mainly the intrapersonal component e.g., beliefs in one's ability to - know what questions to ask - get information from the doctor - understand information from the doctor - ask for further explanations etc.

	interviewer administered		information from and communicate information to their physicians, as well as confidence in their ability to get their physicians to address and act on their main medical concerns.		The authors suggest that this instrument may be useful in measuring the impact of empowerment interventions to increase patients' personal sense of effectiveness in obtaining needed health care.
The Cancer Behavior Inventory (CBI-L) [3]	Developed for cancer patients USA	43 About 8 empowerment related items	To measure self-efficacy for coping with cancer.	6 factors: 1) Maintenance of Activity and Independence 2) Coping with treatment related side effects 3) accepting cancer/maintaining positive attitude 4) Seeking and Understanding Medical Information 5) Affective regulation 6) Seeking Support Patients were asked to rate the importance of each behavior and the difficulty in performing each behavior.	Measures mainly the intrapersonal component e.g., the patients belief in own ability to perform certain behaviors such as - Asking health professionals questions - Actively participating in treatment - Seeking information about cancer - Understanding information etc.
The Patient Activation Measure (PAM) [4]	Developed for chronic disease patients (PROWG – a set of recommended PRO measures across the cancer continuum) USA	22 About 5 empowerment related items	Focus on patient activation	1) Believes active role important 2) Confidence and knowledge to take action 3) Taking action 4) Staying the course under stress Statements were respondents indicate degree of agreement	Measures mainly the intrapersonal component e.g., to what extent the patient is confident in the ability to - Inform health care professionals about important concerns (confidence in talking to healthcare providers) - Find trustworthy sources of information - Know when to seek help etc.

The scale also measures the interactional component e.g. the patient knows

- The purpose of the medicine
- All the possible treatment options etc.

*This measure is on the limit of being considered relevant in this review with a high focus on lifestyle and concerns in the home

Primary focus on the INTERACTIONAL COMPONENT of PE

- How people think about and relate to their social environment, and the need to be attentive to different behavioral options and choices of actions that can serve as appropriate to achieve one's goals

Includes elements of navigating in relation to knowledge. Patient's ability to use health information for their own benefit can be a means to participate in their own health care.

Accessing, understanding and using relevant knowledge is an important factor to navigate the health care system and taking control in situations regarding ones illness.

The Decisional Conflict Scale (DCS) [5]	Developed for decisions about influenza immunization and breast cancer screening. Considered appropriate to be administered to patients with cancer in a Japanese study. Canada	16 About 5 empowerment related items	Measures: 1) health-care consumers' uncertainty in making a health-related decision; 2) the factors contributing to the uncertainty; and 3) health-care consumers' perceived effective decision making	3 subscales: 1) Decision uncertainty, 2) Factors contributing to uncertainty, 3) Perceived effective decision making Aiming to measure if patients are feeling equipped to make a decision (having the proper information, knowing ones options, not being pressured, knowing what one wants, knowing different consequences to different choices etc.) There are three different versions of the scale – the statement format has 5	Measures mainly the interactional component e.g., patients knowledge about - available options - benefits, risks and side effects of each option * This measure is about one specific situation/decision and not
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				response categories from ‘strongly agree’ to ‘strongly disagree’.	useful for a whole treatment process
Patient Satisfaction With Cancer Care Measure (PSCC) [6]	Developed for cancer patients Aimed to measure the spectrum of cancer-related care from screening to treatment of diagnosed cancer USA	18 About 6 empowerment related items	Measuring patient’s satisfaction with cancer care – addressing satisfaction with care during evaluation of screening abnormalities and treatment.	No subscales reported – 1-dimensional measure – 1 component structure Patients were asked to rate statements from strongly agree to strongly disagree. Such as if they felt included in decisions, knew the next step in their care, felt confident in how to deal with the healthcare system etc.	Measures mainly the interactional component e.g., assess if the patient knows - the plan of the treatment - Who to contact when having questions The measure also entails some items covering the intrapersonal component and enablement.
Cancer Assessment for Young Adults – Testicular (CAYA-T) [7]	Developed for Young Men with Testicular Cancer. USA	90 About 6 empowerment related items	Patient-reported outcome instrument to measure health-related quality of life (HRQOL) in young adults with cancer.	17 scales: physical, sexual confidence, sexual functioning, body image strength, positive masculine self-image, positive adult self-image, cognitive-emotional regulation, disclosure ability, relationship maintenance, social connectedness, healthcare confidence, goal navigation, goal facility, financial maintenance, recreational pursuit, spiritual stability, and finding meaning. “...how often would you say the following has been true for you?” From none of the time to almost all of the time.	Measures mainly the interactional component e.g., the patients knowledge of - How to get relevant information about ones health - How to get health-related questions answered The scale also measures the interpersonal component e.g., the patients confidence in - Taking health-related decisions - Talking with health care professionals
Cancer Care Coordination Questionnaire for Patients [8]	Developed for cancer patients Australia	20 About 5 empowerment related items	Measures patients’ experience of cancer care coordination	2 factors 1) Communication 2) Navigation The patient were asked to state their level of agreement with statements	Measures mainly the interactional component e.g., the patients knowledge of - The plans for tests, treatment and follow-up - The reasons for having the tests and or treatment

