



EUROPEAN
CANCER
PATIENT
COALITION

CHAMPIONING THE INTERESTS OF EUROPEAN CANCER PATIENTS

Mission of ECPC

- The European Cancer Patient Coalition has been established to represent the views of cancer patients in the European healthcare debate and to provide a forum for European cancer patient organisations to exchange information and share best practice
- At the 2nd ECPC Masterclass held on 28./29.5.2005 in Milan a keypad voting under the ECPC member patient organisations was conducted with several questions concerning cancer issues, e.g. screening, access to treatment and patient information etc.

Question overview

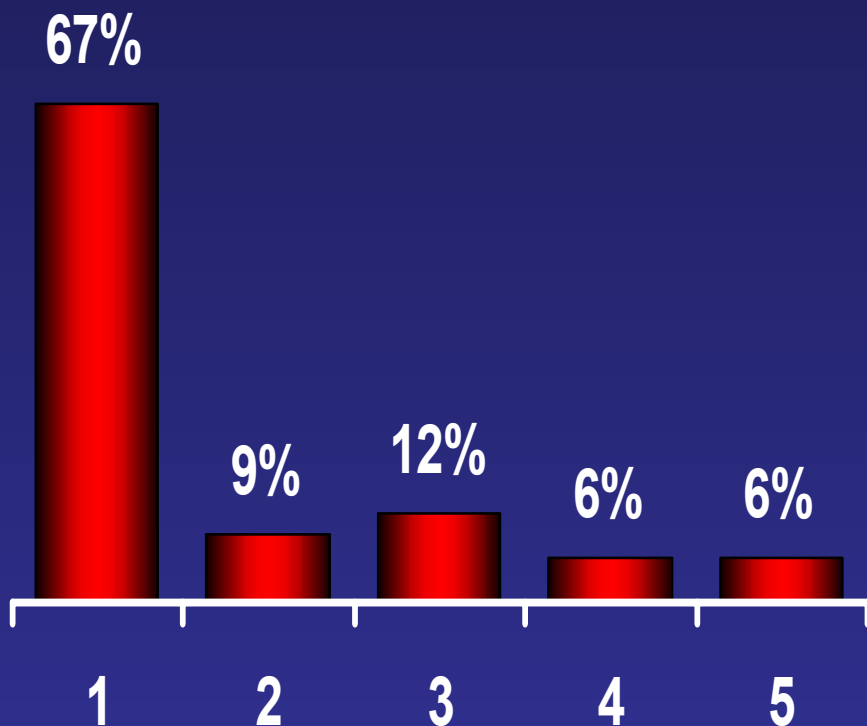
- statistical and general question
- cancer screening
- access to optimal treatment and care
- clinical trials
- patient information
- patient mobility

Countries represented (n>20)

| | | | |
|----------------|----|---|-----|
| Austria | 6 | Latvia | 1 |
| Belgium | 4 | Poland | 10 |
| Cyprus | 2 | Portugal | 6 |
| Czech Republic | 2 | Slovakia | 2 |
| Denmark | 2 | Spain | 3 |
| Finland | 1 | Sweden | 1 |
| France | 5 | The Netherlands | 9 |
| Germany | 10 | United Kingdom | 13 |
| Greece | 0 | EU enlargement country (ie. Romania, Bulgaria) | 5 |
| Hungary | 3 | Other | 4 |
| Ireland | 4 | Total votes | 108 |
| Italy | 5 | | |

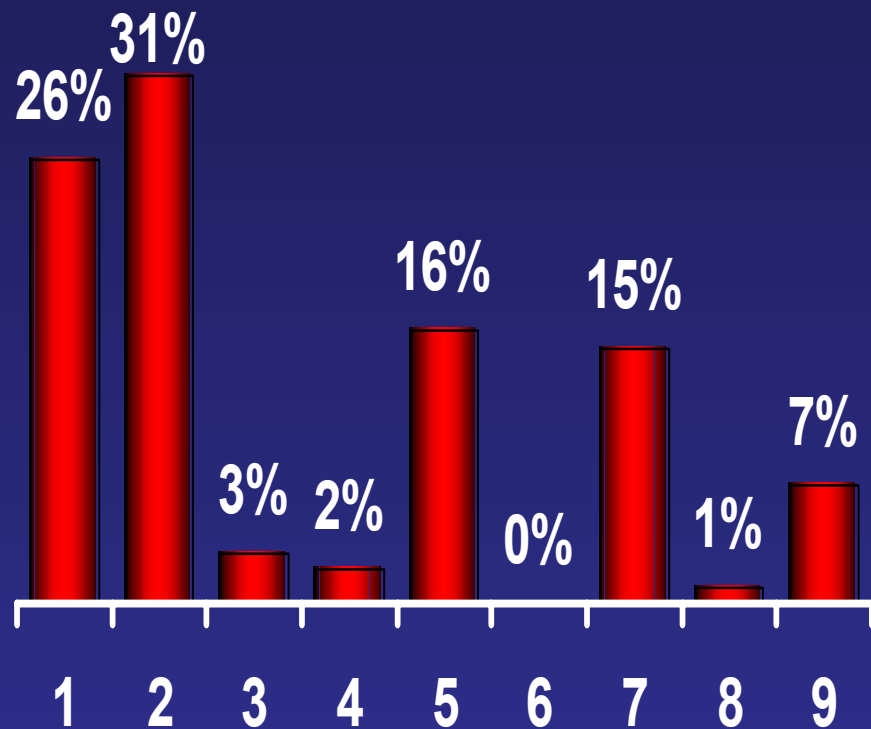
Q1 Are you?

1. Cancer patient
2. Relative/friend of a cancer patient
3. Staff working for a patient advocacy organisation
4. Health Professional (eg. doctor, nurse etc.).
5. Other



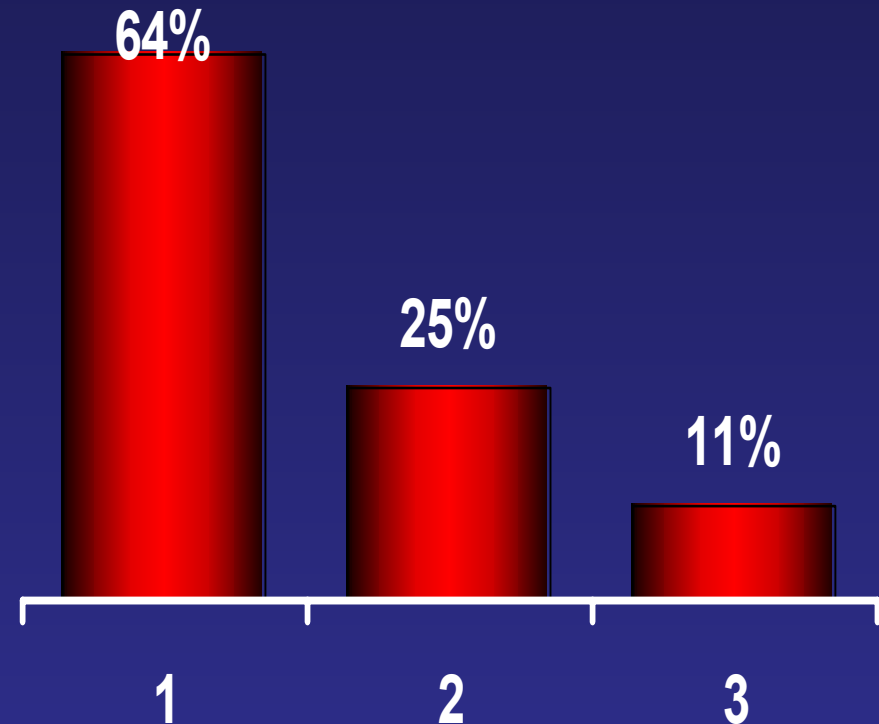
Q2 Which type(s) of cancer does your organisation represent?

