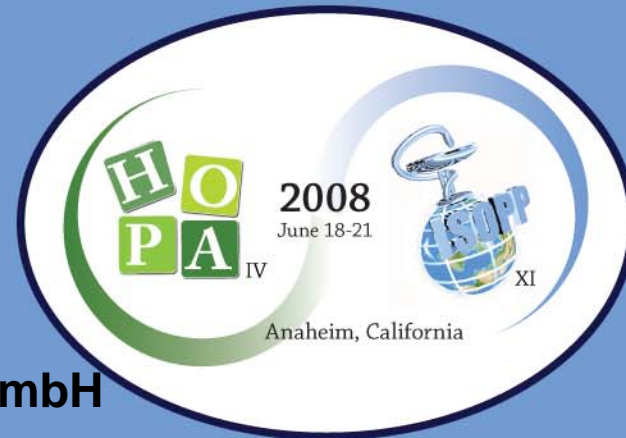


Patients' Information and Support Needs



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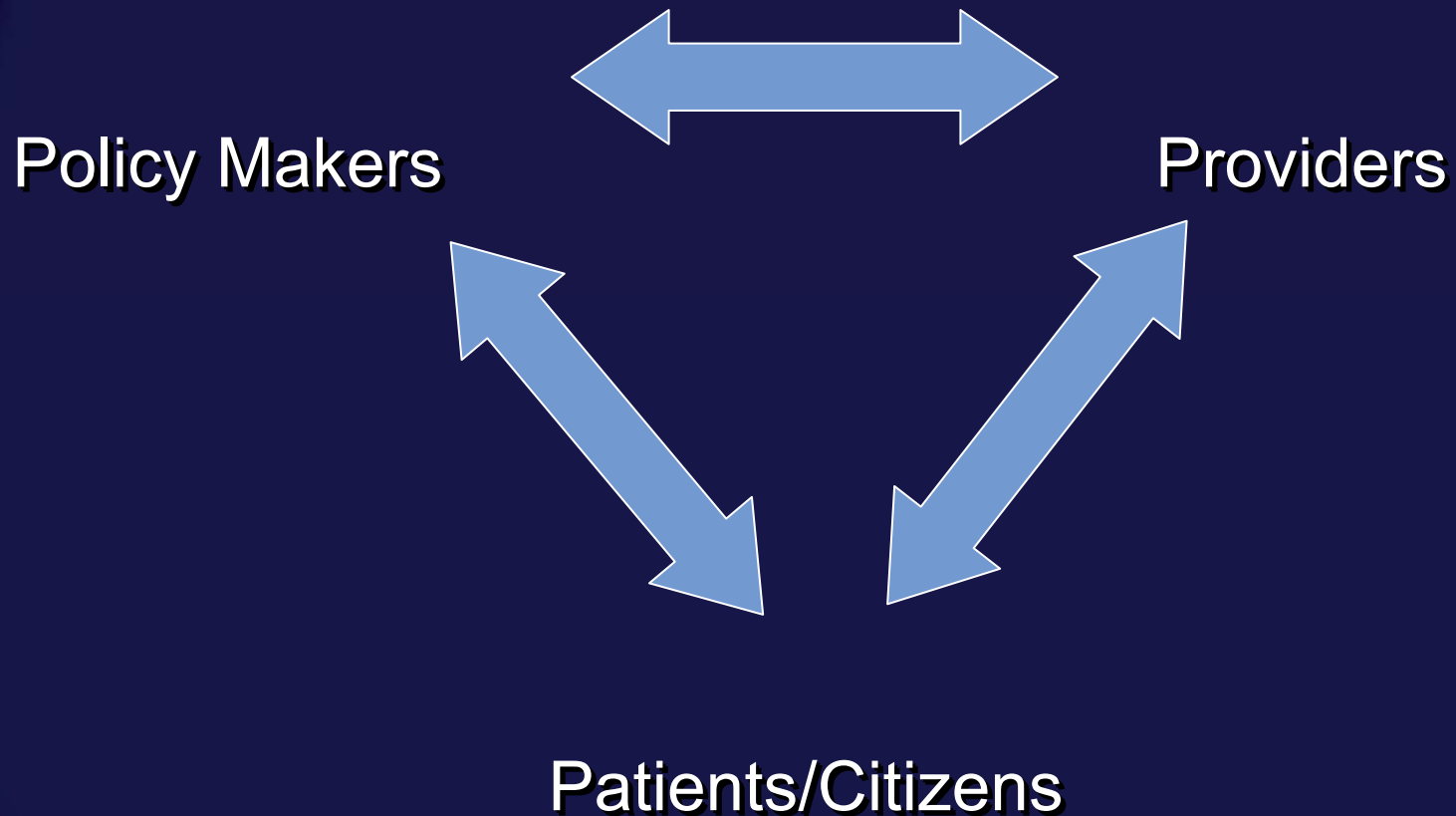
Disclosure