				about their received care (from ‘strongly disagree’ to ‘strongly agree’)	- The any advantages and disadvantages of treatments etc.
The HELP questionnaire [9]	Developed for patients with musculoskeletal diseases Used in one study with cancer patients Germany	18 About 10-12 empowerment related items	To measure self-reported health education literacy. “HELP items aim to capture the patient’s aggregate perception of the difficulties he or she has with comprehension (i.e. understanding foreign words and medical terminology) and communication (i.e. posing questions, expressing needs) in various health education or treatment situations”.	Three subscales: 1) comprehension of medical information 2) applying medical information 2) communicative competence in provider interactions Patients were asked “how much difficulty do you have in talks with doctors, therapists or nursing staff...” (e.g. understanding medical information given to you) - “no difficulty” to “extreme difficulty”.	Measures mainly the interactional component e.g., the patients ability to - Understand medical information - Understand the medical information in term of their own disease - Distinguishing essential from less important information etc.

Primary focus on the BEHAVIORAL COMPONENT of PE

- refers to actions taken to directly influence outcomes

Functional, communicative and critical health literacy [10]	Developed for diabetes patients Tested on breast cancer patients and patients with rheumatic diseases. (The Netherlands)	14 About 7 empowerment related items	Measuring three different levels of health literacy (i.e., functional, communicative, and critical) in patients	Three subscales: 1) Functional Health Literacy 2) Communicative Health Literacy 3) Critical Health Literacy Patients are asked to inform how often they have had trouble with, or have performed certain actions in relation to health information. A 4-point likert scale ranging from	Measures mainly the interactional component e.g., assess the patients capacity to - To access, understand and use health information The authors argue that critical health literacy is advanced skills for critically analyzing
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				“never” to “often”.	information and using information to exert control over life events and situations.
A patient questionnaire measuring communication competence in the context of patient–provider interaction - The CoCo questionnaire [11]	Developed for patients with chronic illnesses Developed and tested on patients with breast cancer, chronic back pain and chronic-ischemic heart disease who underwent inpatient rehabilitation.	28 About 10 empowerment related items	Measuring communication competence in the context of patient-provider interaction.	Four-factor model: 1) Patient adherence in communication (ADH) 2) Critical and participative communication (CRI) 3) Communication about personal circumstances (PER) 4) Active disease-related communication (ACT) The patients were asked for their agreement (‘strongly disagree’ to ‘strongly agree’) in statements about their own communication behavior in their meeting with the health professional.	Measures mainly the behavioral component e.g., the patients behavior regarding - showing interest in treatment - expressing one’s opinion and discussing with the doctor - asking questions when information is needed The authors argue that active patient-provider interaction corresponds closely with the aims of patient empowerment and self-management.
The Patient Self-Advocacy Scale (PSAS) [12]	Germany Developed for HIV/AIDS patients. The measure has been adapted to measure self-advocacy among cancer patients USA	13 About 5 empowerment related items	Measuring self-advocacy among cancer patients.	1) Increased illness education 2) Increased assertiveness with a doctor, 3) Potential for mindful non-adherence to prescribed treatments ‘strongly disagree’ to ‘strongly agree’ Patients were asked about their behavior in seeking information or questioning the doctors decisions and things they didn’t understand	Measures mainly the behavioral component e.g., the patients behavior regarding - actively seeking information - asking questions - Making suggestions - Discussing with the doctor etc. The measure aims to assess the concept self-advocacy, understood by the authors as a set of beliefs concerning being an informed health care consumer. This requires skills such as accessing information, asking questions, communicating one’s own views and preferences with health.