1. All cancers
2. Breast Cancer
3. Lung Cancer
4. Colorectal cancer
5. Prostate Cancer
6. Gynaecological Cancers – for example, ovarian, uterine or cervical cancer
7. Haematological Cancers – for example, leukaemia, myeloma, lymphoma
8. Childhood cancers
9. Other



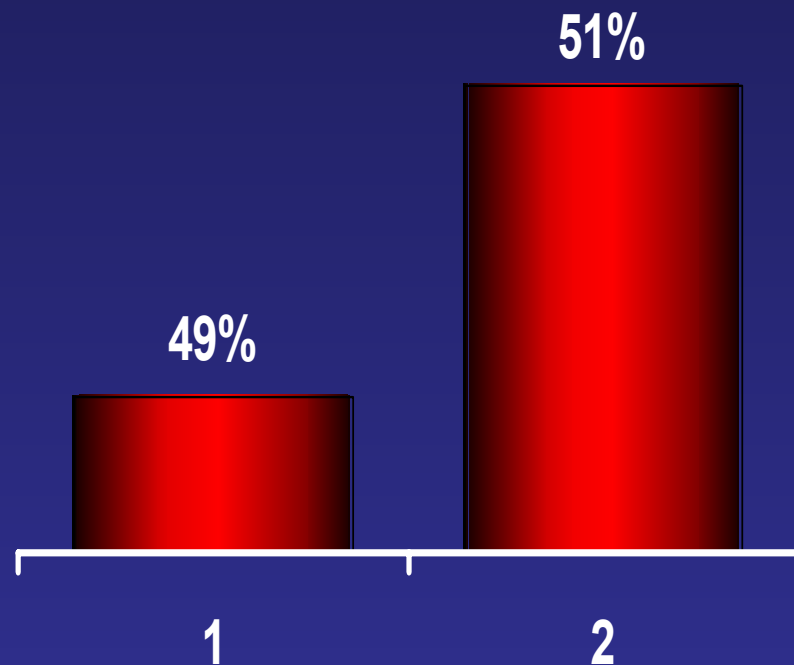
Q6 Does your country have a National Cancer Plan?

1. Yes
2. No
3. Don't know



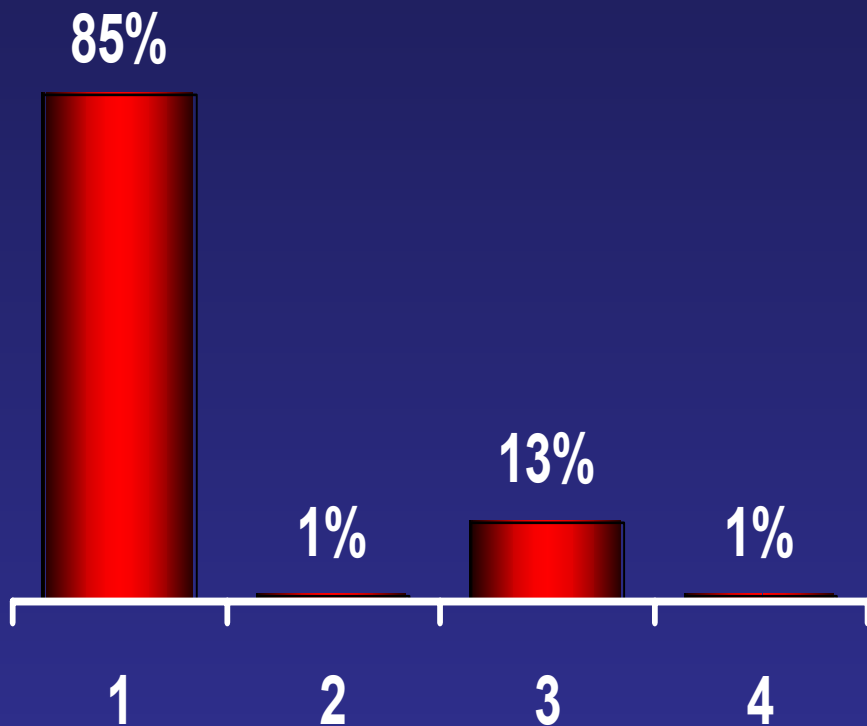
Q7 Is your organisation represented on committees that have a formal role in making policy or overseeing the delivery of cancer treatment or screening services?

1. Yes
2. No



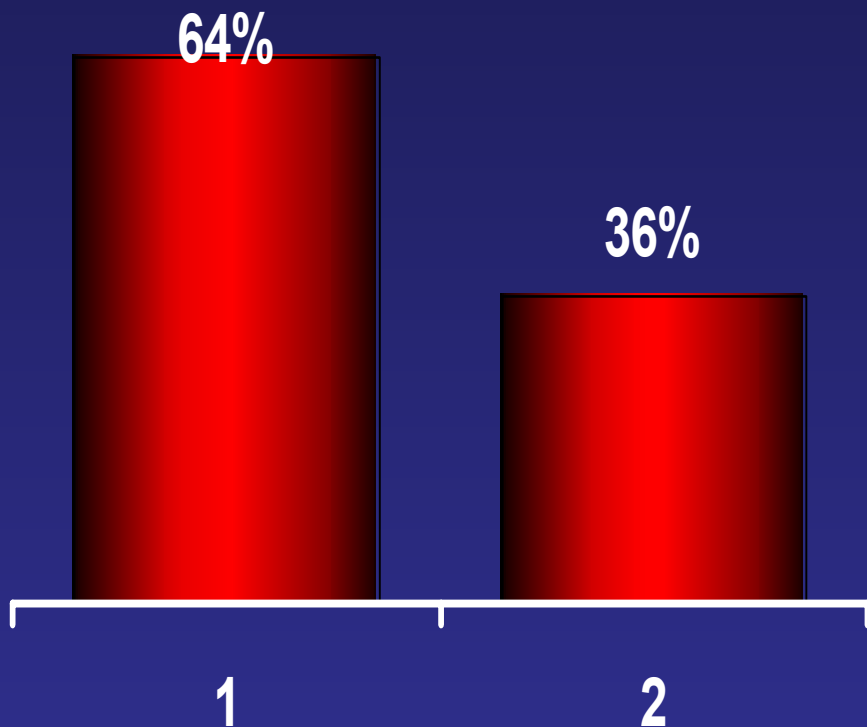
Q8 Do you think that the quality of cancer care has changed in your country over the past 10 years?

1. The quality of cancer care is better than it was 10 years ago
2. The quality of cancer care is worse than 10 years ago
3. The quality of cancer care is much the same today but is slowly improving
4. Don't know



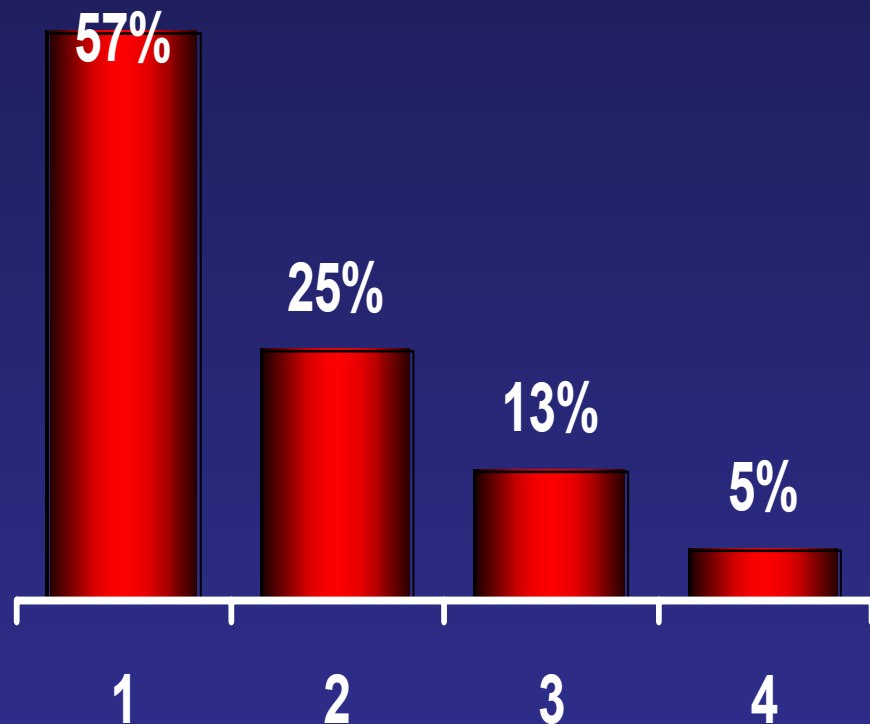
Q9 Are you aware of the European Union Recommendations on cancer screening?

