

Role of Patient Associations in Allergy Investigation in Europe

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European Federation of Allergy and Airways Diseases Patients' Associations



The Presentation

- Who is EFA
- Role of patient organisations
- EFA involvement in allergy research
- APA involvement in allergy research
- Patient evidence
- Meaningful research – involving patients/groups
- Tools
- Best practice
- Patient experience
- How can patients add value to research?

- 32 member associations in 22 countries, in which over 500.000 patients/carers
- Representing people with allergy, asthma & chronic obstructive pulmonary disease COPD
- **Vision:** To become the leading reference point for people with allergy, asthma and COPD
- **Mission:** making Europe a place where people with allergy, asthma and COPD
 - have the right to best quality of care & safe environment,
 - live uncompromised lives and
 - are actively involved in all decisions influencing their health



 = EFA Presence

23 European countries
35 member
organisations
representing over
400,000 patients
& carers

In Portugal
APA
RESPIRA



Objectives

For patients

- Provides transparent access to information and educational tools in patient-friendly language
- Provides opportunities to participate actively in projects
- **Facilitates communication in patient-friendly language focusing on patient needs**
- **Develops and promotes long term partnership on equal level**
- **Develops training and educational projects**
- **Ensures active participation of patients in all decisions regarding their wellbeing**
- Acts as liaison between people with allergy, asthma and COPD and EU policy-makers
- Negotiates to raise standards of care, environment and research
- Communicates and updates about patient needs

For Healthcare Professionals/ Scientists

For Policy makers

Role of Patient Organisations

- **Listen, collect & summarise** patient voices, experience, needs and expertise, facilitate patient **participation**
- Represent these to **healthcare professionals & policy makers** – anyone having impact in care/prevention
- **Facilitate** communication, partnership, collaboration and greater understanding between them
- **Take advantage of unique position** of patient organisations: neutral, non profit-seeking, patient at the core – ideally placed
- Take **patient centered action** in care, patient empowerment
- **ENSURE PATIENT VOICE IS HEARD** – in research, policy, funding and public arena

What can EFA do at the EU level? – *“Giving voice to patients”*



1. ADVOCACY:

- ✓ Represent patients with asthma, allergies and COPD towards the EU decision makers
- ✓ Allow for constructive participation in the relevant EU policy formulation

2. COMMUNICATION:

- ✓ Follow up and communicate EU policy developments to all members associations
- ✓ Share best practices and try to develop EU-wide guidelines on the basis of the former

3. PROJECT MANAGEMENT:

- ✓ Represent patients in EU funded research and health projects & run
- ✓ EFA patient driven projects

EFA involvement

- FP7: **MEDALL** *Mechanisms of the Development of Allergy* <http://medall-fp7.eu/>
- IMI: **U-BIOPRED** *Unbiased Biomarkers in the Development of Severe Respiratory Disease* www.ubiopred.eu
– *best practise*
- FP7: **AirPROM** *Airway Disease Predicting Outcomes through Patient Specific Computational Modelling* www.airprom.eu
- FP 7: **EARIP** *European Asthma Research and Innovation Partnership*
- Past: Health Vent, EuroPrevall, GA²LEN, PINCHE, AIRNET



MEDALL EFA Role

- WP10: ‘Translational integration of systems biology outcomes into healthcare to propose early diagnosis, prevention and targets for therapy’ =
 - health care policy in allergy – European template programme on allergy – to be adapted locally
 - EFA to insert patient perspective & advocate locally & EU level
- WP11: Dissemination
 - Integration MEDALL evidence into EFA advocacy
 - Disseminate in lay language
 - Liason for MEDAL local events – patient groups



MEDALL EFA Role in short

- Promotion to
 - EU institutions
 - European and international network of patient groups & EFA partnerships
- Dissemination in lay-language on
 - project (interim) results
 - what they mean for patients
- Impact
 - In policy
 - In care
- Patient perspective

*Sounds good but currently
nothing happening –
looking forward to fulfil our role*