- Klaus H. Meier has no real or apparent conflicts of interest to report

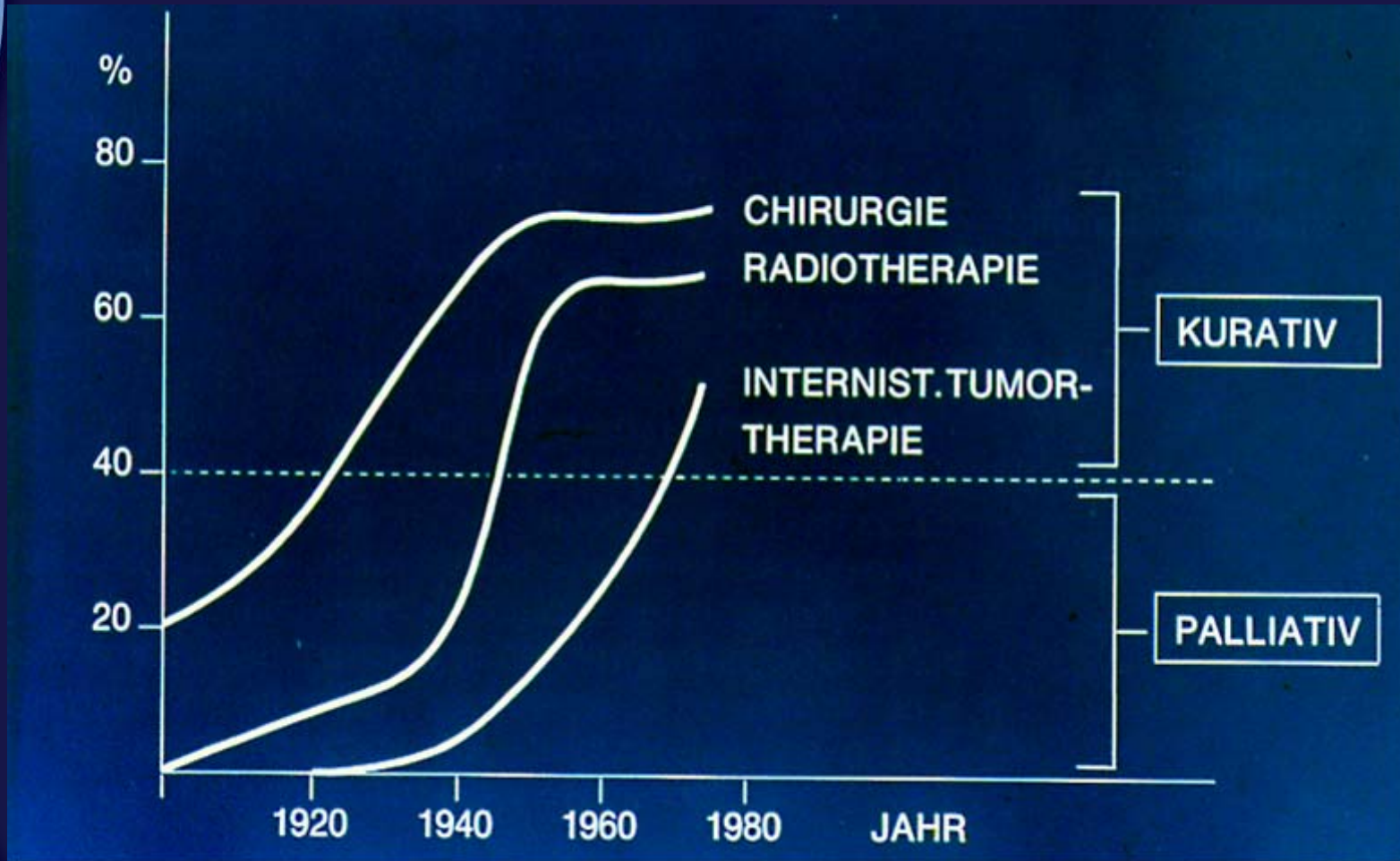
Learning Objectives

- Identify important questions to patients by understanding an illness from the patient's perspective
- Extract important information from the patient information literature
- Describe how cancer patients can share their expertise with physicians and pharmacists

The Information Loop



The History of Treatment in Oncology Therapy



Compliance of Cancer Patients

Entity	Oral Therapy	Compliance (%)
Hematology Illness	Prednisone	26,8
	Allopurinol	16,8
Breast Cancer	Cyclophosphamide	53
	Prednisone	
Breast Cancer		97,9 (*)
	Tamoxifen	92,1 (#)
		85,4 (§)

* = self info # = drug counting § = electronic control

Information Flows

- Information FROM patients (needs assessment, feedback for quality improvement, values, and preferences)
- Information TO patients (prevention, self-care, treatment decisions, policy options)

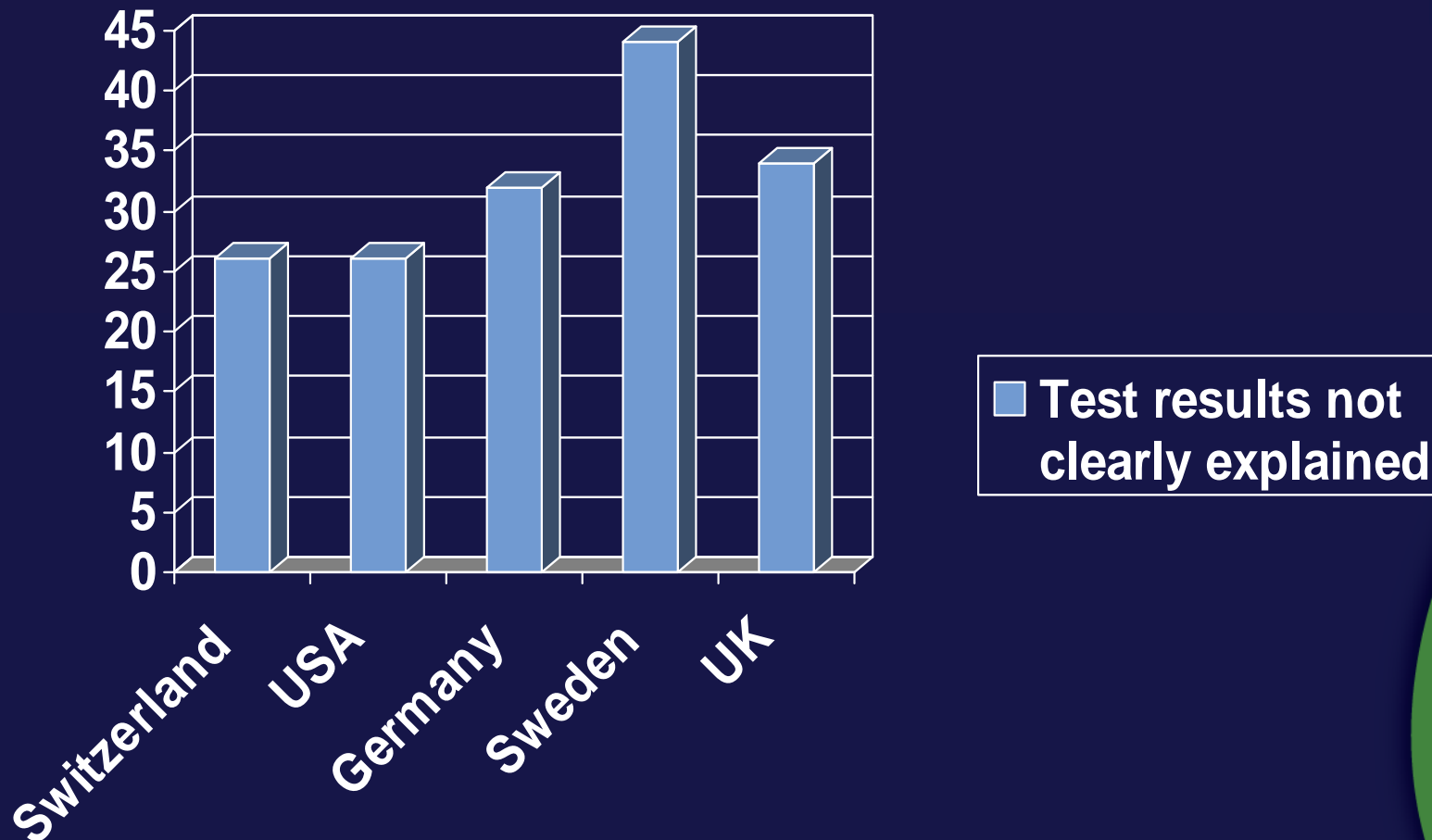
Information for Patient Empowerment

- Good communication with health professionals
- Printed and online information
- Telephone helplines and support groups
- Education for self-help
- Evidence-based decision aids