1. Yes
2. No



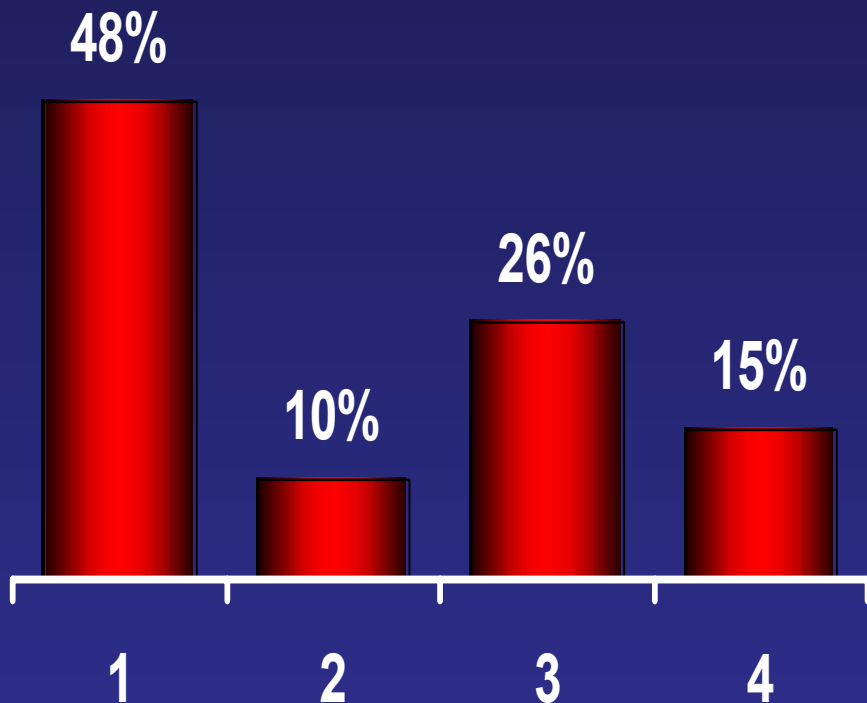
Q10 In your country is there a population-based national screening programme for breast cancer?

1. Yes there is a population-based national screening programme for breast cancer
2. A population based breast cancer screening programme is available but only in some regions
3. There is no national screening programme for breast cancer
4. Don't know



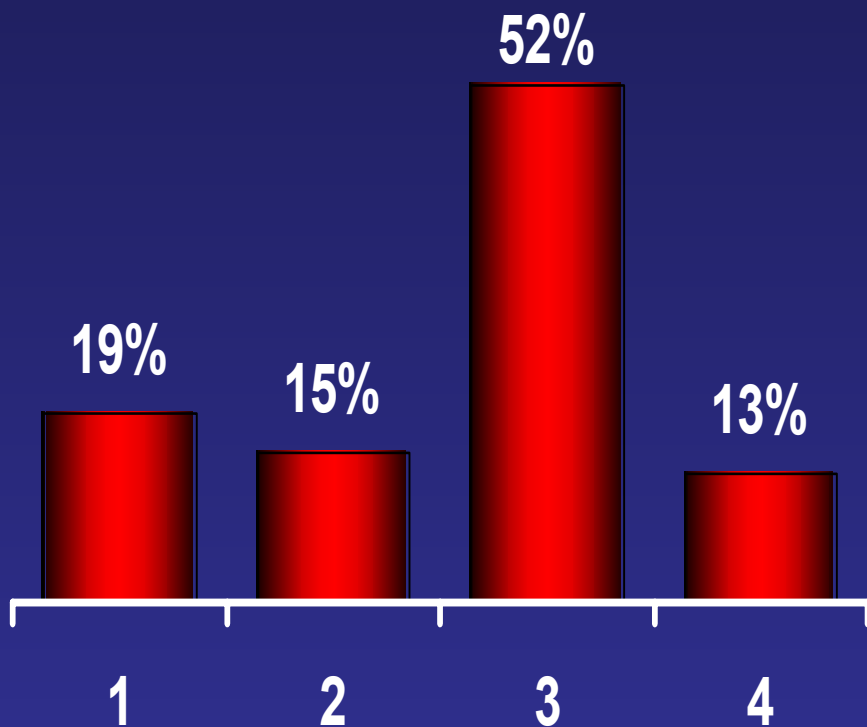
Q11 In your country is there a population-based national screening programme for cancer of the cervix?

1. Yes there is a population-based national screening programme for Cancer of the Cervix
2. A population-based cervical cancer screening programme is available, but only in some regions
3. There is no national screening programme for cancer of the cervix
4. Don't know



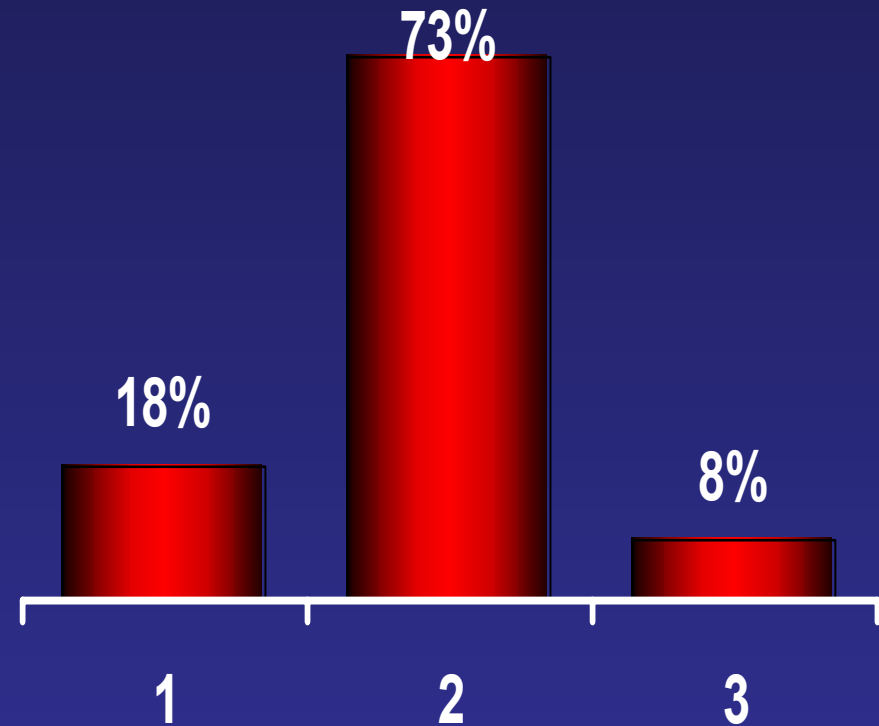
Q12 In your country is there a population-based national screening programme for colorectal cancer?