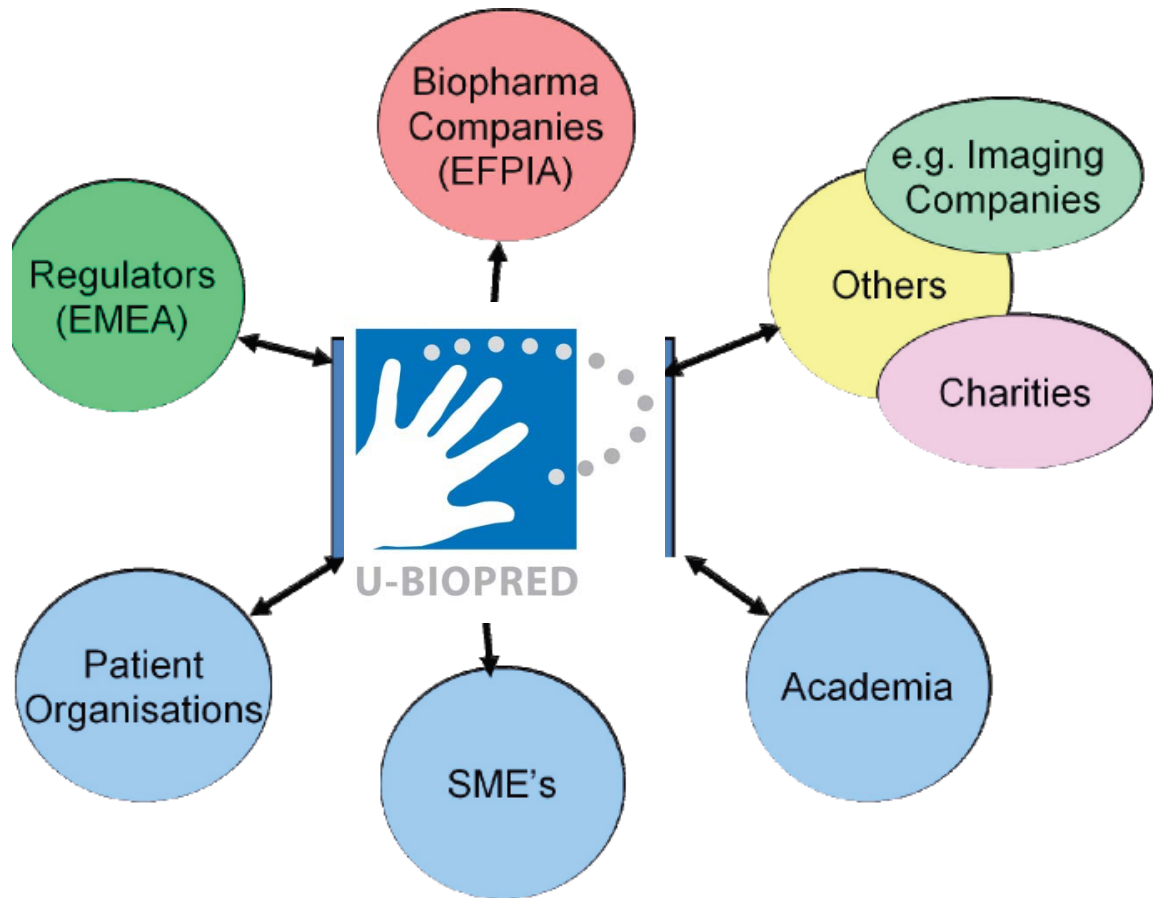


Innovative Medicines Initiative: priority 'understanding severe asthma'



Aim: to better understand the different types of severe asthma to:

- Better consider individual characteristics of patients (personalised medicine) in their diagnosis and management
- Make it easier to develop new and more effective medicines by overcoming the present bottlenecks to advancing new therapies.



U-BIOPRED Patient Input Platform PIP



Patient input (EFA, Longfonds NL & Asthma UK):

- ✓ Patient-oriented outcomes
- ✓ Defining research questions
- ✓ Disease knowledge
- ✓ Access to patient networks
- ✓ Ethics
- ✓ Safety
- ✓ Strategic Advise
- ✓ Help in planning and running study
- ✓ Teaching
- ✓ Informed consent
- ✓ Dissemination, training, exchange
- ✓ Patient-public-private partnerships
- ✓ Consensus generation



The project is great but you need to be aware of this, this and this

U-BIOPRED Annual Meeting 2011, Barcelona
Lina Buzermaniene, Lithuania, patient representative in the Ethics Board
Per-Ake Wecksell, Sweden, patient representative in the Safety Board



First time in U-BIOPRED meeting – good to get the overview & the feel of the project

Asthma art contest



U-BIOPRED (Unbiased BIOmarkers in PREdiction of respiratory disease outcomes) is a research project to understand more about severe asthma.

To bridge the gap between doctors' and patients' perception of asthma, U-BIOPRED have opened an art contest to the public.

This is your chance to express your experiences of asthma through art.

How to Enter

Anyone can enter this competition, just log on to www.ubiopred.eu and upload your artwork.

Winners will be invited to a multimedia science/art show in Brussels.

The deadline for entries is 01/05/2011.



Entries will be judged on three main categories:

1. Artistic skills
2. Composition of the piece
3. Emotional impression

This is an IMI funded project



efpia

European Federation of Pharmaceutical Industries and Associations

Disclaimer: The content on this Flyer reflects only the author's views and neither the IMI JU nor the Commission is liable for any use that may be made of the information contained herein.

For more information, please go to: www.ubiopred.european-lung-foundation.org

Understanding Severe Asthma

Asthma remains a major health problem around the world. People with severe asthma, who have little control of their asthma, require a lot of healthcare resources.

U-BIOPRED knows that the current treatments are not sufficient and not all severe asthma is the same.



U-BIOPRED

1. An improved understanding of severe asthma, which will open the way to the development of more effective treatments.
2. A personalised process of translating science into therapy.

How will U-BIOPRED achieve this?

A large clinical study will identify different types of asthma patients who may respond better to different treatments.

Collaborating for the future of Severe Asthma treatment

40 organisations, academic severe asthma treatment centres, research departments of pharmaceutical companies and patient groups are working together to develop our understanding of severe asthma.

This is an IMI funded project



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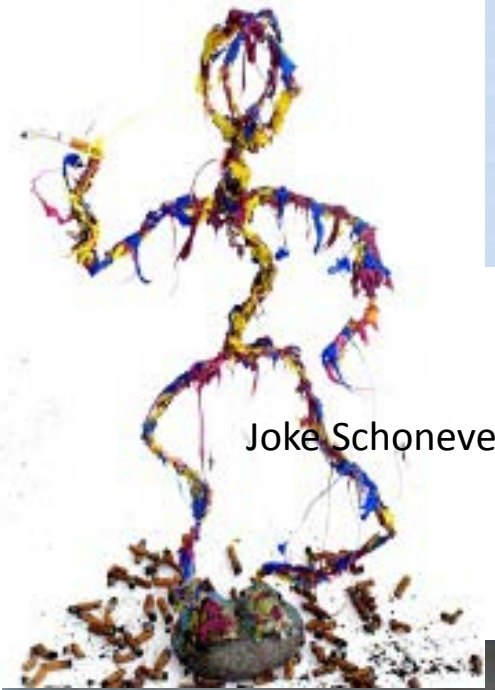
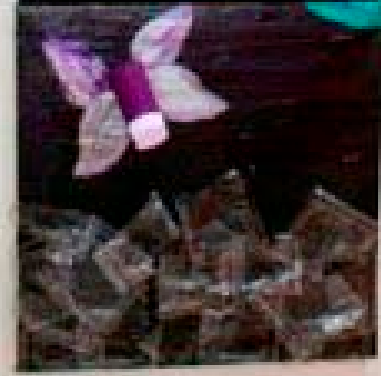
English
French
Polish
Italian
Danish
Norwegian
German
Hungarian
Spanish