Measurement of patient competence [13]	Developed for cancer patients Germany	57 About 16-20 empowerment related items	Measuring patient competence in the context of shared medical treatment decision making and coping with cancer.	Five problem focused subscales: 1) Seeking information, 2) Self-regulation, 3) Being assertive in interaction with physician, 4) Striving for autonomous decisions, 5) Interest in social services Three emotion-focused subscales: 1) Managing distress, 2) Dealing explicitly with threat posed to life by cancer, 3) Avoidance Most items is to be rated on a 5-point Likert scale according to the degree to which they applied to the respondent (1=not true at all, 5=completely true)	Measures mainly the behavioral component e.g., the patients behavior regarding - actively seeking information - asking questions - expressing one's opinion and discussing with the doctor etc. Patient competence is defined by the authors as: "an ability or set of skills of the patient essential for mastering tasks arising in the context of cancer and its treatment".
The Patients' Perceived Involvement in Care Scale – the modified version (M-PICS) [14]	Developed for patients with pain. Also tested on breast cancer outpatients USA	20 About 8-9 empowerment related items	A measure designed to assess pain patients' perceptions of patient health care provider communication during the medical consultation.	4 factors: 1) Reflected health care provider information behaviors 2) Health care provider facilitation of patient involvement 3) patient information provision 4) patient participation in decision making items asking the patient to report the extent to which she asked questions, offered opinions, and expressed concerns when meeting with each physician.	Measures mainly the behavioral component e.g., the patients behavior regarding - asking questions - making suggestions - expressing one's opinion and discussing with the doctor - making requirements for tests and treatments etc.
The Patient Communication Pattern Scale (PCPS) [15]	Developed for cancer patients Israel	14 About 6-7 empowerment	A tool for evaluating patients' communication patterns.	1)Relaying clear information about the illness and symptoms 2) Questioning and requesting clarifications	Measures mainly the behavioral component e.g., the patients behavior regarding - asking questions about

ent related
items

- 3) Initiating request for information from the physician
- 4) Guiding the physician according to one's own preferences
- 5) Reporting one's feelings

The patient had to express agreement (strongly disagree to strongly agree) related to statements about their specific communication in meeting with the doctor.

- treatment options and their side-effects
- asked for explanations when information was unclear
 - taking part in decision making

The health care systems **ENABLEMENT** of PE (PE understood as a relational concept)

- How the health care system/health care professionals makes opportunities for the patient to be informed and involved (e.g., providing relevant information, enabling participation in decision-making, listening, answering questions etc.)
- As such it measures facilitators rather than manifestations of empowerment

Consumer Quality Index Questionnaire – Cancer Patients Care – Cancer Patients' Experiences of Hospital Care (CQI) (v2)
[16]

Developed for cancer patients

The Netherlands

99

About 9 empowerment related items

Measures cancer patients experiences with hospital care

Themes:

- 1) Organisation of the hospital
- 2) Patient-centered approach by nurses
- 3) Patient-centered approach by doctors
- 4) Information and communication
- 5) Personal input
- 6) Skills and knowledge of the health professionals
- 7) Cooperation and communication between healthcare professionals
- 8) Guidance and support
- 9) End of the treatment
- 10) After care
- 11) Grading of the hospital

Apart from the questions regarding patient characteristics all questions had one of the following response categories 'never-sometimes-usually-always', 'no not at all-somewhat-largely-yes completely', 'none-some-

Measures mainly the health care systems enablement of empowerment e.g., if the health care professionals

- provide understandable information, information about side effects, treatment effect, information about available treatments
- made it possible to participate in decisions, gave information to enable participation in decisions etc.

				most-all', or one through ten for grades.	
EORTC QLQ-INFO25 [17]	Developed for cancer patients 7 European countries and Taiwan	25 About 19 empowerment related items	Evaluates the information received by cancer patients	4 multi-item scales: 1) Information about disease, 2) Information about medical test, 3) Information about treatment, 4) Information about other services And 8 single items Measures how much information the patients have received about different aspects of their disease and their treatment ('Not at all' to 'Very much')	Measures mainly the health care systems enablement of empowerment e.g., the amount of information provided by the health care professional on - diagnosis of disease - extent of disease - purpose of medical tests - procedures of the medical tests - the medical treatment - Possible side-effects etc. Adequate information is important to gain an increase in empowerment, because it is a prerequisite for having control over the situation. Therefore the healthcare systems provision of information to cancer patient is relevant to enable the patient to be involved and take control.
The Quality of Patient-Centered Cancer Care Measure (QPCCC) [18]	Developed for cancer patients Developed and tested among Hematological cancer survivors Australia	48 About 18 empowerment related items	A measure that addresses all the 6 objectives for achieving patient-centered care recommended by The Institute of Medicine (IOM). "The 6 dimensions are: care must be respectful of patients' values, preferences, and expressed needs; be coordinated and	10-factor structure: 1) Treatment delivery, 2) Treatment Decision Making, 3) Coordinated and Integrated Care, 4) Emotional support, 5) Timely care, 6) Follow-Up Care, 7) Respectful communication, 8) Patient Preferences and Values, 9) Cancer Information, 10) Equitable Care Patients were asked to indicate their agreement with statements about	Measures mainly the health care systems enablement of empowerment e.g., if the health care professionals - Provided information - Explained treatments, side-effects and consequences of not having treatment - Explained the content of follow-up care etc.

