

Patient & *Carer* Involvement in Guidelines?

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Quality of life

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Life: Managing
everyday & special
situations/environments

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

PATIENT,
carer/s

Guided self-
management?

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PATIENT INVOLVEMENT MAKES SENSE

Models

- **‘Consumerist’** model -> right to be involved: empowered, active patient, informed choice, personalised HC
- **‘Democratic’** model -> democratic, accountable HC policy base on values
- **‘Expert patient’** model -> patients’ experiential knowledge & quality of HC

Evidence?

- Involvement of patients and public increasingly advocated by

1. Quality standards for guideline development
2. Editorials in medical journals
3. Research articles
4. Increasingly public authorities
5. And of course patient group

1. AGREE Collaboration 2003. Qual Saf Health Care. 1(1):18-23. Institute of Medicine 2011 Clinical Guidelines We Can Trust. Improving the use of research evidence in guideline development 2006. Health Res Policy Syst, 4, 22.
2. The next step in guideline development 2008. JAMA, 300, 436-8. Paternalism or partnership 2008. Ir Med J, 101, 232. Public involvement in guideline production; CMAJ 176(9):1308-9.
3. Patient and Public Involvement in Clinical Practice guidelines 2011. Med Decis Making 31(6):E45-74. How to integrate individual patient preferences in clinical practice guidelines? A research protocol. Implement Sci.:5:10. A strategy for patient involvement in clinical practice guidelines 2011. BMJ Qual Saf 20(9):779-84. Raising the standard: practice guidelines & consumer participation. Int J Qual Health Care 8:485e90. Do clinical practice guidelines incorporate evidence on patient preferences? Med Dec Making 2007;27:E63-4. Why Consider Patients Preferences? 2009. Med Care 47:908-15. Bringing the Patient back in. Int J Technol Assess Health Care, 18(4). 747-761.

Tools/Training (for involvers&involved)

- G-I-N PUBLIC Toolkit: Patient and Public Involvement in Guidelines <http://www.g-i-n.net/document-store/working-groups-documents/g-i-n-public/toolkit/toolkit-combined.pdf>
- EPF Value+ toolkit for 1. EU project co-ordinators, leaders & promoters 2. patient groups/patients <http://www.eu-patient.eu/whatwedo/Projects/EPF-led-EU-Projects/ValuePlus/>
- ELF European Patient Ambassador Programme EPAP www.epaonline.eu
- EFA Meet & Greet EU institutions training & 2014 EMA training for members



The Value+ Handbook

For Project Co-ordinators, Leaders And Promoters
On Meaningful Patient Involvement

Module 4

[Supporting research development](#)



The Value+ Toolkit

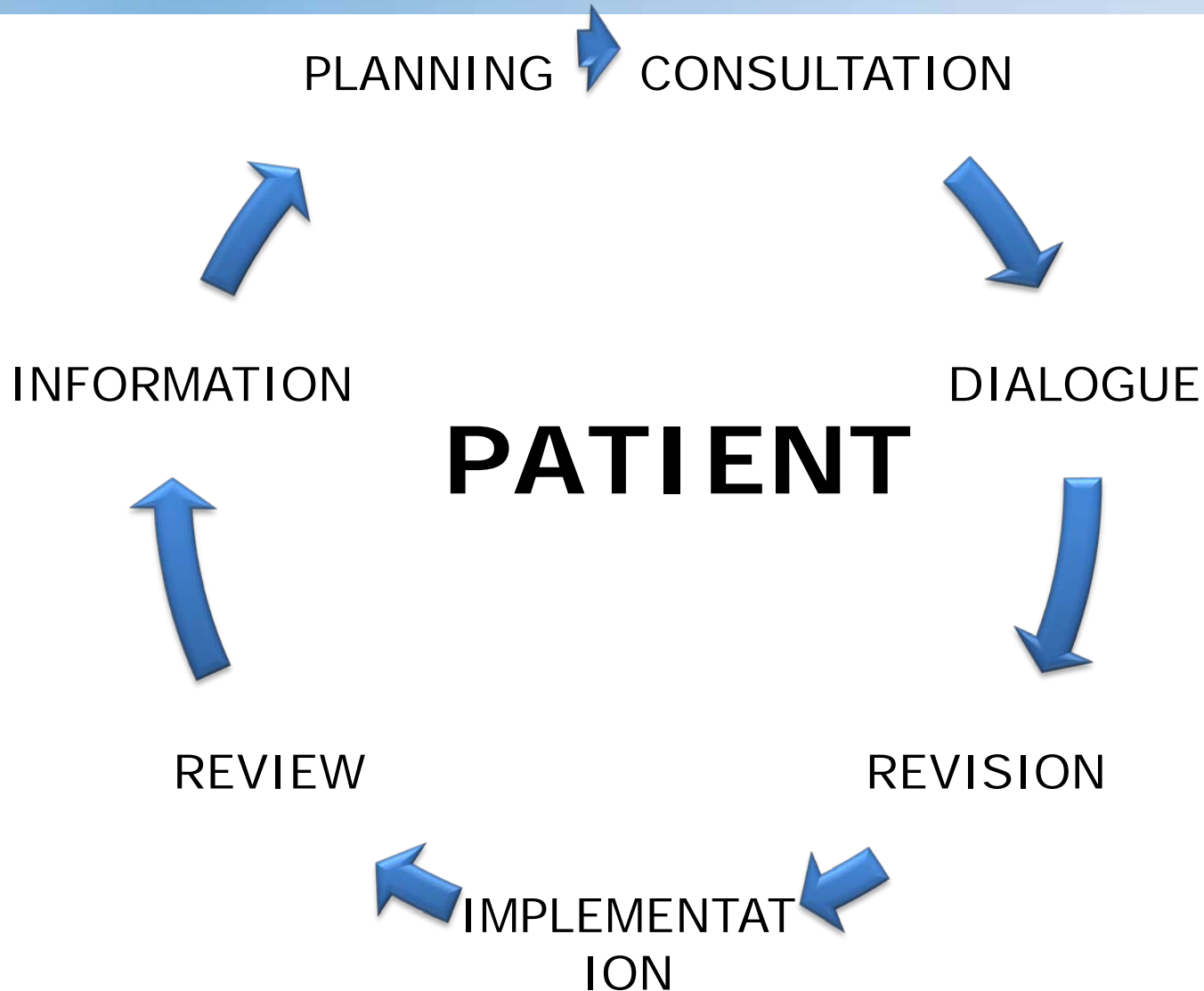
For Patient Organisations On Meaningful Patient Involvement
Patients Adding Value To Policy, Projects And Services