In collaboration with EFA members in Belgium, Denmark, Norway, Poland, Italy, Ireland, Sweden, UK, Netherlands



Marije Kootstra

Yvette Moerdijk



Joke Schoneveld



Maria Rubin

Asthma as seen by patients
U-BIOPRED Asthma Art Contest winners

Patients Leading: EARIP

- New project FP7 **European Asthma Research & Innovation Partnership**
- **Objective:** coordinate a pan-European research activity to reduce asthma attacks, emergency healthcare utilization and asthma deaths in both adults and children
- **Partners:** academia, clinicians, patients, industry
- **Lead** asthma patient charity Asthma UK
- **EFA** leads WP on Health Care Change, based on the best practice of the Finnish National Asthma Programme
 - Literature review on asthma programmes
 - Stakeholder WS at European Parliament on best practice
 - Expert WS to recommend health care change & research for Europe
- **EARIP outcome:** Roadmap for asthma research & Asthma research innovation partnership

Patient groups generating patient evidence: EFA Allergy Project



- **EFA Book on Respiratory Allergy** in Europe *Raise Awareness Relieve Burden*, available in 15 languages <http://www.efanet.org/efa-book-on-respiratory-allergy-in-europe-relieve-the-burden/>
- **Survey in 16 countries** on the state of play of allergy care, patient group involvement, successes & main issues from patient perspective
- **Published** in an event at the European Parliament, following symposium at the ERS conference 2012
- **Call to Action** for Europe <http://www.efacallaction.net>
- **Evidence for advocacy**
- In partnership with the EAACI, ERS, ARIA



EFA Allergy Project

- **Alert paper:** Allergology in Europe under threat with UEMS, EAACI, ARIA
 - Request for EU Support in the Development of Allergology Education
- **Pilot project in Austria on Pharmacist role** in detecting people at risk of respiratory allergy in collaboration with PGEU
 - Questionnaire in all pharmacies.
- **Training on Finnish Allergy Programme – *how to do*** - 2012 & 2014 for country delegations
 - Result: Bulgaria & Norway on their way, Italy considering – patients leading/contributing

Portugal - APA

- Partnering in nationwide allergy research projects with real impact in patients life's
- Control and Burden of Asthma and Rhinitis (ICAR)
 - the prevalence and control of asthma and rhinitis in Portugal
 - evaluate the factors underlying asthma control.
<http://clinicaltrials.gov/ct2/show/NCT01771120?term=icar&rank=2>
- Partners in CARAT - "Control of Allergic Rhinitis and Asthma Test"
 - first questionnaire to evaluate in combination asthma and rhinitis control
 - Translated to +13 languages
 - endorsed by ARIA and WHO
 - important tool to evaluate patients with both diseases
- **APA: *‘one of the main roles for patient groups is to collaborate in research & trying to bring a more patient centred view to research. We think we have proven that we can do it’***

Good Practice: EMA

- Patient and Consumer Working Party PCWP
- Patient reps in Management Board
- **Patient reps/patients in PRAC, PDCO, COMP**
- Patient involvement in guidelines
- **Patient involvement in SAGs**
- Patient reviewers for PILs & EPARs
- Patient reviewers in safety communications
- Plan to involve in guidelines
- Training: annual training day, online modules, videos

[http://www.ema.europa.eu/ema/index.jsp?curl=pages/partners and networks/general/general_content_000317.jsp&mid=WCOB01ac058003500c](http://www.ema.europa.eu/ema/index.jsp?curl=pages/partners_and_networks/general/general_content_000317.jsp&mid=WCOB01ac058003500c)

EMA PCWP



Lina
Buzeraniene
EFA Board
Member



Annual training of patients

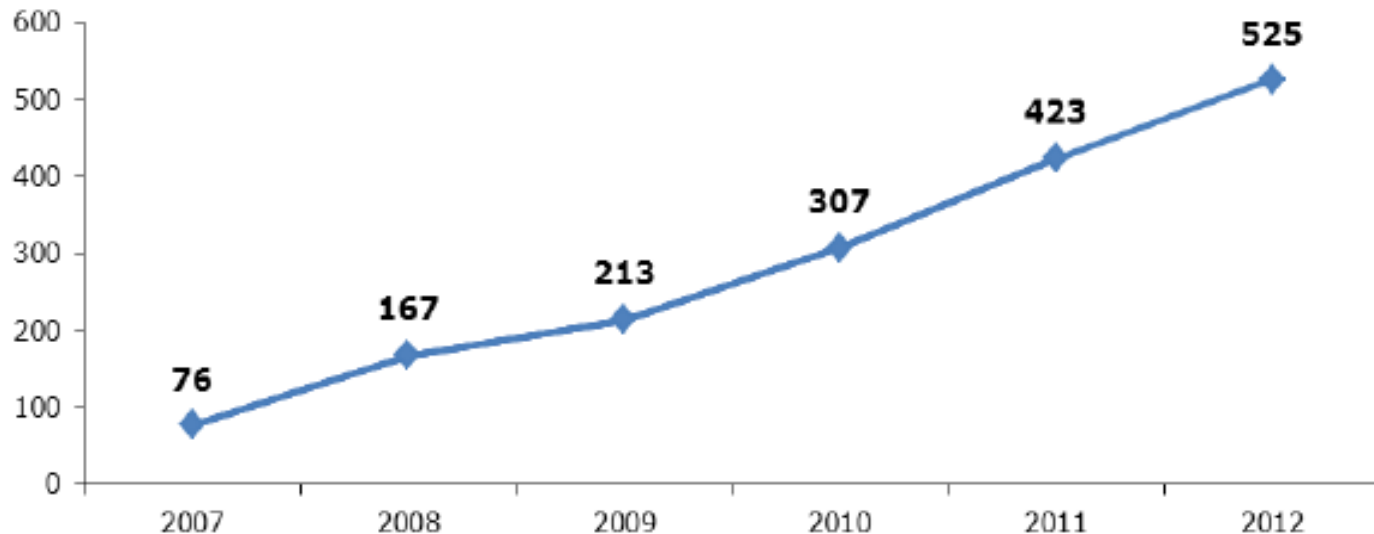
Good Practice: EMA



Activities are split into three categories;