Feedback From Hospital Patients

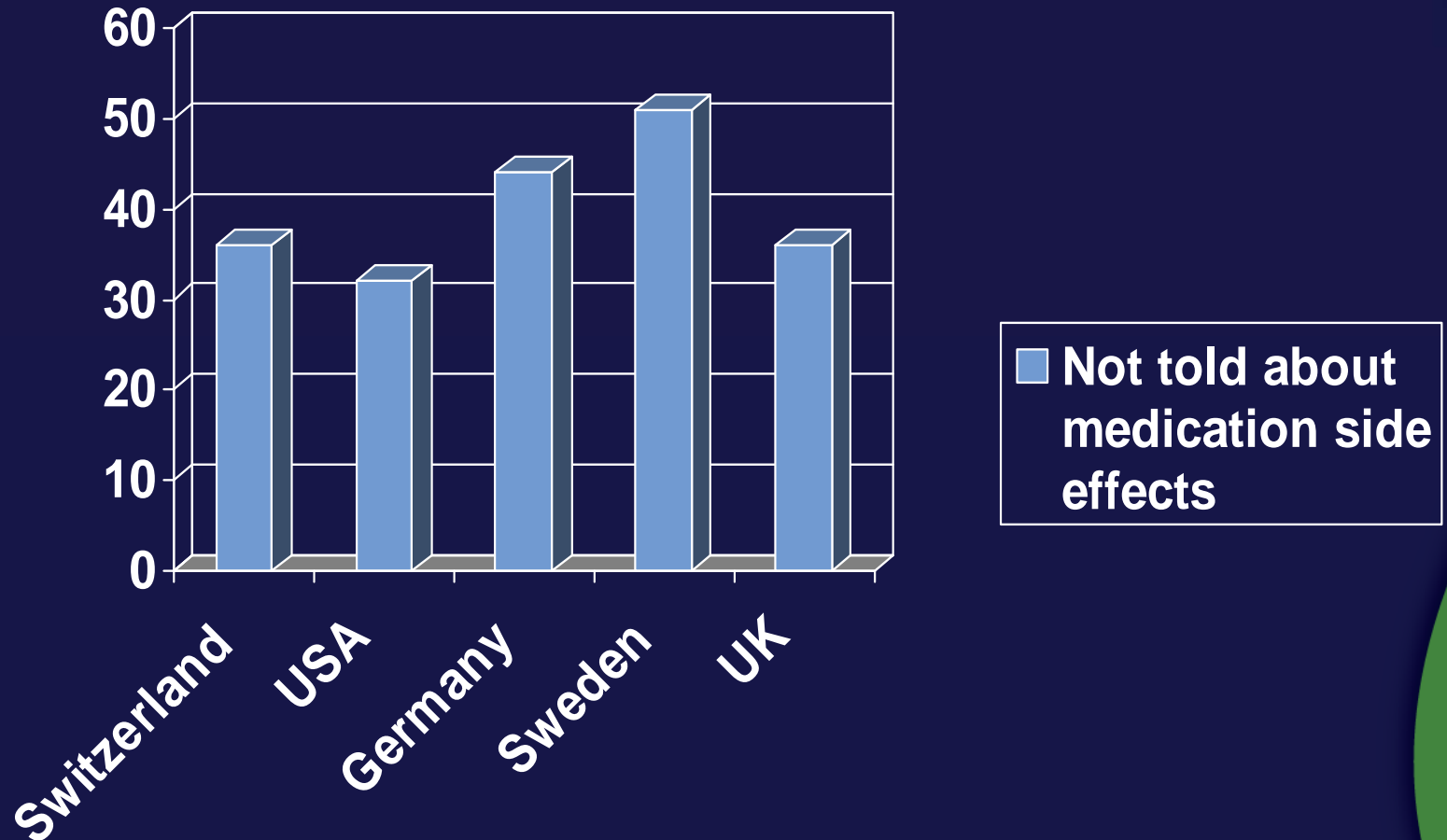
- No one to talk to about anxieties and concerns
- Tests/treatments not clearly explained
- Not enough involvement in decisions
- Insufficient information for family/friends
- Insufficient information about recovery