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

Meaningful patient involvement



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)

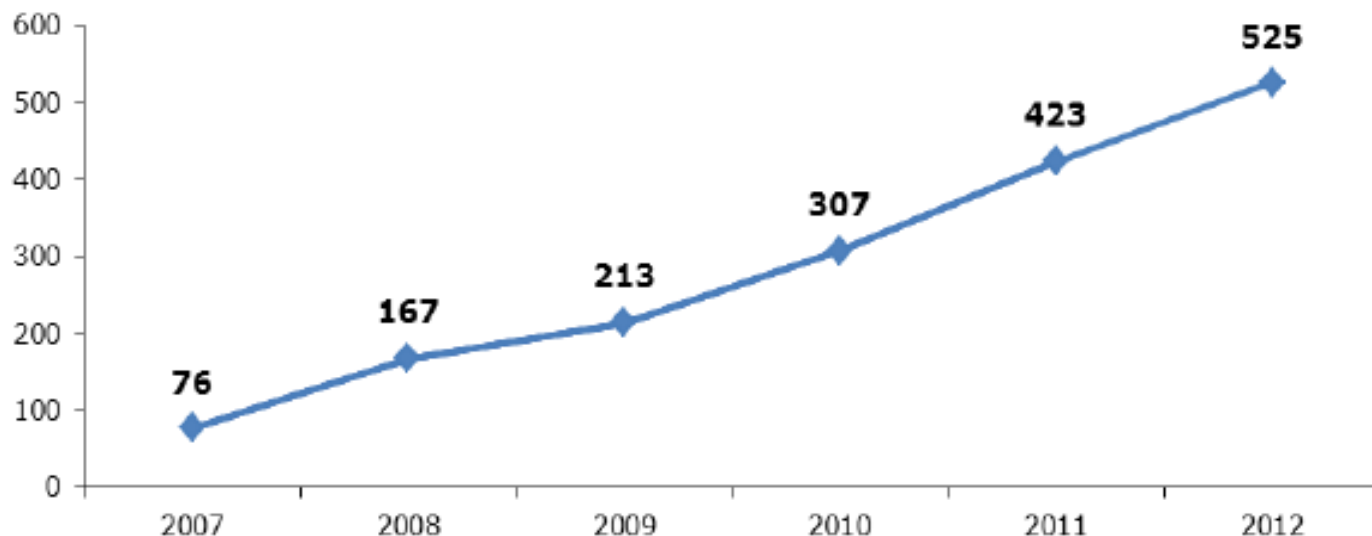
Good Practice: EMA



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

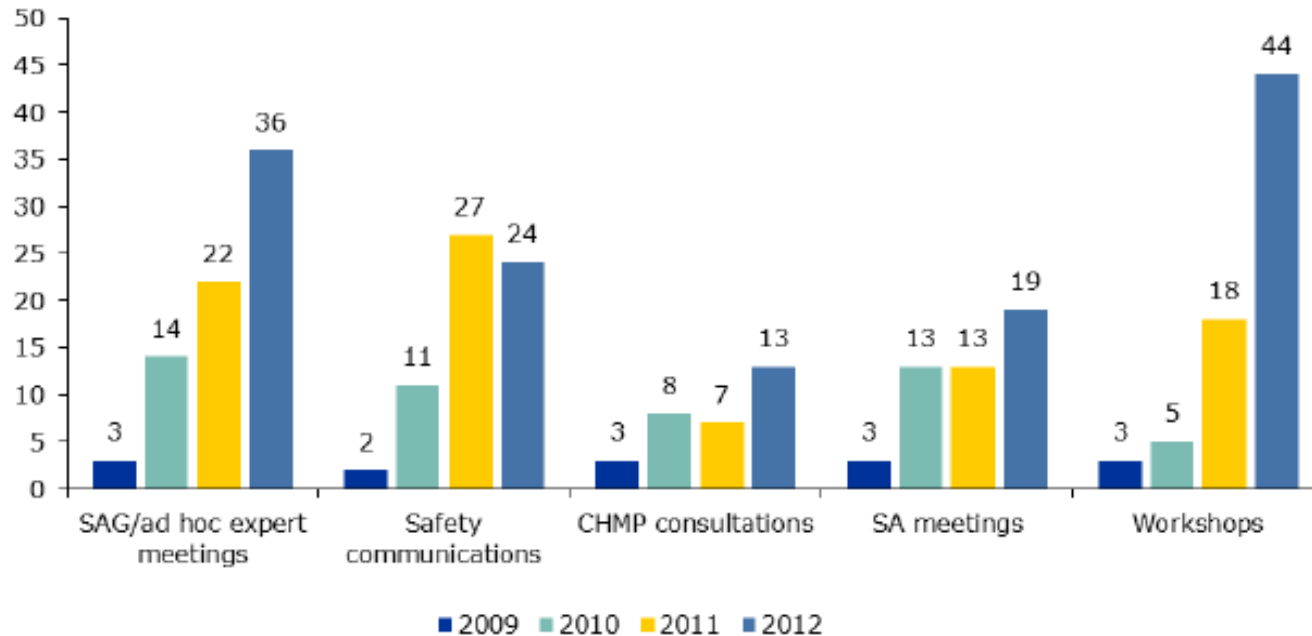


Good Practice: EMA



Comparison of involvement in core activities

2009–2012





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

Patient groups as partners

- Informed patient
- Representative patient voice *versus* individual patients
 - For example for EMA SAG, 2 patients/patient reps will be reimbursed. EFA would send 1 informed patient, 1 EFA rep (patient or not)