1. activities in which patients/consumers are members, alternates or observers,
2. activities involving individual patient experts, and
3. activities requiring organisation representatives.

Overall number of patients and consumers involved in Agency activities
2007-2012

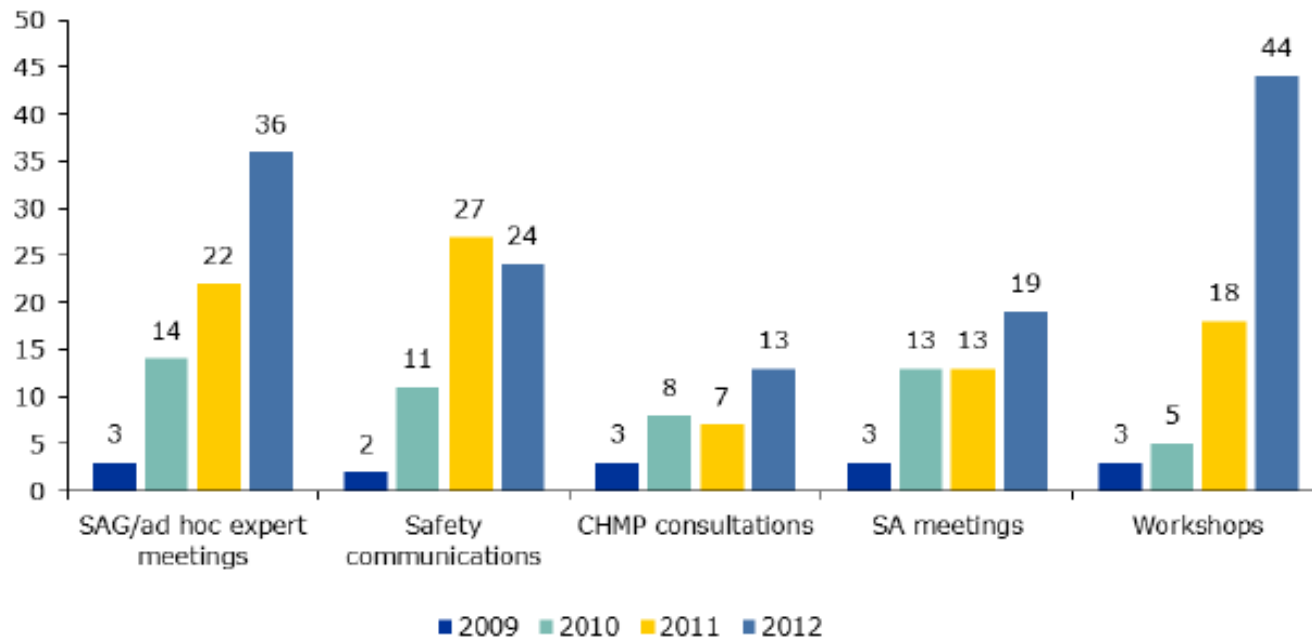


Good Practice: EMA



Comparison of involvement in core activities

2009-2012

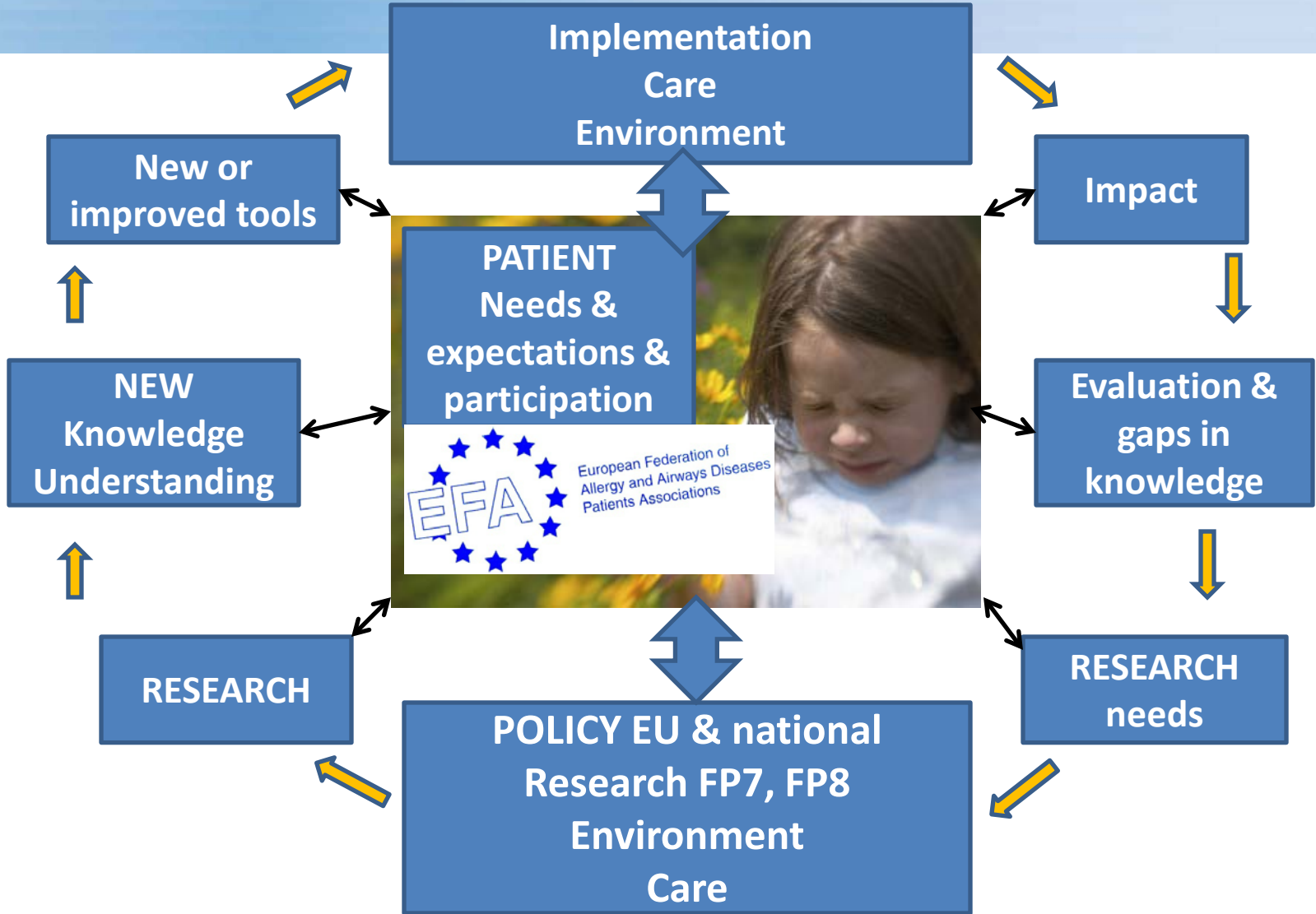


Common mistakes..

- Last minute
- Tokenistic - endorsement
- Not planned
- Not resourced
- No training
- Meaningful patient involvement: From the beginning to the end

To think: usually one patient/patient representative expected to deliver patient perspective

EFA strategy – meaningful research



  = patient involvement

Meaningful Patient Involvement

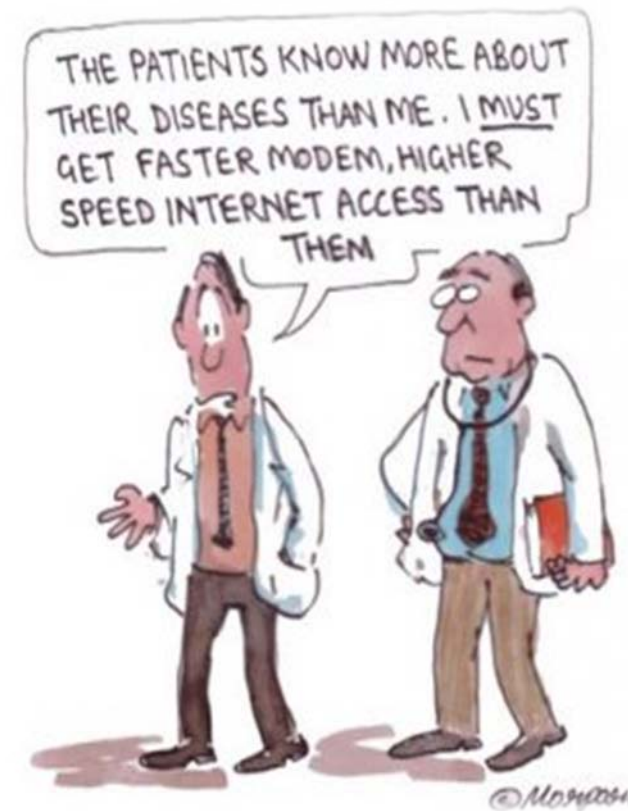
Patients take an active role as equal partners in activities and decisions that will have a consequence for the patient communities

Patients are experts because of their knowledge and relevant experience as patients



Patients are active partners in the research process rather than the subjects of research

MUTUALLY ACCEPTABLE SOLUTIONS TO HEALTH RESEARCH PROBLEMS



Patient meaningful involvement in R&D aims to:

- ❑ Ensure that the way **research** is designed, undertaken, evaluated and disseminated **reflects the needs and views of the patients**
- ❑ **Integrate researchers'** theory expertise with **patients' real-world knowledge** and experiences of the condition
- ❑ Ensure that research doesn't just measure outcomes considered important by professionals
