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Patients want to be heard

Patients are asking to be consulted more and listened to when decisions affecting their health are made. This includes decisions about their own healthcare and decisions taken by health authorities.

Joint healthcare decisions. Some patients are asking to be involved in healthcare decisions that affect them: "*having complete confidence in the dialogue between professionals and patients to arrive at the best treatment strategies and joint decisions*" (1). *Prescrire* has long upheld the same position for healthcare professionals, i.e. that the harm-benefit balance of an intervention must be determined for and with each patient (2).

A say for patients in marketing authorisation decisions? Patient participation in healthcare decisions in everyday practice, through direct dialogue with the health professionals they consult, is completely justified and in their best interests. Some patient groups are also calling for patient participation in decisions on marketing authorisations (3,4). Some patient groups support a number of worrying plans, proposed by the European Medicines Agency, to reduce the evaluation drugs undergo before they are granted marketing authorisation (4-6). Despite the fact that, as Europe's main consumer organisation has pointed out, these proposals pose a risk to patients in general, both current and future (7).

Good decisions require robust data. It is completely justified and appropriate that patients' opinions, preferences and experiences be taken into account in healthcare and in decisions taken by health agencies. But always on condition that the decisions are based on robust clinical evaluation data.

To achieve this, drugs must be evaluated rigorously before their market introduction, to accurately document their potential benefits and harms. If patients and patient representatives have and understand these data, and contribute their perspectives, uncertainties and preferences, they can participate fully in reasoned, rational decisions.

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Selected references from Prescrire's literature search.

1- CISS "Le prix des médicaments ne doit pas menacer l'accès aux soins", press release, 20 June 2016: 2 pages.

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3- Genetic Alliance UK "New medicines for serious conditions: how patients would weigh the risks and benefits. Report of findings from phase 1 and 2" 2014: 54 pages.

4- European Patient Forum "ADAPT SMART project kicks off". www.eu-patient.eu accessed 5 July 2016: 1 page.

5- EURORDIS Rare Diseases Europe "Activity report 2015 & workplan 2016": 88 pages.

6- Prescrire Editorial Staff "Adaptive Pathways: EMA's dangerous plan" *Prescrire Int* 2016; **25** (174): 223.

7- The European Consumer Organisation "A fast-track approval for new medicines-Patient safety at risk? BEUC position on adaptive pathways": 12 pages.

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