1. Yes there is a population-based national screening programme for colorectal cancer
2. A population-based colorectal cancer screening is available, but it only in some regions.
3. There is no national screening programme for colorectal cancer
4. Don't know



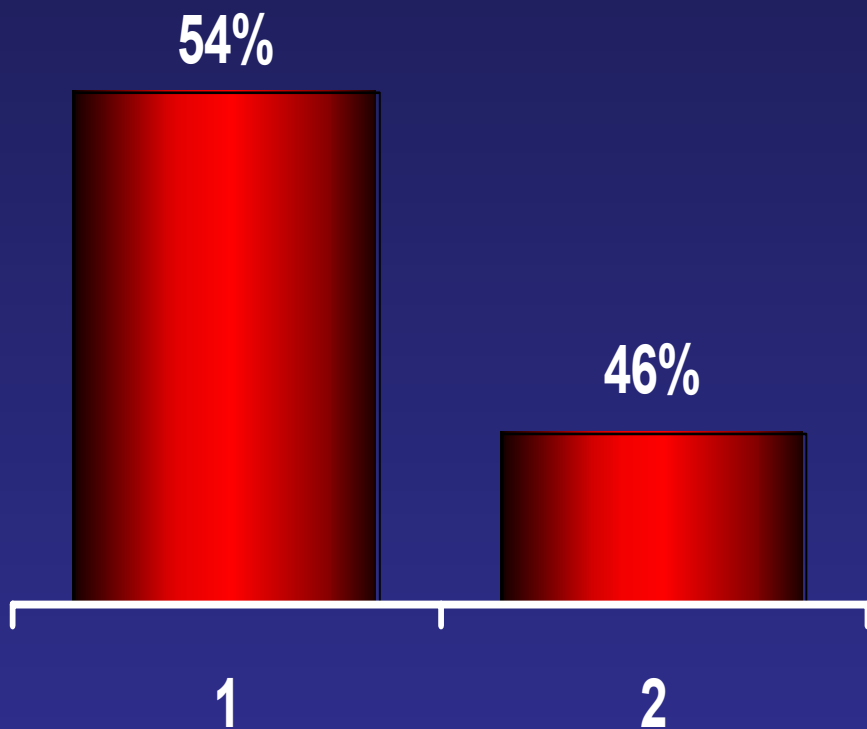
Q13 Is screening for prostate cancer available in your country?

1. Yes
2. No
3. Don't know



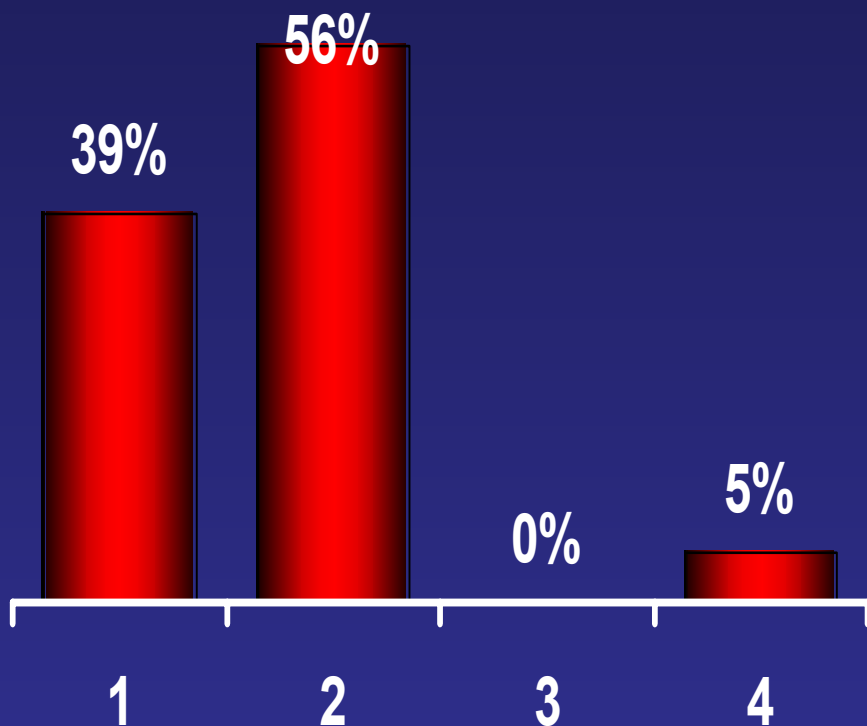
Q14 Are you aware of any cancer drugs that are not available in your country but are available in others?

1. Yes
2. No



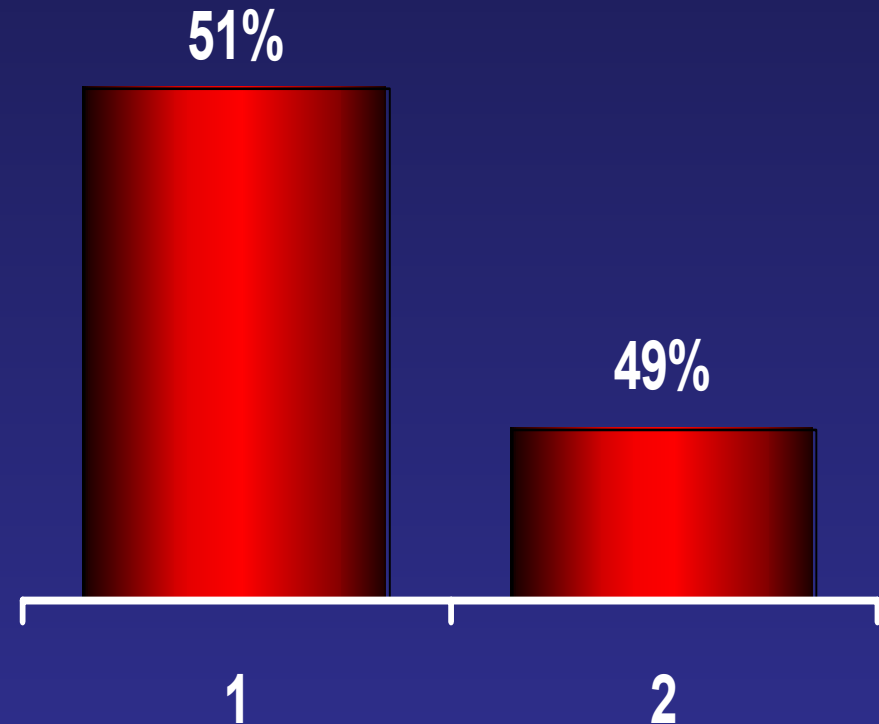
Q15 If yes, why is the drug not available?

1. The drug(s) are not licensed in my country
2. The public health authority will not reimburse the drug(s)
3. Physicians will not prescribe the drug
4. Don't know



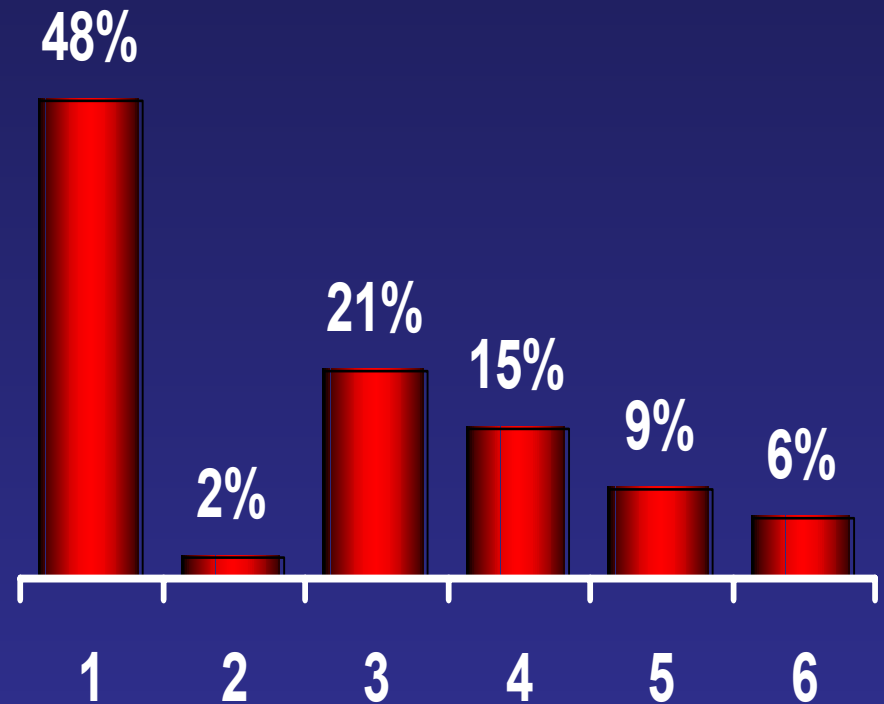
Q16 Do you know of anyone who has been refused access to a cancer treatment, because it was considered too expensive?