- ❑ Strengthen **trust and acceptance** of research results
- ❑ Promotion of reasearch results by patient organisations because of sense of ownership of the process (**enhanced visibility**)



Produce results that can be used to effectively improve practice in health care for the benefit of the patients

Level of Patient Involvement

Consultation	Collaboration	User control
<p>Advantages</p> <ul style="list-style-type: none"> -safe way to start -enables you to obtain a view of patients' needs without committing yourself to acting on them -fairly simple 	<p>Advantages</p> <ul style="list-style-type: none"> -increase likelihood of relevant research outcomes -support with recruitment -patients feel ownership and are more committed 	<p>Advantages</p> <ul style="list-style-type: none"> -innovative user-driven approach -patient empowerment -better service outcomes -thorough integration of relevant research questions
<p>Risks</p> <ul style="list-style-type: none"> -patients can be frustrated -high risk of patient/p.o. turning down the invitation -risk of "consultation fatigue" -you can miss out on ideas because of top-down approach 	<p>Risks</p> <ul style="list-style-type: none"> -time consuming -extra costs involved - active commitment from the research might not be easy to get -researchers may require additional skills 	<p>Risks</p> <ul style="list-style-type: none"> -patients may lack necessary skills -potential bias -research may find this unacceptable -the research may not be perceived as independent

Levels of Patient Involvement

Consultation

Collaboration

User control

Which level of involvement is best?

