# Patient reporting: the perspective of patients

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# Why reports from patients?

- we desperately **need more reports** – now far fewer than 10% of ADRs are reported! So it can still take years to discover major harms
- there are vastly more patients than professionals
- patients report different drugs and different reactions than those professionals report
- they report **directly** & in much more detail
- they say **how the ADRs affect their life** and family and work – clinicians don't know or ask

# **Benefits** for patients and society

- reporting makes patients active participants instead of passive ‘subjects’
- reporting improves health literacy, and helps mutual communication with health professionals
- it describes the burden of ADRs for individuals, which escapes current PV systems and remains largely unknown

# Patients' experiences now

- their ADRs are rarely followed up
- few get any feedback or explanation from their doctor nor the regulatory agency
- no one checks whether they need support or are getting any

# Feedback

Many patients and families may wish to know

- more about their ADR, how common it is, how it could be prevented or predicted, & how to manage it
- whether other family members might get it
- in research on what is not known about it

**How should we try to tell them?**

A task for doctors and regulatory agencies?

# Where we are now

- On 31.12.2010 a **new EU Directive on PV** arrived. It requires Member States to facilitate the reporting of suspected adverse reactions by patients, and to offer them methods for such reporting them.
- This is now happening: reports from patients are being treated like reports from professionals, but separately.
- Details of the reports or the analyses so far remain unpublished; we don't know whether patients (or professionals) are getting any feedback
- **good feedback**, **public and personal, could encourage both patients and professionals to report**
- **without feedback, the real participants feel left out!**

# Participatory Medicine* means sharing decisions

- doctor and patient must **understand** the choices: the pro's and con's of the possible treatments – their expected benefits and possible harms, also when to expect them and their likely duration
- Personal preferences differ between people: those of patients come first – many need help to express them

**See www.participatorymedicine.org

# Some principles in Health literacy 1

a. **The different uses** of medicines:

- **preventive** – eg prevention of infections, of anaemia in pregnancy
- **supportive**—helping to maintain bodily function
- **symptomatic**—to relieve or attenuate symptoms
- **curative**—to cure a disease or condition

# Some principles 2

b. **Which medicines** to use?

- Choose those that have been long and widely used, so that their effects are well known
- If a newer drug **is** needed, its effects should be monitored closely by the medical team and the patient, and any unexpected events recorded in detail

# Some principles 3

c. **Starting, changing, stopping**:

- use the lowest dosage that works well
- decide when and how to stop
- observe the effects when they are expected
- if not satisfactory, consider adjustment or change

# **Joint reporting** by doctor and patient

- Is so far rare: patients may blame the doctor, the doctor may feel uncomfortable or even guilty
- But both want to help prevent repetition of the ADR. Their accounts complement each other, giving a clearer and more complete description
- Such collaboration takes time and effort – it should be encouraged and recognised
- A published example by a patient and me:

P. Chandler, A.Herxheimer. Unexpected aggressive behaviour: interaction of bupropion and alcohol. *Int J Risk & Safety in Medicine* 2011; 23:133–137

# Research on PV reports

- At present Data Protection rules prevent full access to the reports held in PV databases, so little research can be done
- It would help if all reporters were enabled to agree access to their reports by bona fide independent researchers
- Such research will also need proper funding, preferably not from a national regulatory agency
- It makes no sense to accumulate vast data hoards that remain locked away

# For all of us to describe and discuss

- What's happening now in your country/ organisation/ professional community?
- Are any plans being made or discussed?
- What would you like to see happen?
- What would you like to do yourselves?
- Would you like to work internationally? (not just by coming to Uppsala!)
- An international web discussion, with examples?
- **LET'S GET STARTED**