			integrated; provide information, communication, and education; ensure physical comfort; provide emotional support; and involve family and friends.” The goal of patient-centered care is to let patients’ needs, and patient values guide decisions.	different health care professionals actions (from ‘strongly agree’ to ‘strongly disagree’).	
QUOTE Breast Cancer (Quality Of care Through the patients’ Eyes)[19]	Developed for breast cancer patients The Netherlands	33 About 8-9 empowerment related items	Measures patients’ perceptions on quality of breast cancer care. Assesses the professionals’ performance and patients’ needs in the care process.	5 factors 1) patient education regarding aspects related to postoperative treatment 2) Services by breast nurse 3) Services by surgeon 4) Patient education regarding activities at home 5) Patient education regarding aspects related to preoperative treatment + separate items The questionnaire consists of four different sections. In this context one section is relevant; section A: here patients were asked to rate perceived performance of healthcare professionals/services.	Measures mainly the health care systems enablement of empowerment e.g., to what degree different health care professionals - Informed the patient about side-effects and consequences of treatment - Explained things understandably - Informed about different treatment options etc.
Assessment of Patient Experiences of Cancer Care (APECC)[20]	Developed for cancer patients in follow-up care. Tested among leukemia, bladder, and colorectal cancer survivors.	33 About 6 empowerment related items	Assessing survivors’ perceptions of the quality of their follow-up care.	Areas and subscales: 1) Access to care (getting needed care, timeliness of care, waiting time in physicians’ office) 2) Interaction with physician (Information exchange, affective behavior, physicians’ knowledge) 3) Interaction with other members of	Measures mainly the health care systems enablement of empowerment e.g., to what degree the health care professionals - provides sufficient and understandable information - makes sure patient

	USA			the health care team (interaction with nurses and interaction with office staff) 4) Discussion of health promotion 5) Perceptions of coordination of care + Survivors overall ratings of their care A majority of items had following response options: not a problem to a big problem, never to always, yes definitely to no, or poor to excellent.	understands information - provides satisfactory answers - encourage to ask questions etc.
Oncology Patients' Perception of the Quality of Nursing Care Scale (OPPQNCs Long Form)[21]	Developed for cancer patients USA	40 About 5 empowerment related items	Measures the quality of cancer nursing care from the patient's perspective.	4 factors 1) Responsiveness 2) Individualization 3) Coordination 4) Proficiency Patients were asked to rate the frequency of nursing activities presented in the scale (from 'never' to 'always') The questionnaire is divided into five sections: 1) GP visits and referral (17) 2) Tests at the hospital (19) 3) Diagnosis and treatment decision (30) 4) Treatment and discharge (25) 5) Monitoring (15) Several different response options.	Measures mainly the health care systems enablement of empowerment e.g., to what degree nurses - answer questions - help to get information - discusses care options - encourage to actively participate in care.
The Prostate Care Questionnaire for patients (PCQ-P)[22]	Developed for prostate cancer patients England	106 About 20 empowerment related items	An instrument designed to measure patient experience of prostate cancer care.		Measures mainly the health care systems enablement of empowerment e.g., if health care professionals - took patients concerns seriously - provided information about diagnosis - explained treatment options and their consequences - explained next steps after treatment etc.
The Perceived Physician's Communication Style	Developed for cancer patients	30 About 6-8	Evaluates the physician's communication	Four factors: 1) Acceptive 2) Patient-centered	Measures mainly the health care systems enablement of empowerment.