No single answer

Different types of involvement will be appropriate for different research projects depending on:

- the topic of research
- the methodology used
- the patient group concerned
- The skills required
- the requirements of the funding body
- The stage of research (design, implementation, evaluation, etc.)

Involvement can occur during any or all of the processes involved in R&D including

Planning and designing the research



Helps you...

- better understand user requirements, needs, expectations and constraints, i.e. eHealth and telehealth
- better understand ethical implications of research
- have a clear understanding of how to manage patient involvement throughout the research projects

.....ultimately

enhance your chances to get your research project funded

Involvement can occur during any or all of the processes involved in R&D including

- Planning and designing the research
 - Managing the research
- 

Helps you...

- ensure that user needs, requirements and expectations are effectively integrated throughout the research projects
- ensure that patients have a ownership of the research project
- better manage the involvement of patients in the various project activities

Involvement can occur during any or all of the processes involved in R&D including

- Planning and designing the research
- Managing the research
- Undertaking the research



Helps you...

- Design and fine tune the research instruments (e.g. questionnaires, surveys, various stages of clinical trials)
- Enhance patient participation and motivation
- Benefit from patients' own expertise

Involvement can occur during any or all of the processes involved in R&D including

- Planning and designing the research
- Managing the research
- Undertaking the research
- Interpreting results of research



Helps you...

- Obtain feedback and comments that aid analysis and interpretation
- understand which areas of the findings are of most interest to them and which they would like to be explored further or featured in the research reports
- Identify options for further actions/research

Involvement can occur during any or all of the processes involved in R&D including

- Planning and designing the research
- Managing the research
- Undertaking the research
- Interpreting results of research
- Disseminating research results



Helps you...

- Effectively reach out to patients through patient-friendly, understandable dissemination tools and language
- Raise the research in different fora outside the researchers community which researchers do not have usually access to
- Give your research project more visibility and enhance its sustainability

Involvement can occur during any or all of the processes involved in R&D including

- Planning and designing the research
- Managing the research
- Undertaking the research
- Interpreting results of research
- Disseminating research results
- Evaluating research process and results



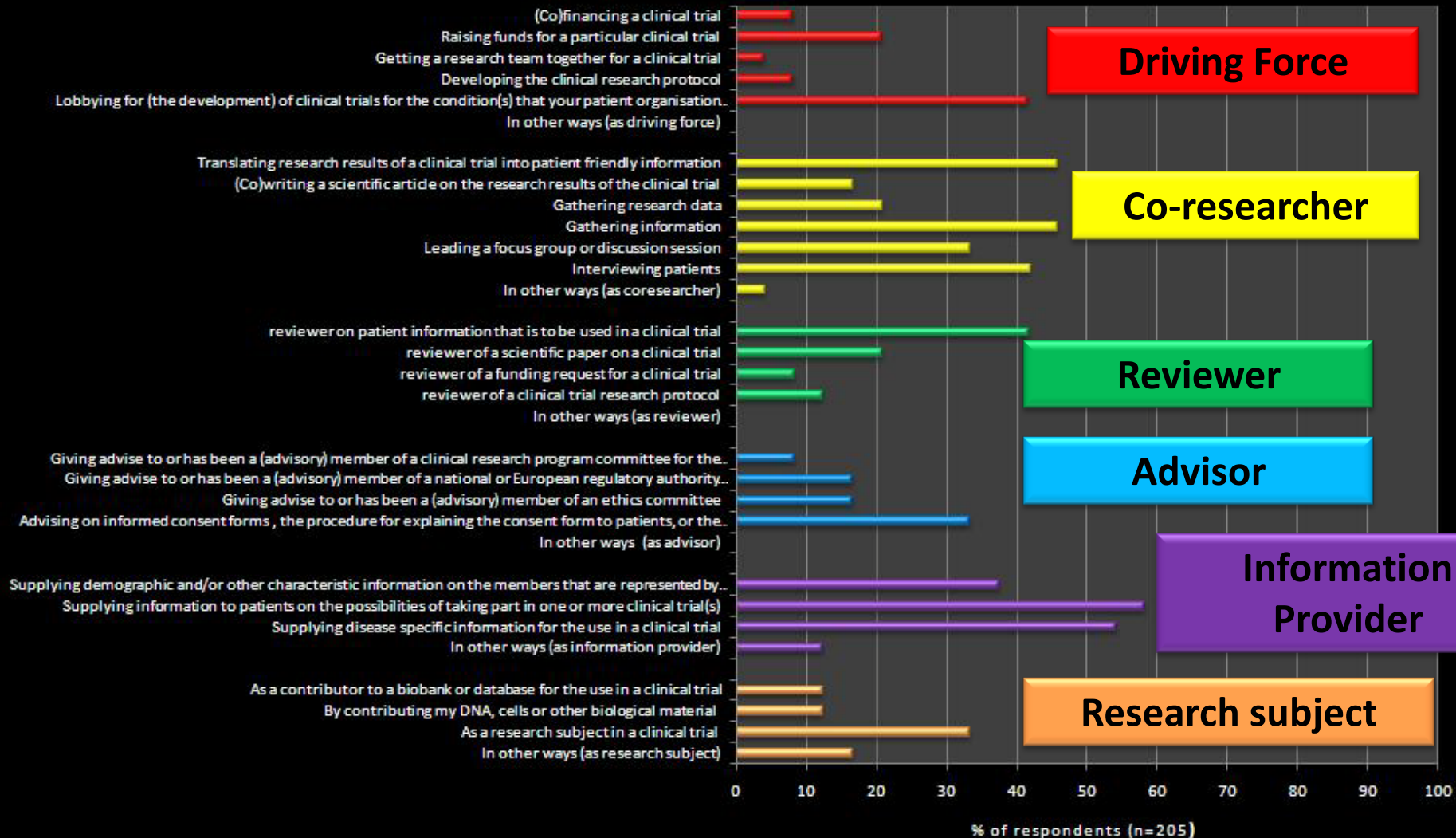
Helps you...