1. Yes
2. No



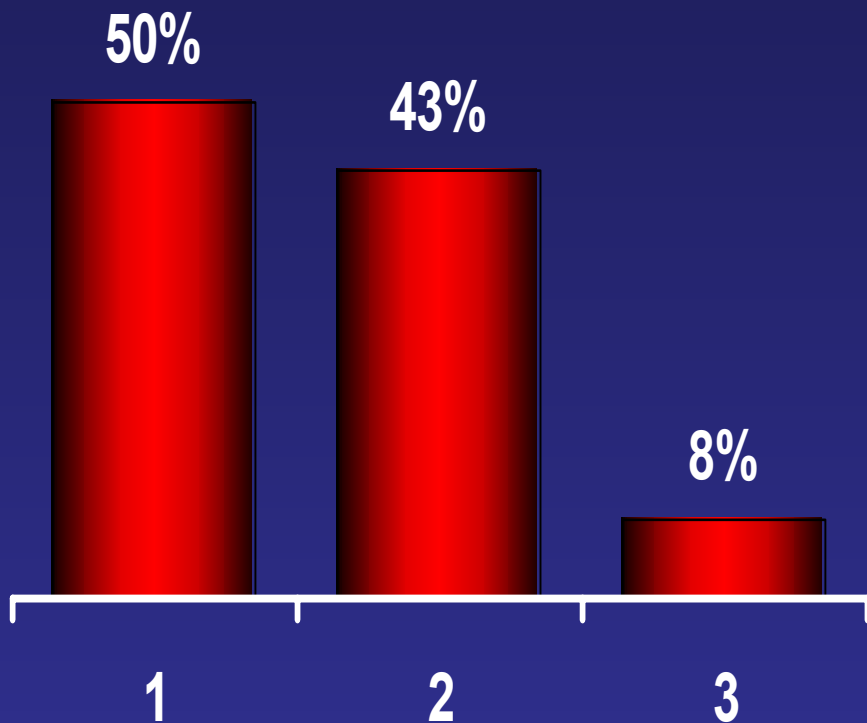
Q17 Can cancer patients in your country readily obtain a second opinion paid for by the healthcare system?

1. Yes - cancer patients can easily obtain a second opinion paid for by the nation's healthcare system.
2. Yes — but not in all parts of the country.
3. Yes — but bureaucratic procedures hinder the process.
4. Sometimes — it depends on the healthcare provider
5. No — the system will not pay for a second opinion
6. Don't know



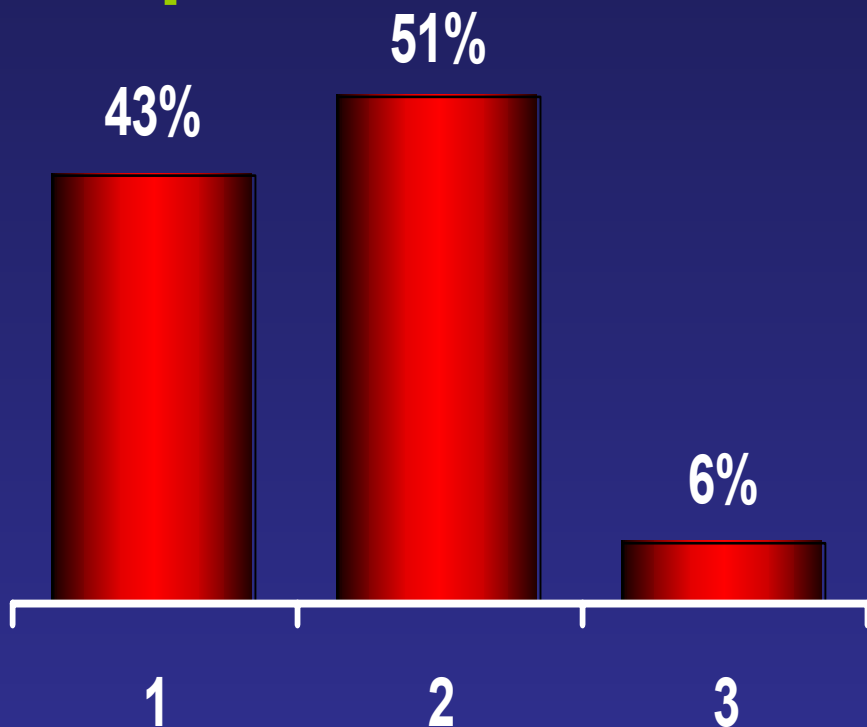
Q18 Do patients in your country have timely access to high quality radiotherapy services?

1. Yes
2. No
3. Don't know



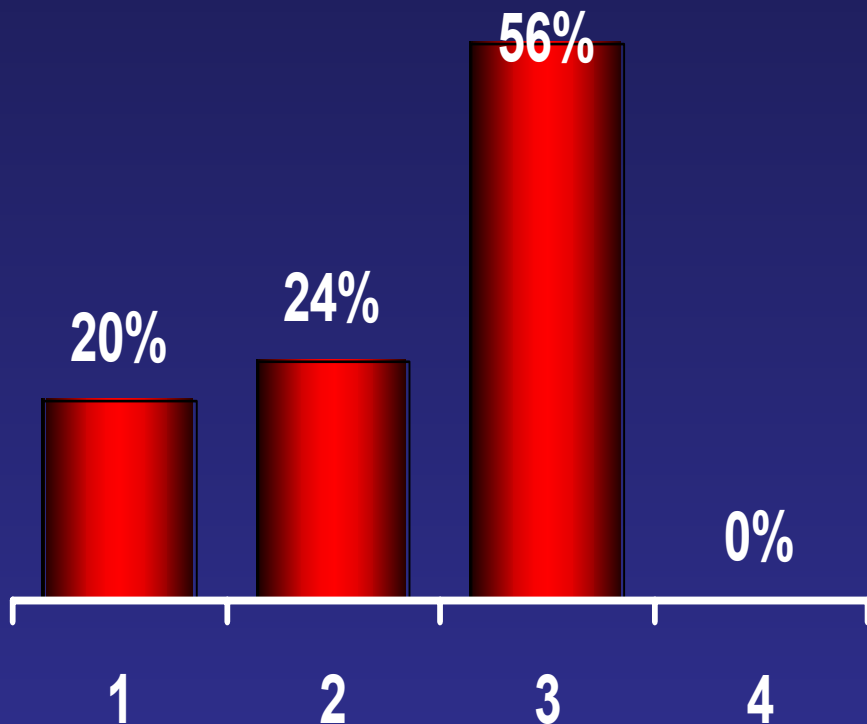
Q19 In your country does complex cancer surgery have to be carried out in a specialist centres by surgeons with adequate training and experience?

1. Yes
2. No
3. Don't know



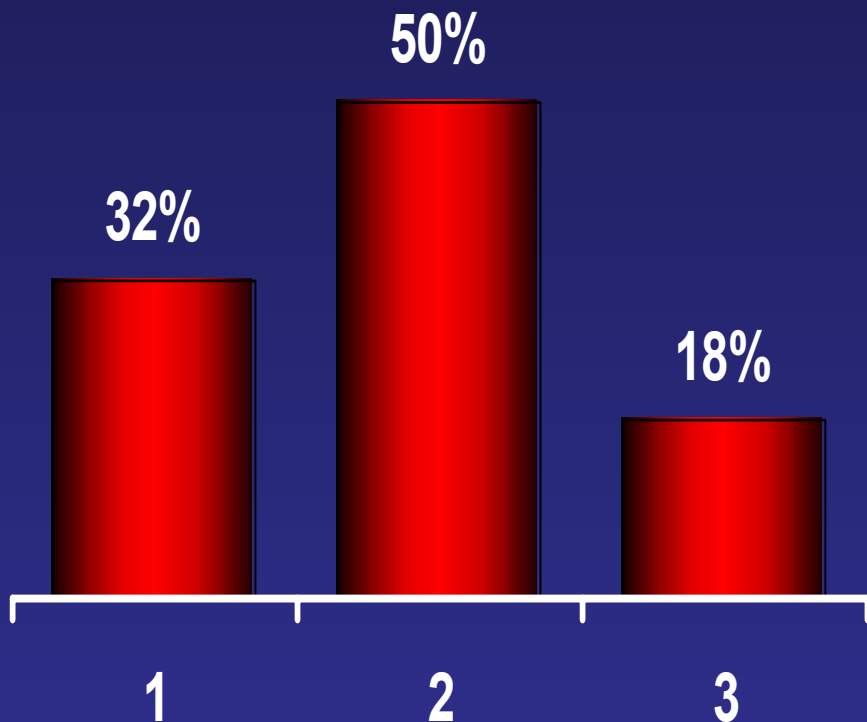
Q20 Do cancer patients in your country have to wait an unacceptable period of time before receiving cancer treatments?