- Difference between patient representative and individual patient

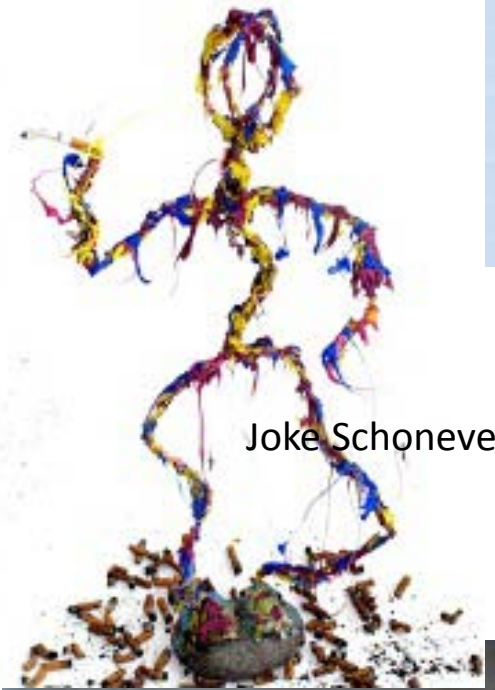
Current situation in our disease areas

- GINA – no involvement
- GOLD – no involvement
- ARIA – EFA rep in ARIA Committee
- ERS – no involvement, but on their way to do so, facilitated by ELF and their PAG
- EAACI – some *ad hoc* and some organised involvement through POC. On their way.



Marije Kootstra

Yvette Moerdijk



Joke Schoneveld



Maria Rubin

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

**Little Aleks
advocating at the
European Parliament**

Thank you for your attention!

European Federation of Allergy and Airways Diseases Patients'
Associations (EFA)

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