- learn from patient's experience of their involvement
- better understand what went well and what went wrong and why
- assess whether user requirements, need and expectations have been met
- improve the way future research is undertaken

Meaningful Patient Involvement

Is (has) your patient organisation (been) involved in clinical trials
Central and Eastern Europe

Level of patient involvement



% of respondents (n=205)

Assessed patient involvement in EU health projects

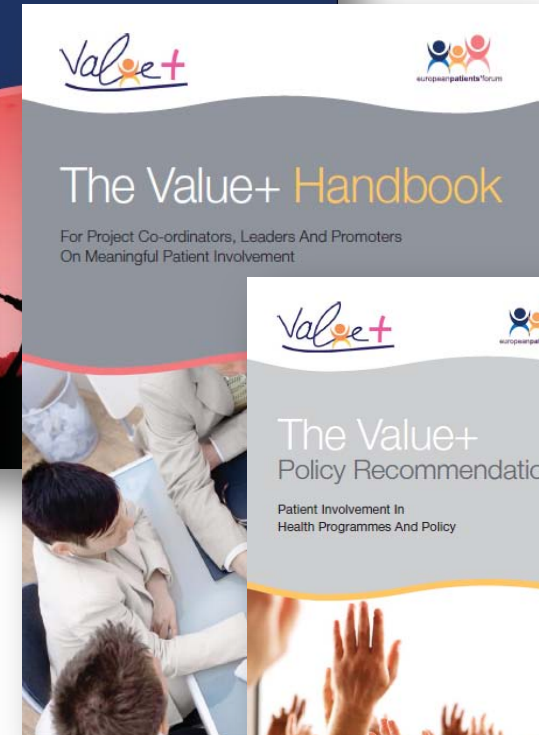
Approx. 100 EU-funded health related projects for the period 1998-2008

FP6 and FP7 some key findings:

- ❑ **Different understanding of patient involvement**
- ❑ **Patient involvement** was generally clearly weaker in research projects than in other projects, especially those focused on **clinical trials, studies or development of technologies and devices**
- ❑ Limited patient involvement at the inception and planning stage, and in the governance structures of projects
- ❑ **Limited resources** devoted to patient involvement
- ❑ Researchers and project coordinators are interested in promoting more effective patient involvement in health research projects but is **difficult to translate this in practice**

Series of Tools:

- ❑ to enable patients to become more involved in EU funded projects including research projects (Value+ Toolkit)
- ❑ for project promoters and coordinator to acquire more skills to enable them to facilitate in practice (Value+ Handbook)
- ❑ a series of policy recommendations looking at linking research project outcomes with patient – centred policy development
- ❑ a database of patient organisations in all EU Member States



Purpose

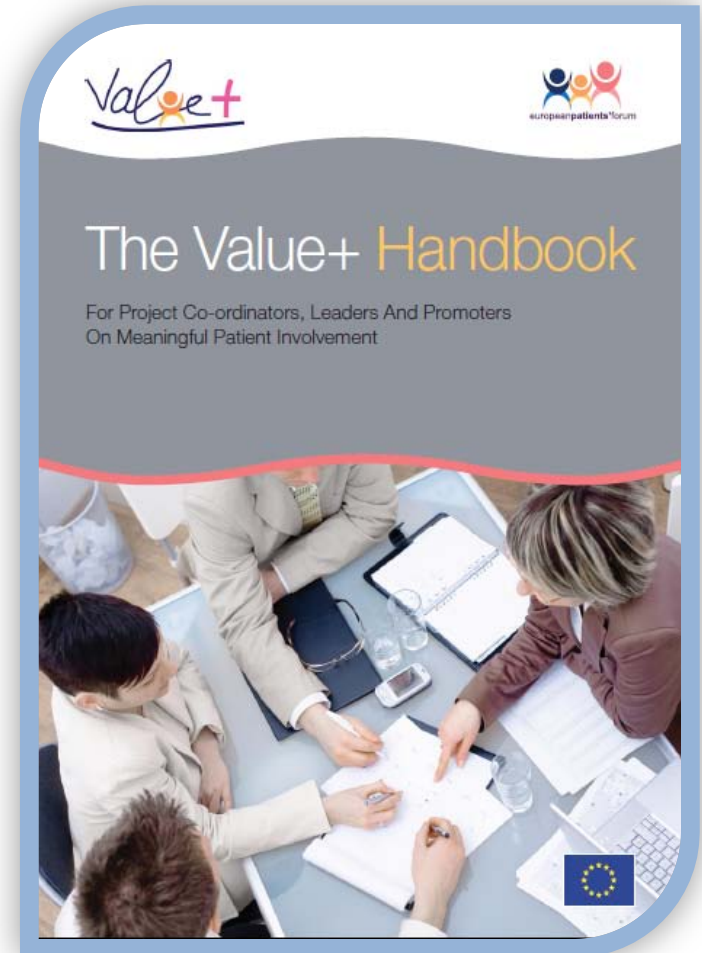
- ❑ Two-fold purpose: raising awareness and providing and disseminating know-how

