

## Working with Pharma

ENGAGE YOUR PATIENTS' RIGHTS, NEEDS & VOICES – WHAT DO THEY NEED NOW AND IN THE FUTURE

ASK FOR THE INFORMATION AND SUPPORT YOU NEED TO ACHIEVE YOUR GOALS

WE WILL WORK WITH YOU TO RESPONSIBLY & OPENLY COMPLY WITH REGULATIONS AND CODES

- **Know your Patients' Rights & your Rights** National rules & Codes, European Convention on Human Rights
- **Collaboration models between pharma and patient groups:** Models in every Country

Patient-centric initiatives Funding of nurses to advise patients, of rooms & facilities for Oncology patients  
Funding of patient group websites

Collaboration between Pharma companies and patient groups

Support for Conferences  
Education and training  
Independent Responses to Pricing Authorities' consultations, appeals

- **Compliance and transparency rules:** be open about who supports you & about potential conflicts
  - EFPIA code [www.efpia.eu/sites/www.efpia.eu/files/PO\\_Code\\_-\\_SGA\\_14\\_June\\_2011-20110627-004-EN-v1\\_0.pdf](http://www.efpia.eu/sites/www.efpia.eu/files/PO_Code_-_SGA_14_June_2011-20110627-004-EN-v1_0.pdf)
  - National Country Codes [www.efpia.eu/national-member-associations-code-practice-relationships-between-pharmaceutical-industry-and-patient](http://www.efpia.eu/national-member-associations-code-practice-relationships-between-pharmaceutical-industry-and-patient)
  - European Commission funding conditions
  - Pharma Company Codes & Compliance [www.novartis.com/corporate-responsibility/responsible-business-practices/ethics-governance-and-compliance/index.shtml](http://www.novartis.com/corporate-responsibility/responsible-business-practices/ethics-governance-and-compliance/index.shtml)

- **What can a company do and what it cannot do ?** [http://ec.europa.eu/health/human-use/index\\_en.htm](http://ec.europa.eu/health/human-use/index_en.htm)

- **no 'promotion/advertising' to patients in Europe**

Can't advertise prescription medicines to the public or to patients (can do so in the US)

Can't provide detailed information about future medicines (may do so in the US)

- **Can provide information - after you request it**

Can provide standard information about prescription medicines via internet

Can provide information about health & disease prevention through disease awareness campaigns

Can provide information about clinical trials via media

Can provide information for physicians to provide to patients

Can provide information about future medicines that is provided to shareholders

Can provide some information about medicines that are reimbursed

- **Why is there a difference in the codes of pharma companies ?**

Differences in interpretation of codes & national rules and of level of information made available to patients

In Europe there is a commitment to be consistent with EFPIA Code, in US with PhARMA

- **Tips for working with pharmaceutical companies**

- Be open about how your group wants to work, taking into account the company's code & other rules
- Be clear about the support you need & how you will use it
- Ask for the information you need from companies and from other stakeholders
- Allow for time for necessary internal process & for company to maybe approve only part of your request
- Give your patients' feedback & share their experience