Picker Surveys of Patients' Experience

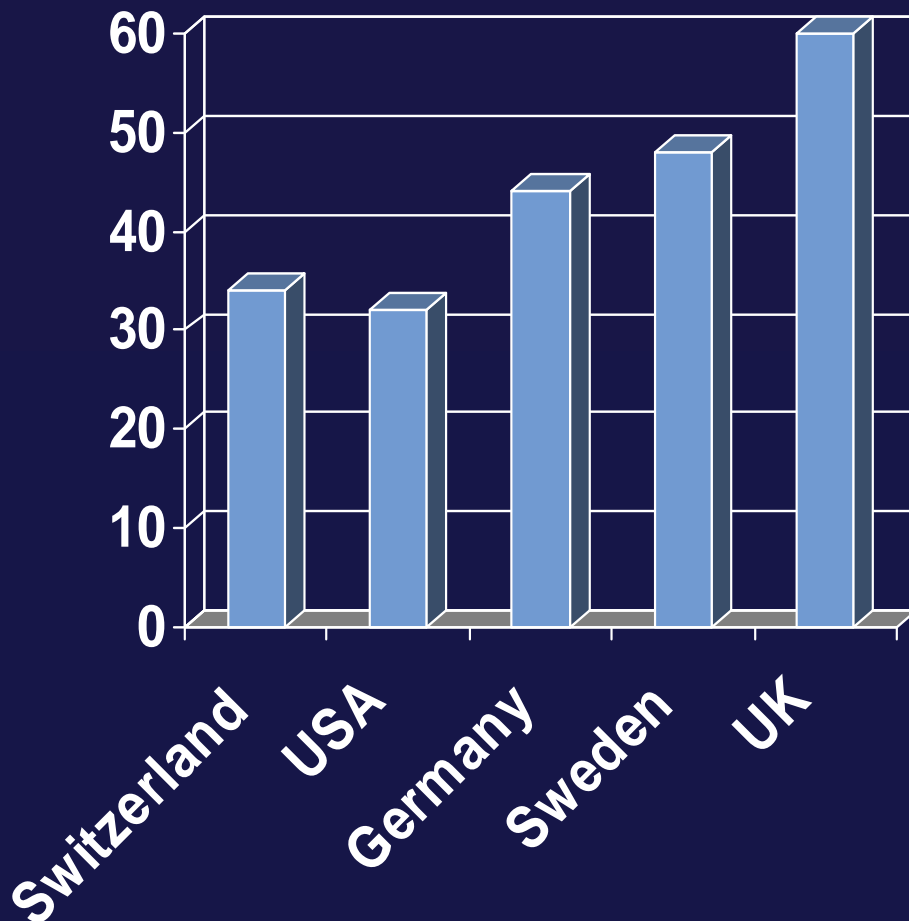


■ Test results not clearly explained

Picker Surveys of Patients' Experience



Picker Surveys of Patients' Experience



■ Not told about danger signals to watch for at home

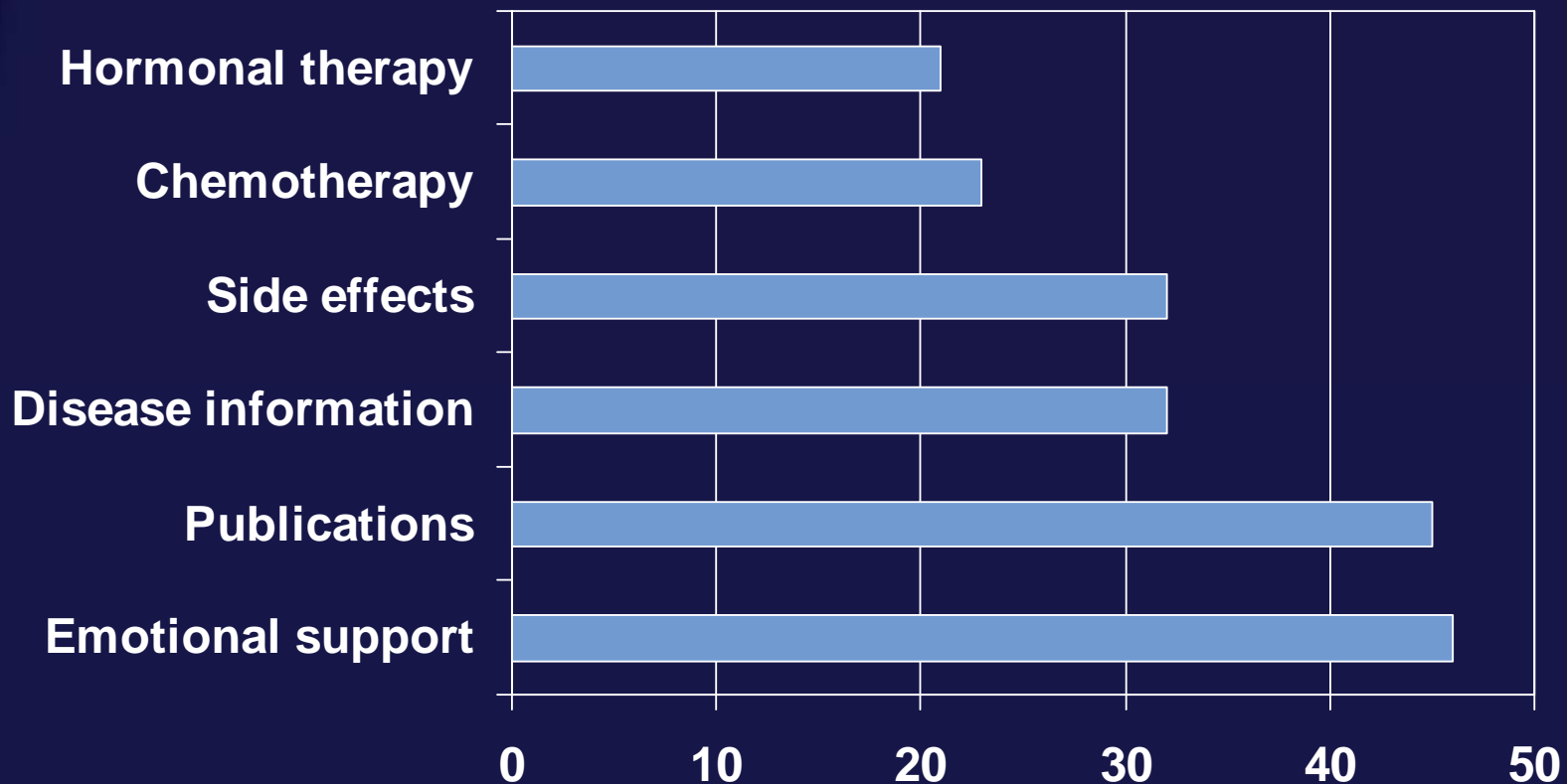
Research Findings: Information and Participation

- Most patients want more information
- Many, but not all, patients want to participate in decisions about their care
- Clinicians underestimate patients' desire for information
- Clinicians are often unaware of patients' preferences

Patients' Information Needs

- Illness and symptoms
- Tests and treatment options
- Self-help and prevention
- Services and sources of help
- Quality of health care providers

Breast Cancer Helpline Inquiries (ECCO Data)



Patients' Questions (Diagnosis)

- What is wrong with me?
- What is causing the problem?
- What are the tests for?
- How certain is the diagnosis?
- How does my experience compare with others with this problem?

Patients' Questions (Treatment)

- What are the options?
- What are the benefits and harms?
- Will treatment relieve the symptoms?
- Is treatment essential?
- What is the recovery time?
- What is the impact on quality of life?

Patients' Questions (Screening)

- What is the purpose of screening?
- What is the probability of false positive/negative?
- What are other likely benefits or harms?
- Is further investigation necessary?
- What is the access to counseling or support?

Patients' Questions (Sources of Help)

- How can I help myself?
- Where can I find further information?
- Which are the best hospitals/specialists?
- How can I access these hospitals/specialists?
- How can I be sure I'm getting the best treatment/care?
- Who can help me to cope?