1. Yes
2. No
3. Sometimes
4. Don't know



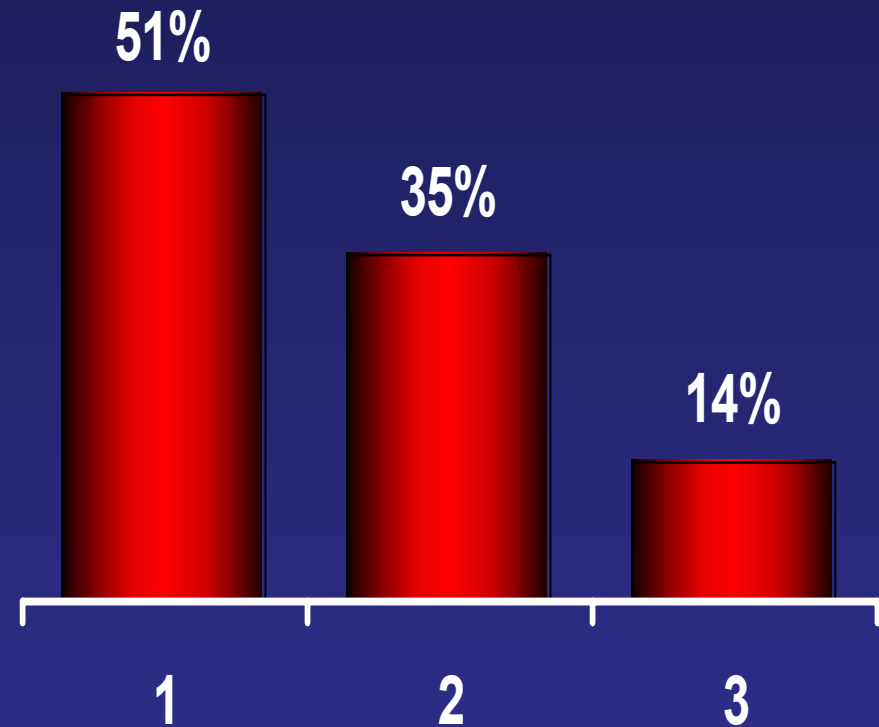
Q21 Do cancer patients in your country have timely access to high quality palliative care?

1. Yes
2. No
3. Don't know



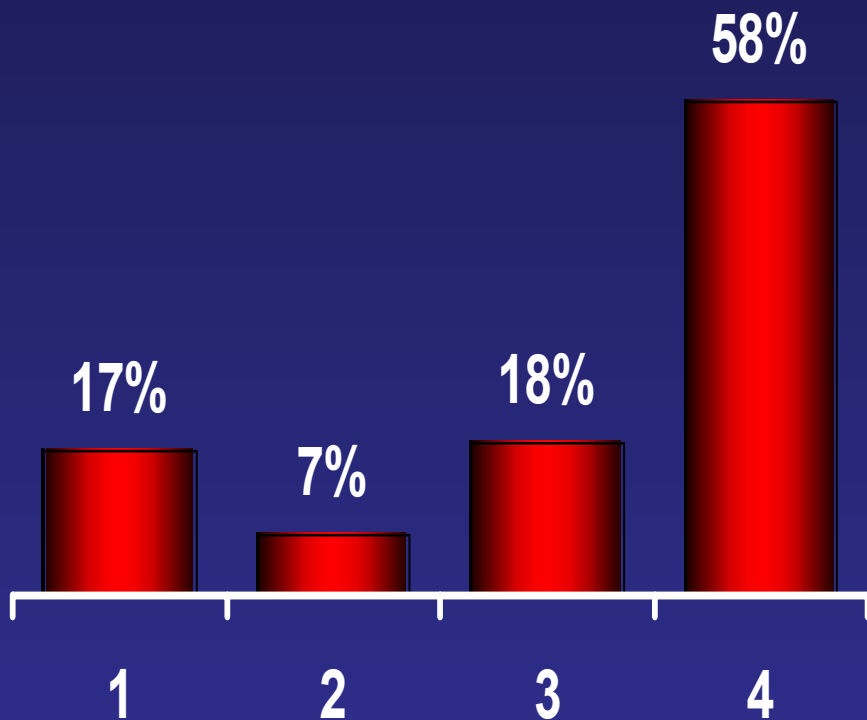
Q22 Do national guidelines for treating different cancers exist in your country?

1. Yes
2. No
3. Don't know



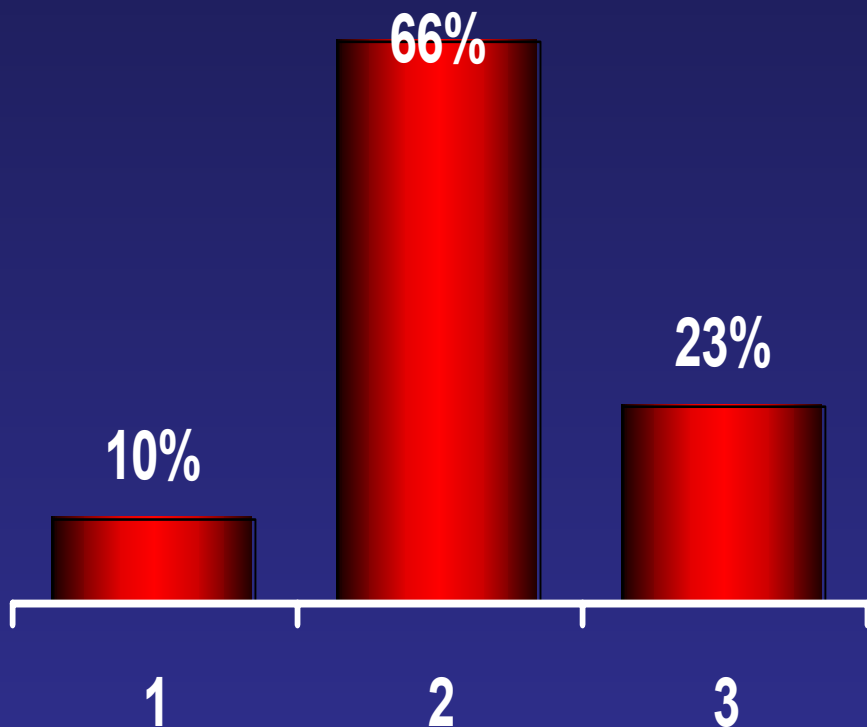
Q23 Has the EU Directive on Clinical Trials had an impact on cancer research in your country?