Scale[23]	(developed on a group of breast cancer patients) Japan	empowerment related items	style	3) Attentive 4) Facilitative Patients were asked to which extent they agreed with statements. A high value indicate high appraisal of the doctor's communication style.	The measure aims to assess - the amount and the quality of the information provided by the physician - the physicians attempt to engage the patient in the medical dialogue (e.g. through asking patients' opinions and confirming with the patients whether they understand what they were told by the physician)
Cancer patients' decision-making regarding treatment and nursing care[24]	Developed for cancer patients Finland	124 About 11 empowerment related items *We didn't have access to the full scale in the article, but sufficient items to assess the scales relevance	Measures to what extent patients participate in decision-making about their treatment and nursing care	Five main areas: 1) demographic data 2) mood 3) information obtained 4) relationships with staff 5) decision-making Area 3: "Information obtained" is divided into three domains: A) method of providing information (16) B) receiving information about different issues (16) C) search for additional information (8) Area 5: "Decision-making" is divided into four domains: A) participation in decision-making about treatment (12) B) perceived importance of that participation (12) C) participation in decision-making about nursing care (10) D) perceived importance of that participation (10)	Measures mainly the health care systems enablement of empowerment e.g., to what degree the patient has - been involved in discussions about treatment - had opportunities to express opinion - asked about consent for treatment - been encouraged to participate in care - had the opportunity to choose alternatives etc. The measure also entails elements of the behavioral component of empowerment, e.g., it measures the extent to which respondents used different sources of information, if they make their own decisions.

				Participation was measured using “to a great extent” to “not at all”.	
The communication behavior questionnaire (KOVA)[25]	Developed for chronic back pain patients and chronically ill patients Used among breast cancer patients Germany	32 About 9-10 empowerment related items	Measures the communication behavior of physicians	Four scales: 1) Patient participation and patient orientation 2) Effective and open communication 3) Emotionally supportive communication 4) Communication about personal circumstances The patients were asked about their physicians behavior on different aspects (e.g. “Your physician has discussed the treatment plan with you”) with the response options from ‘strongly agree’ to ‘strongly disagree’.	Measures mainly the health care systems enablement of empowerment e.g., to what degree the physician - discussed treatment with the patient - explain the treatment plan - explained treatment procedures - discuss the next stage with the patient etc.
Decision Quality Index - DQI[26] 3 different versions/target groups: - Chemotherapy and Hormone Therapy v2.1 - Early Prostate Cancer Treatment v1.0 - Breast cancer Surgery[27]	Developed for cancer patients USA	17/22/17 About 7/8/7 empowerment related items	Decision quality instruments include decision-specific items to assess (1) the extent to which patients are informed (2) patients' goals and concerns and the treatments received (3) the extent to which patients are involved in their decisions about their care.	1) What matters most to you 2) Facts about treating prostate cancer/breast cancer surgery/chemotherapy and hormone therapy 3) Talking with health care providers Several different response categories	Measures mainly the health care systems enablement of empowerment e.g., to what degree the health care provider discussed - treatment options, reason to choose or not to choose treatment - different treatment options - involvement in the decision etc.
Prostate Cancer Needs Questionnaire version 2	Developed for prostate cancer	69	Measuring perceived needs of	The measure is presented in two parts.	Measures mainly the health care systems enablement of

(PCNQv2)[28]	patients Australia	About 7-8 empowerment related items	men diagnosed with prostate cancer. Both needs at diagnosis and initial treatment, and current needs.	A) Past issues and experiences (time at diagnosis, time of treatment decisions', initial treatment experiences) consists of seven factors: 1) Specialist support 2) Anxiety and Urgency 3) Knowledge of prostate cancer & tests 4) GP support 5) Confidence in Treatment 6) Informed choice 7) Support from other sources B) Current issues and experiences (How do you feel now?) consists of six factors: 1) Role limitations 2) GP ongoing support 3) Impotence & sexual issues 4) Incontinence 5) Personal integration & control 6) Specialist ongoing support Items are framed as statements of issue or problem with the response options from "strongly Disagree" to "Strongly Agree".	empowerment e.g., - the patient received clear explanation of diagnosis and treatment options etc.
The Medical Interview Satisfaction Scale (MISS) [29]	Developed for patients in general USA	26 About 6 empowerment related items	Measuring patient satisfaction with an encounter with a physician or other primary care provider	1) cognitive subscale 2) affective subscale 3) Behavioral subscale	Measures mainly the healthcare systems enablement of empowerment e.g., - The doctor provided information the patient understood - talking with doctor gave answers - understanding of the plan - understanding of prescribed medicines * This measure is about one specific situation and not useful

Informational needs [30]	Developed breast cancer patients and later on adapted for prostate cancer patients	29	Measuring patients informational needs and to which extent these needs have been covered in the meeting with the healthcare system	Five subsections of need: 1) disease 2) treatment 3) physical 4) psychosocial 5) investigative tests	for a whole treatment process
	UK	About 18 empowerment related items		The scale consisted of two parts a) assessed the informational needs b) assessed how well each need had been addressed through the patient's care	Measures mainly the healthcare systems enablement of empowerment e.g. to what degree the health care provider informed about - how to prepare for treatment - the reasons for tests and understanding of the results - knowledge about side effects and what to do - knowledge about the treatment and estimated time of treatment

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