Quality of Many Patient Information Materials Is Poor

- Topics of relevance to patients omitted
- Incomplete coverage of treatment options
- Inaccurate and out of date
- Biased – more about benefits than risks
- Uncertainties ignored or glossed over

Health Web Sites Can Mislead

- Health Web sites already very popular
- Accessing relevant information is not easy
- Quality assessment problematic
- Commercial sponsorship increases likelihood that information will be biased
- Global system – regulation problems

Quality Standards for Patient Information (1)

- Use patients' questions as starting point
- Address patients' concerns
- Include all treatment options
- Be honest about benefits and harms
- Quantify where possible
- Include questions to ask the doctor

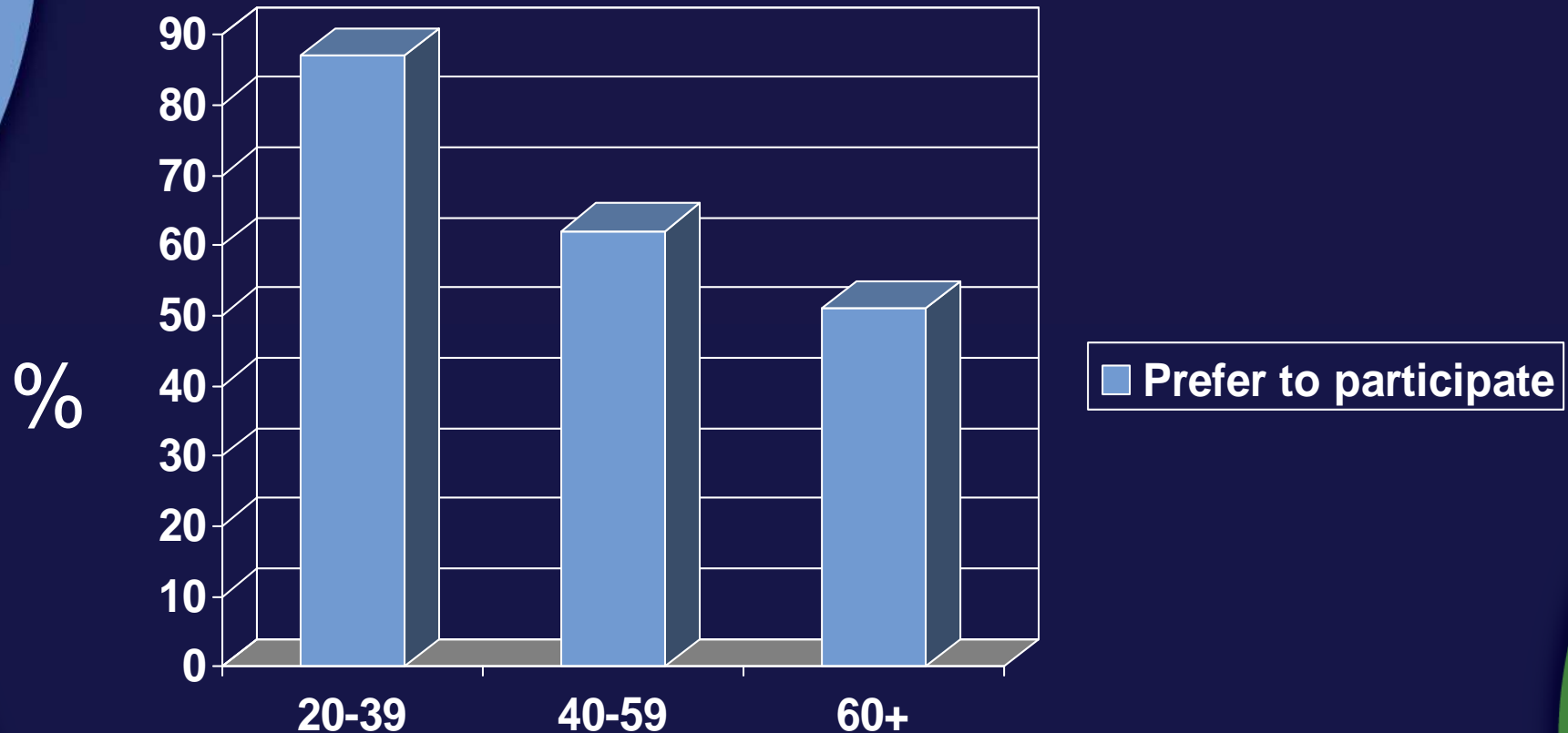
Quality Standards for Patient Information (2)

- Include further information sources
- Be non-alarmist, non-patronizing
- Ensure it's well-designed and concise
- Be explicit about authorship and sponsorship
- Include sources and strength of evidence
- Include publication date