1. The EU Directive has had a negative impact on cancer research
2. The EU Directive has had no impact on cancer research
3. The EU Directive has yet to be implemented in my country
4. Don't know



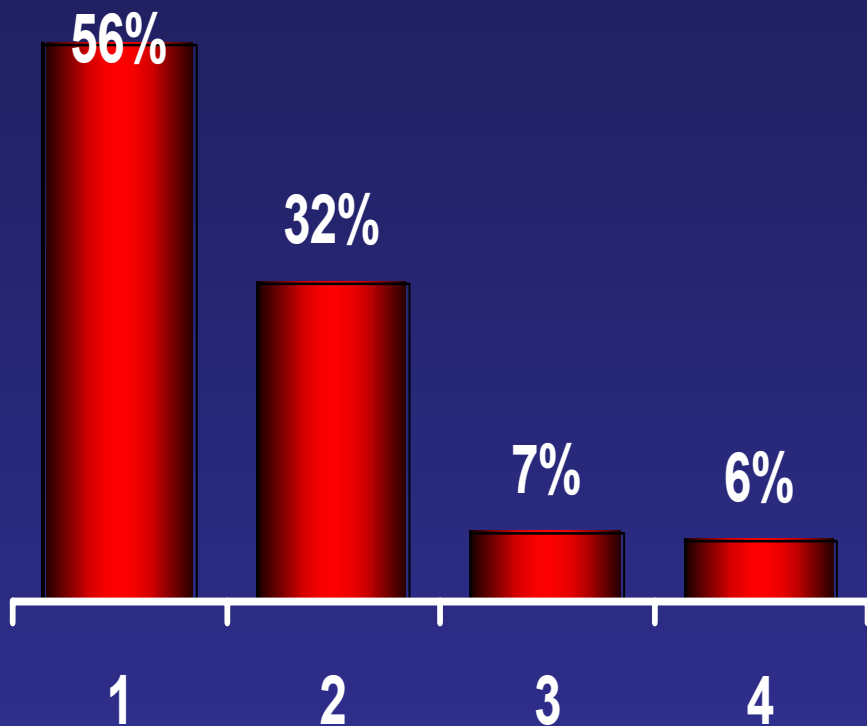
Q24 Are cancer patients in your country able to find the information they need about clinical trials in progress?

1. Yes
2. No
3. Don't know



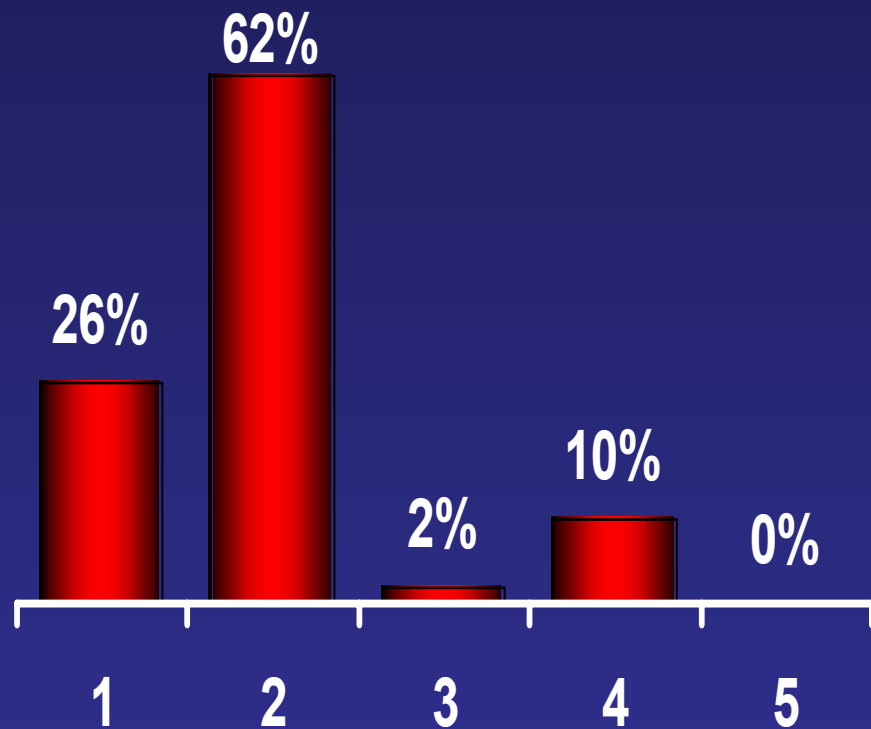
Q25 Should information about all cancer clinical trials in progress be made available to the public in an electronic registry?

1. Yes, information about all clinical trials should be freely available
2. Yes, but only information about phase II, III and IV trials
3. No, it is not necessary to make this information available to the public
4. Don't know



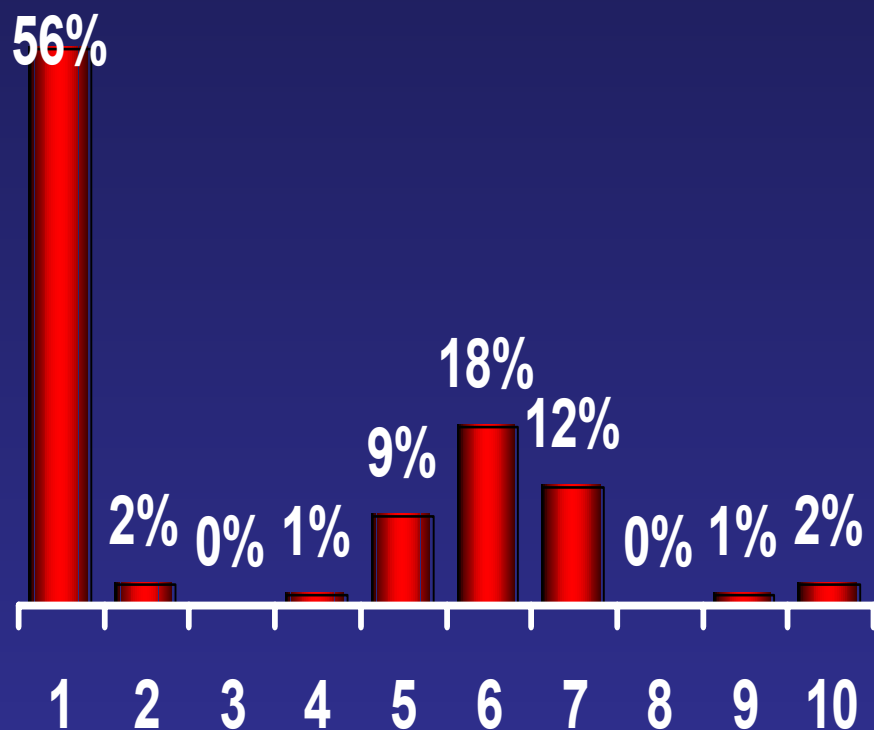
Q26 Do cancer patients in your country have easy access to good quality information about their disease and its treatment?

1. Yes – Good quality information is readily available
2. Good information is available but it can be difficult to find
3. Information is available but it is generally of poor quality
4. There is a huge amount of high quality information available, but not in my native language
5. No information is available



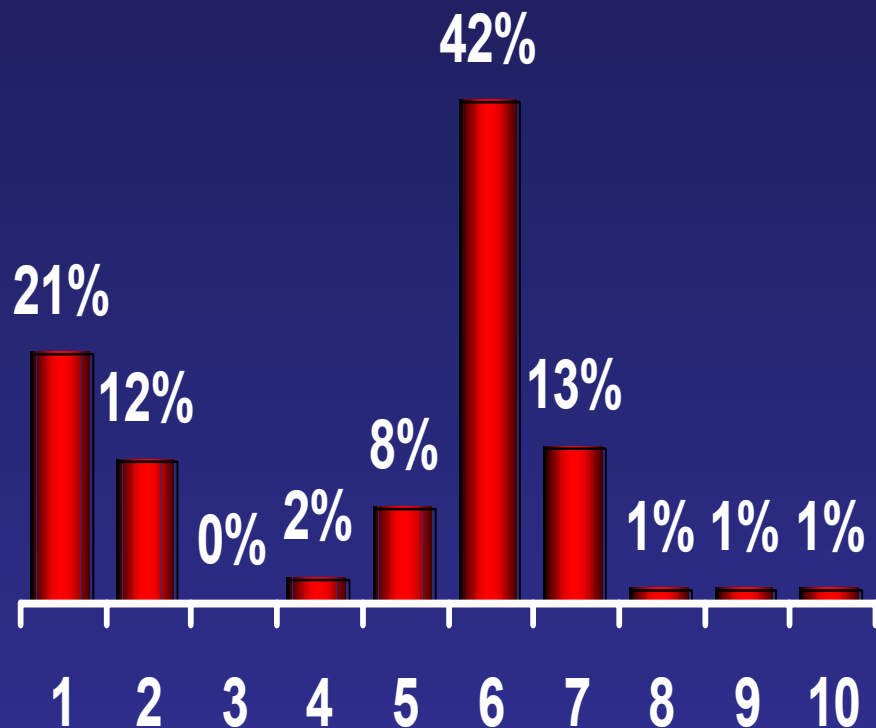
Q27 What is the most important source of accurate and reliable information for cancer patients in your country?