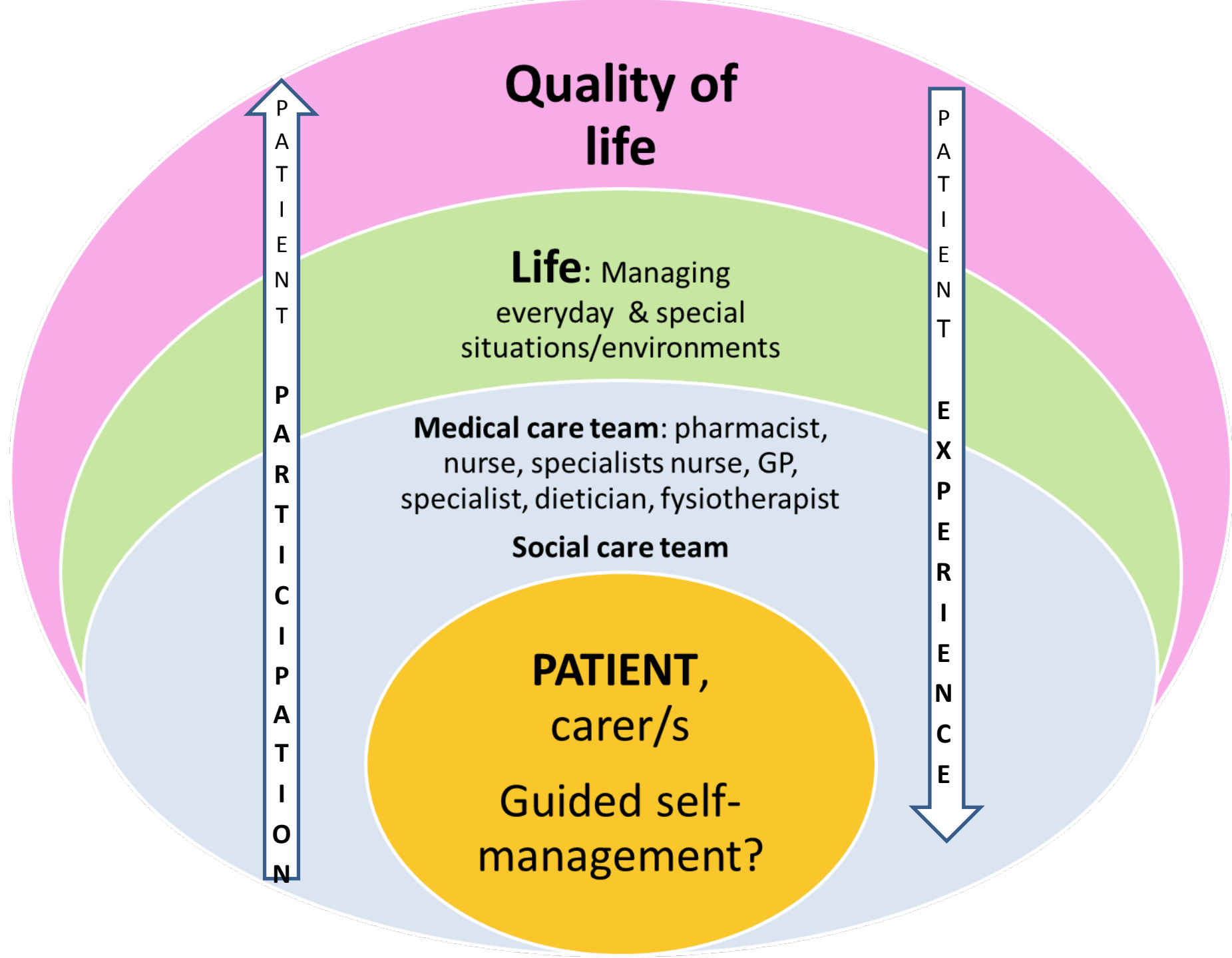
Content

- ❑ Value+ Model of Meaningful Patient Involvement
- ❑ Involvement at each project stage
- ❑ Knowing patients and patient organisations for working with them

Get yourself a copy at:

<http://www.eu-patient.eu/Documents/Projects/Value+%20Handbook.pdf>





Quality of life

Life: Managing everyday & special situations/environments

Medical care team: pharmacist, nurse, specialists nurse, GP, specialist, dietician, fysiotherapist

Social care team

PATIENT,
carer/s

Guided self-management?

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Quality of life

Life: Managing everyday & special situations/environments

Medical care team: pharmacist, nurse, specialist nurse, GP, specialist, dietician, physiotherapist
Social care team

PATIENT,
carer/s
Guided self-management?

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PATIENT INVOLVEMENT MAKES SENSE

Patient groups as partners

- Informed patient
 - Representative patient voice *versus* individual patients
 - Difference between patient representative and individual patient
- > Both have value and can be reached through partnership with patient groups**

We can add value

- **Guide** research agenda setting: priorities of patients
- **Participate**: ethics, informed consent, SOPs, tricky questions arising, evaluation, communication
- **Advocate** for implementation: policy makers, healthcare profs
- **Disseminate**: media, public, members
- **Translate** into lay-language
- **Promote** patient involvement
- **Train** in patient involvement
- Human face for research

We can add value

- **Guide** research agenda setting for patients
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- **Human face** for research

Research WITH vs Research ON patients

Conclusions

Paradigm shift

RESEARCH **WITH** THE PATIENT

Patients as equal
partners in research



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Little Aleksí advocating at the European Parliament for better allergy care at the launch of EFA Book on Respiratory Allergy

EFA Manifesto

for 2014

European Parliament Elections

Three priority areas and fourteen actions to improve the health and quality of life of people with asthma, allergy and chronic obstructive pulmonary disease in Europe

"From 2014, help to improve health among people with allergy and airways diseases"

Sign here 17 October
thereon – patients
need your support:
www.efanet.org
& follow the Campaign
#EFAPatients



400,000 patients
=
400,000 votes

**THANK
YOU**



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Walter Atzori, EPF Senior Programme Officer

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