Patients Are Decision Makers

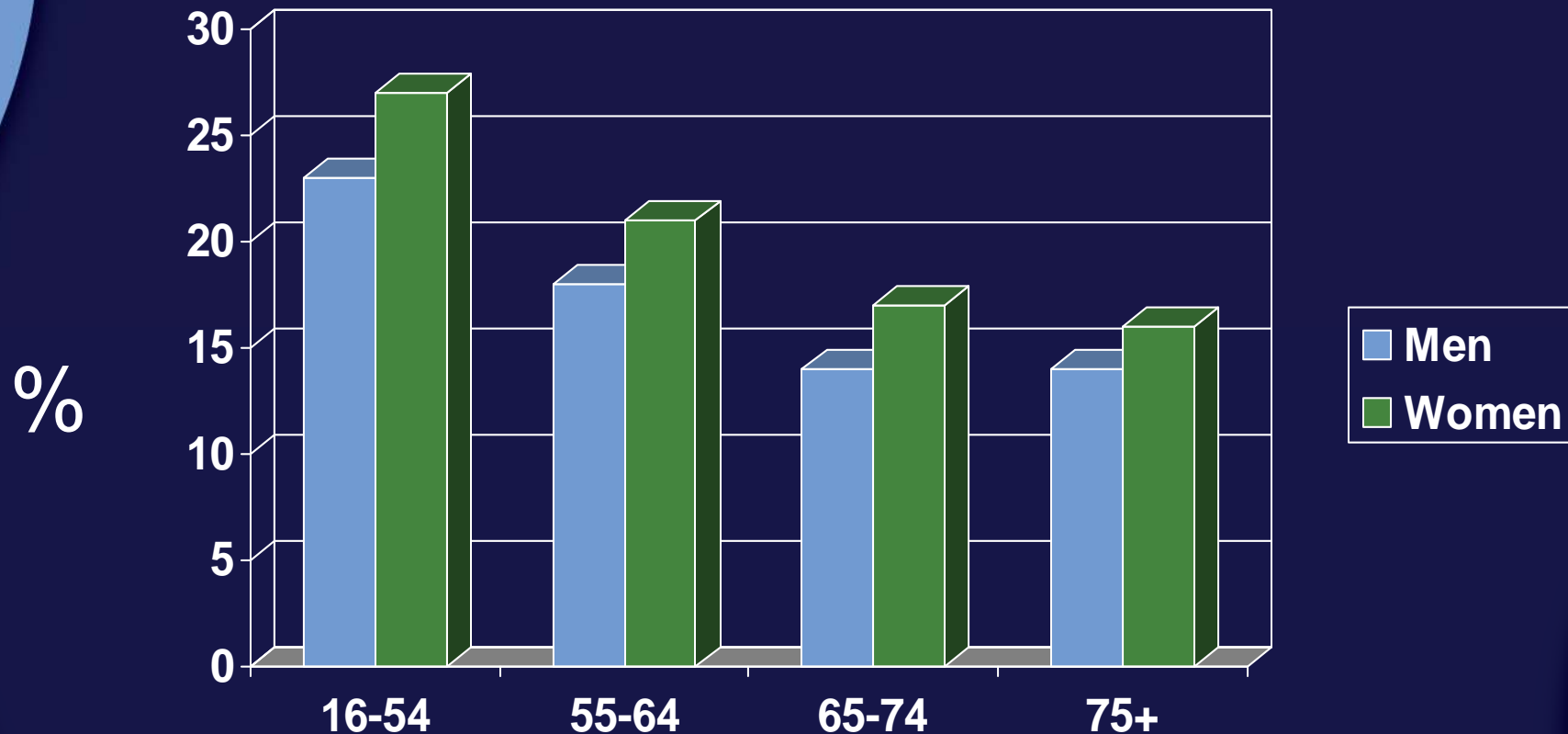
- Decisions about self-treatment
- Decisions to consult
- Decisions along care pathway
- Decisions about prevention

Do Patients Want to Participate in Decisions About Their Care?



N = 256 American cancer patients.
Cassileth BR, et al. *Ann Intern Med.* 1980;92:832-6.

Did Not Feel Sufficiently Involved in Decisions About Care



National Surveys of NHS Patients. Coronary Heart Disease 1999 (n=84,500)

Sharing Expertise

PATIENT

- Experience of illness
- Social circumstances
- Attitude to risk
- Values
- Preferences

CLINICIAN

- Diagnosis
- Disease etiology
- Prognosis
- Treatment options
- Outcome probabilities

Some Practical Problems

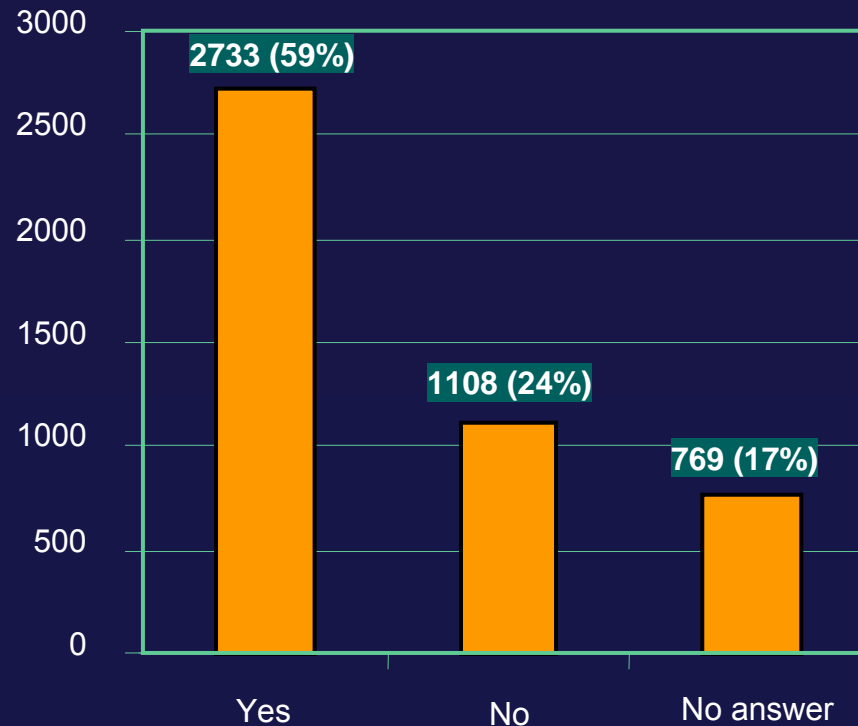
- Consultation times are short
- Patients find it hard to ask questions
- Clinicians don't know all the answers
- Quality information is hard to find

Three Questions Reflecting Pharmaceutical Care

1. Are you interested in learning about side effects and interactions related to your oncology therapy?
2. Has your pharmacist informed you about these topics?
3. In which topics are you most interested in being informed by your pharmacist?