1. Doctors
2. Nurses
3. Pharmacists
4. Family and friends
5. Cancer charities
6. Patient organizations
7. Internet
8. Newspapers and magazines
9. TV and radio
10. Other



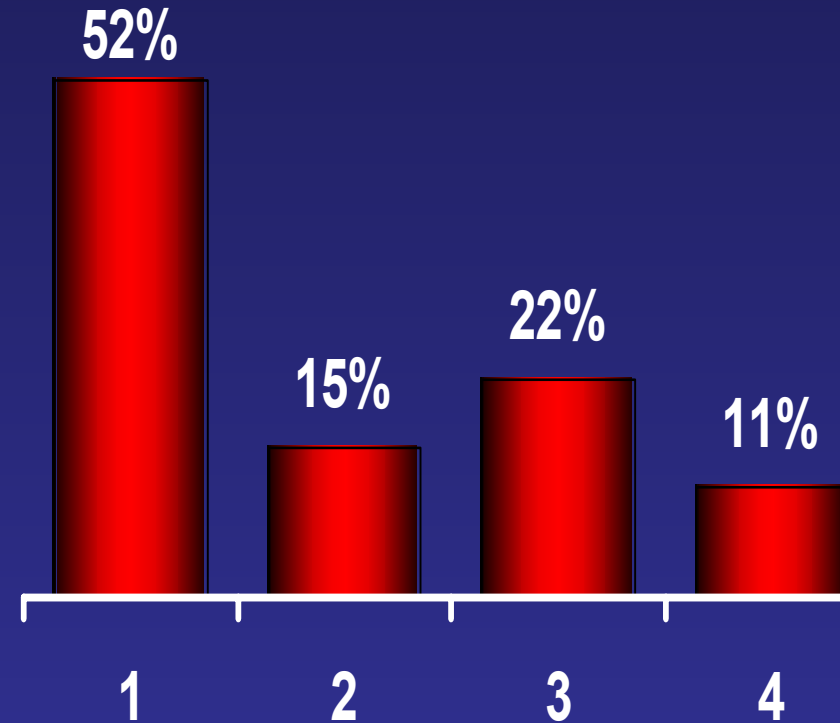
Q28 What is the second most important source of information?

1. Doctors
2. Nurses
3. Pharmacists
4. Family and friends
5. Cancer charities
6. Patient organizations
7. Internet
8. Newspapers and magazines
9. TV and radio
10. Other



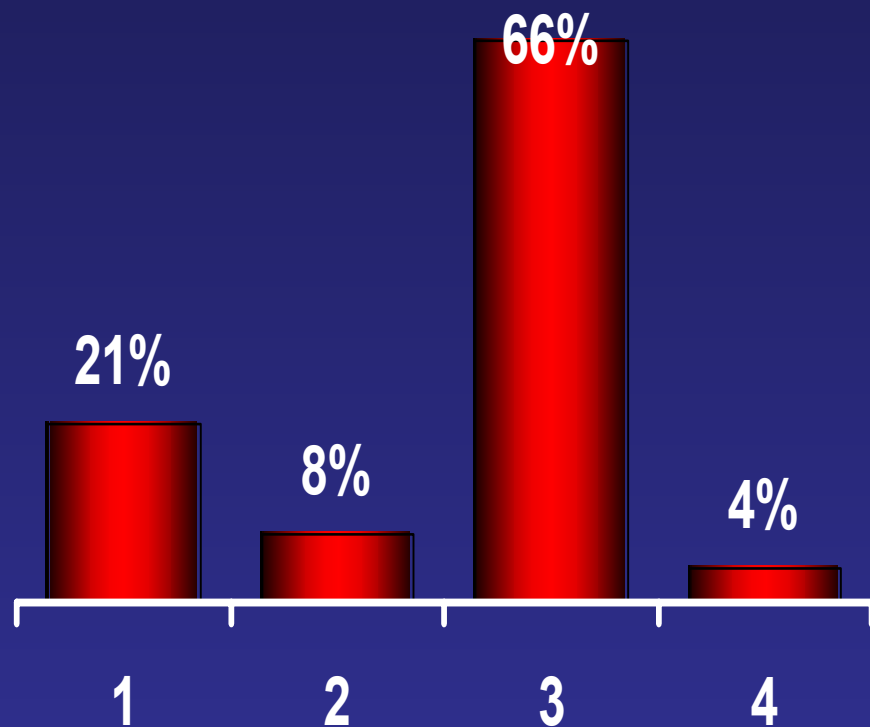
Q29 Does the package information leaflet that accompanies prescription medicine help patients understand how to take cancer medicines properly and how to prevent and manage side effects?

1. The leaflet provides the information required but it is difficult to understand
2. The leaflet provides the information required and is easy to understand
3. The leaflet does not provide the information required and additional explanation should be provided
4. Don't know



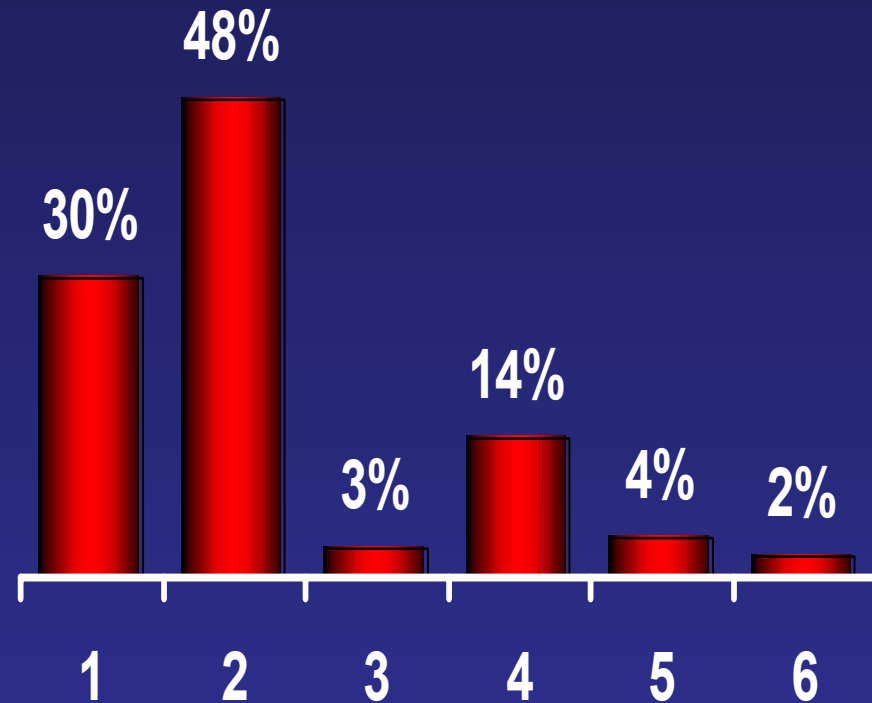
Q30 To what degree are cancer patients in your country involved in the treatment decision making process (i.e. decide what treatment they will have)?

1. Patients are involved in treatment decision making to what ever degree they desire
2. Patients are not involved in treatment decision making at all
3. Patients are sometimes allowed to be involved in treatment decision making
4. Don't know



Q31 Are cancer patients in your country allowed access their own medical records?

1. Yes— with no restrictions.
2. Yes— but some bureaucracy applies.
3. Yes— but only under the supervision of a medical professional.
4. Sometimes — it depends.
5. No
6. Don't know



Q32 If a cancer treatment or test existed that could help improve the outcome for a particular cancer but was not available at a local hospital, would cancer patients in your country:

1. Not want to know it existed because they “can’t do anything about it anyway”
2. Want to know but accept that not everything can be available locally/nationally.
3. Want to know and ask to be referred to the treatment centre providing this service – even if it means travelling up to one hour.
4. Want to know and ask to be referred to the treatment centre providing this service – regardless of how far you would have to travel – even to another country
5. Don’t know