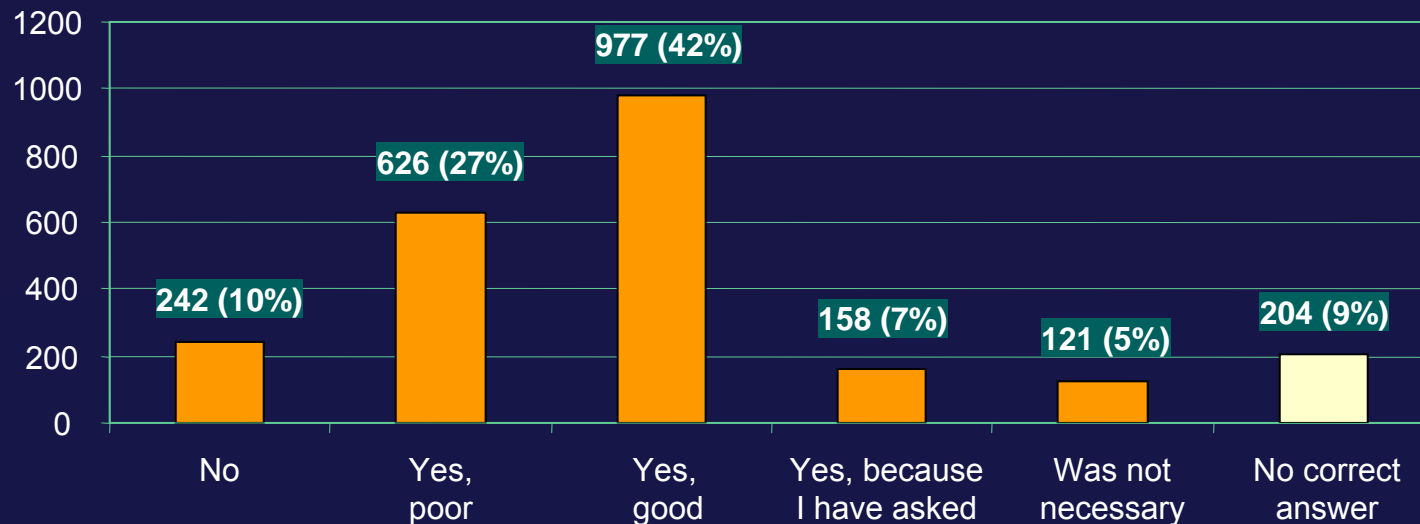
Interest in Information

Question 1



▶ 59% of all like to get information from pharmacy about drugs and related effects

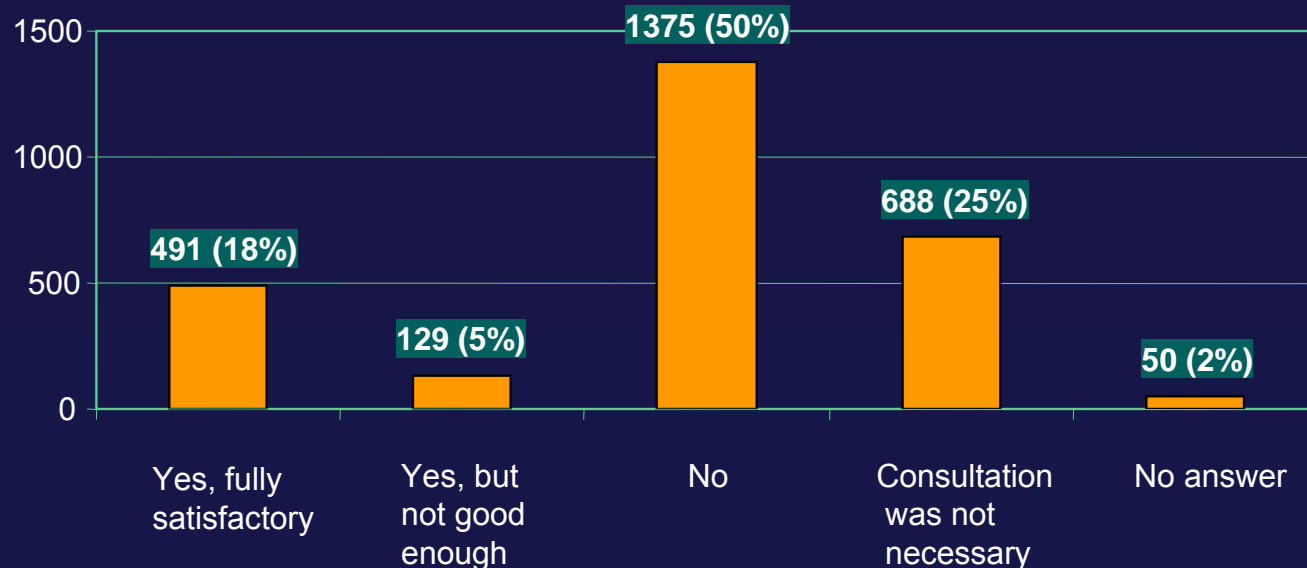
Information by Physicians



▶ 44% of all have answered that they have not been informed enough through their doctors

Satisfaction of Patients

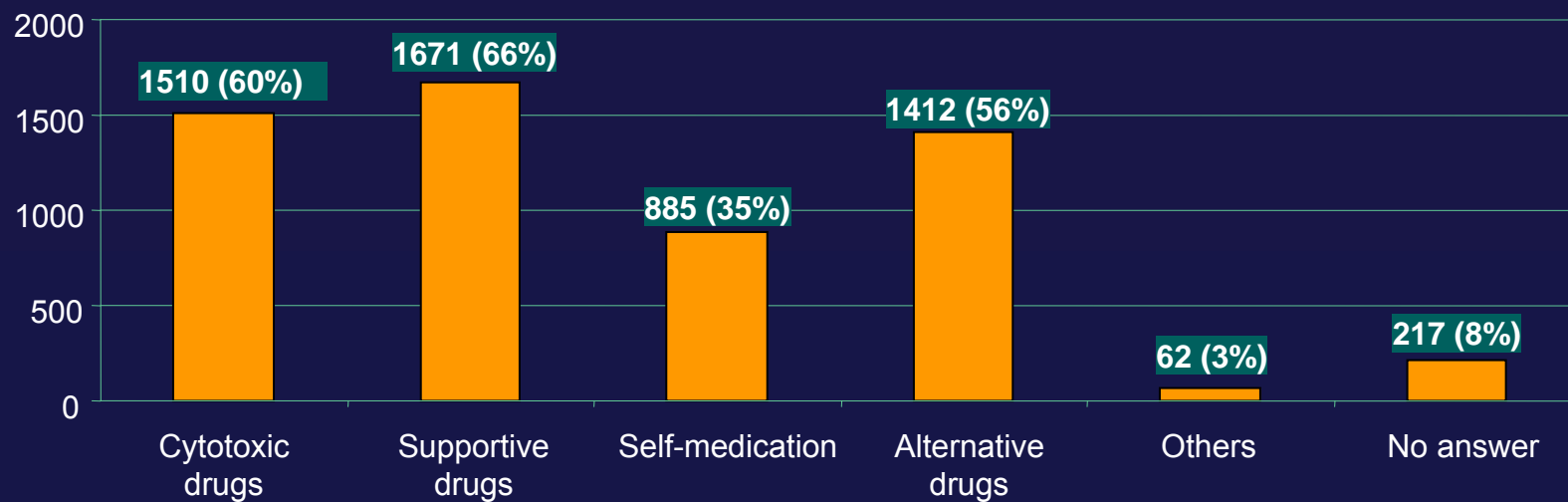
Question 2



▶ 75% of all patients who have looked for information through a pharmacist have not been informed enough (1504 of 4610 patients)

Topics of Information

Question 3



▶ Alternative drugs should also be discussed like the general treatment



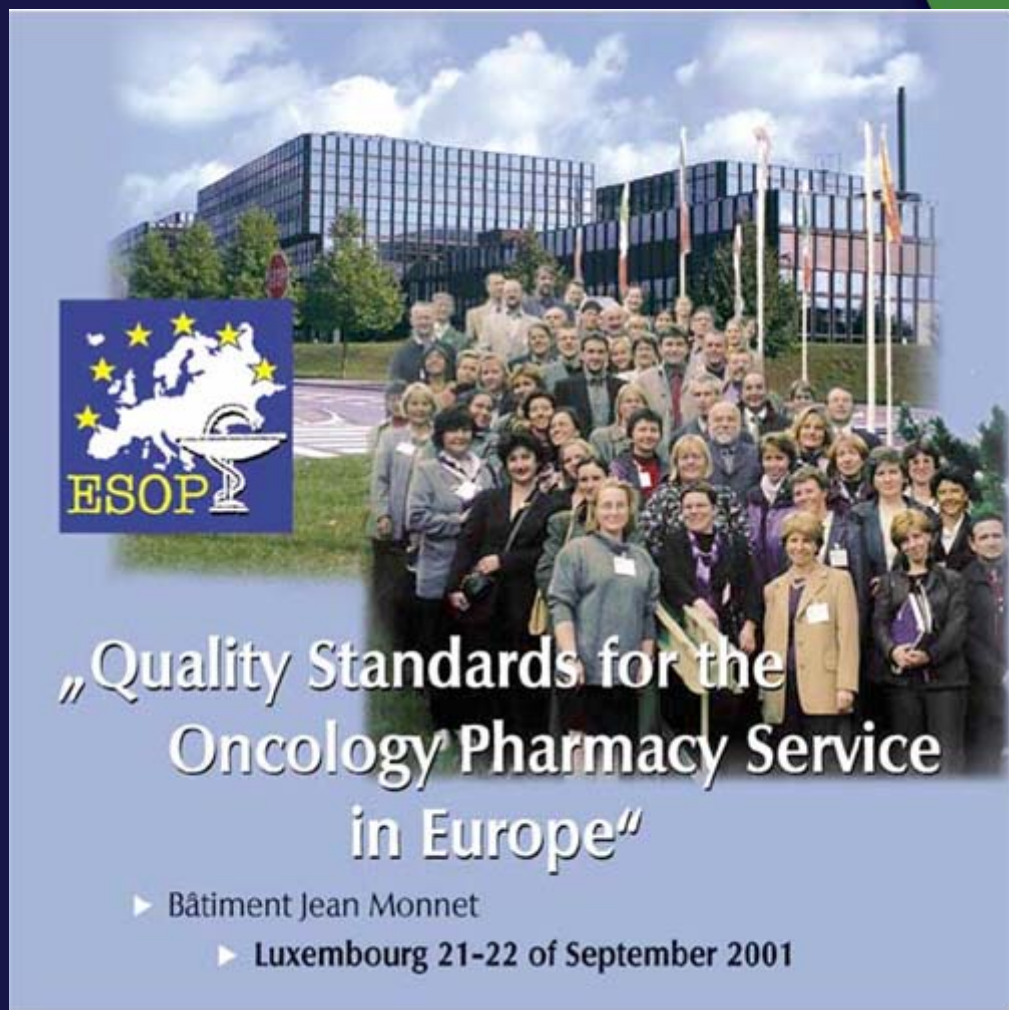
Aim of European Society

- The aim of ESOP is to support optimal treatment for cancer patients

First European Step for Standardization

About 70 delegates from 17 European countries discussed the future position based on the German standard (QuapoS) at the EU-commission under the motto:

„Think global – act local“





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Apotheke mit klinischer Pharmazie



What you should watch out for

- Usually during the chemotherapy the number of your white corpuscles (leucocytes) decreases, which increases your risk of getting infections. Stay away from people with colds, flu, or other infections.
- Contact your health care provider immediately if you have got fever.
- Do not have any vaccines without getting your health care provider's approval first.
- Usually during the chemotherapy the number of blood platelets (thrombocytes) decreases, which increases your risk of bruising or bleeding. Avoid sports and activities that may cause injuries. Use a soft brush to brush your teeth, be careful while shaving cutting fingernails or toenails, or when using sharp objects.
- Contact your health care provider immediately if you notice such symptoms as bruising and bleeding.
- Don't take any nonsteroidal-anti inflammatory drugs (Aspirin) or other anticoagulant drugs. Ask your health care provider or pharmacist for information if you want to take any other drugs besides your chemotherapy-medicines
- You will need to have blood tests regularly to see how this medicine affects your blood and bone marrow. Keep all appointments for these tests.
- If you have mouth sores (red painful oral mucosa) use disinfectant gels or fluids several times a day, especially before your meals. Ask your health care provider or pharmacist for more information.
- Besides your chemotherapy-medicines you get supportive medicines against possible side effects (like nausea, vomiting). Take these medicines regularly and as prescribed from your health care provider.
- Your therapy is made up by your health care provider for you individually, it is very important that you keep all scheduled appointments.
- To avoid bad skin diseases use skin protection cream with a high sun protection factor (SPF>15).
- Don't drive a car or use electric machines if you have troubles seeing colours or feel fatigue.
- Don't get pregnant during your chemotherapy.
- Keep a list of all medicines (prescriptions, non-prescription, supplements, natural remedies, and vitamins) with you. Be sure that you tell all health care providers who treat you about all the products you are taking.

An ECCO Research Program for Patient- Related Leaflets

What Is a Decision Aid?

- A tool to help patients make specific, deliberate decisions about disease management and treatment options, prevention, or screening
- Content based on reviews of clinical research and studies of patients' information needs
- Examples include leaflets, audiotapes, workbooks, decision boards, computer programs, interactive videos, Web sites, structured interviews, group presentations

Decision Aids Help With:

- Information and probabilities
- Values and preferences
- Weighing benefits and harms
- Management plan

Patient Decision Aids Are Not Necessary:

- When there is strong evidence in favor of a specific intervention
- In emergency situations
- If the patient has made it clear that they do not want to participate in decisions about their care

Are Patient Decision Aids Effective?

They can:

- Reduce number of patients who are uncertain about what to do
- Increase patients' knowledge of problems, options, and outcomes
- Reduce decision conflict
- Increase participation in decision making without increasing anxiety

Changing the Culture

Passive dependence



Informed consent



Informed choice

Finally

- Focusing on cytotoxic treatment alone is NOT enough ...
- Thank you all