

Patients' Views on Medical Packaging Informal Survey with Participants at the European Patients' Forum Regional Advocacy Seminar in Sofia, Bulgaria 2009

The European Patients' Forum (EPF) was set up in 2003 to become the collective patients' voice at the European level, manifesting the solidarity, power and unity of the European Union patients' movement. EPF is a not-for-profit, independent organisation and umbrella representative body for patient organisations throughout Europe. We currently represent 44 member organisations that consist of chronic disease specific patient organisations working at the European level, and national coalitions of patient organisations. In total, EPF reflects the voice of an estimated 150 million patients affected by various diseases in the EU.

EPF's vision is to establish patient-centred equitable healthcare throughout the European Union. Our core values emphasize a patient-centred approach to healthcare, inclusiveness, non-discrimination, patient empowerment, consultation and independency and transparency. We adopt a holistic interpretation of healthcare to include prevention, and the social, economic, environmental, cultural and psychological aspects of health.

For patients managing chronic diseases, medications can present challenges in terms of safety, ease of administration and compliance. Too often, instructions in the packaging is in small type font or in a language that is difficult to understand. Studies show that excessive text on medical packages reduces the ability for the patient to locate the information, thus putting them off from reading the content. This can lead to patients overdosing and non-compliance to medicine intake which is essential for the treatment of a disease. Lack of adherence to medicine intake can result in poor health outcomes and lower quality of life. Thus, it is said to reduce patient risk, improving the usability of medical packaging is imperative.

During EPF's Regional Advocacy Seminar held in September 2009 in Sofia, Bulgaria, EPF deemed it important to gather information on the perception of the importance of medical packaging as it relates to patients. EPF therefore, undertook an informal survey on medical packaging with participants of the seminar, who were leaders of patient organisations in Bulgaria, Romania, Hungary, Greece, Cyprus and Slovenia, and for the most part patients themselves. Of the more than 50 patient leaders who were present at the seminar, 30 responded to our survey. In terms of methodology, the survey was conducted in person, without previous information or briefing, and framed around four key questions:

- 1.) Do you think that packaging of medication is an important issue for patients? If so, why?
- 2.) Do you think packaging can play a role in helping patients take their medicine according to the prescription (the right amount of medicines at the right time of the day, for the right period)? Why?
- 3.) Do you or your patient colleagues experience difficulties with the packaging of medication? If so, why?

4.) What do you expect from the packaging of your medication?

1.) Do you think that packaging of medication is an important issue for patients? If so, why?

It was very clear that respondents had not given much thought to medical packaging until the survey and that medical packaging is not a priority issue for patient leaders in Eastern and South Eastern European countries many of whom are experiencing fundamental problems accessing medicines and treatments in the current economic climate.

After giving it some thought, approximately 82% (25 respondents) responded that yes, medical packaging was an important issue. However, all of them emphasised that the first priority of patients in their countries was the supply of medicine.

Asked, why they thought that medical packaging was important, they listed the following reasons:

- The packaging and the information included can help to better understand the medication. The packaging is indeed regarded as the most important source of information at home regarding the medicine, its effects and for understanding how, when and in what quantity to take
- For patients who need to take a variety of medicines, the packaging is important for distinguishing between the different medicines and can help to keep the medicines in order
- For children, nice packaging can make the use of medicine more appealing
- Some patients prefer some medicines over others due to their more attractive or more usable packaging
- The packaging is important as to protect the medicine and to ensure that the medicine gets to the patient undamaged
- Medical packaging is important because for many patients it is an object of everyday use and has therefore to be user-friendly, safe and usable
- Depending on the physical form of the medicine (pill, syrup etc.) the packaging can be important to measure the right amount to take

Approximately 17% (5 respondents) who did not consider medical packaging to be an important issue for patients gave the following reasons for their opinion:

- What is important is the content not how it is packed
- Medical packaging only plays a role for children – for them the medicine has to look nice as to encourage them to take it, because children do not understand the necessity of taking the medication. Adult patients rationally understand why they have to take the medicine; the packaging therefore is of minor importance

- Only disabled (e.g. blind) individuals need special packaging to help them take the medicine; it is not necessary for regular patients
- Doctors prescribe different dosages and usages of medicine anyway; the indications on the packaging can therefore be ignored
- In many cases, it is the caregivers who distribute the medicine; therefore the packaging does not play an important role for the patient

2.) Do you think packaging can play a role in helping patients take their medicine according to the prescription (the right amount of medicines at the right time of the day, for the right period)? Why?

Approximately 59% (18 respondents) agreed that medical packaging can indeed help patients take their medicine in the right amount, at the right time, for the right period. They listed the following examples of how medical packaging could facilitate concordance to the prescribed medication:

- Many patients need to take many different medicines. It is important that each medicine has a very distinguished packaging as to not be confused with other medicines
- Shapes and colours of the packaging but also of the medicine itself are very important for the clear identification of the medicine
- The design of the medicine and medical packaging has a psychological effect on the patient – either encouraging or discouraging him/her to take the medicine.
- Clear indications on the packaging can help patients when they forget when, how and how much of the medicine to take
- Some medicines are already available in different dosages. This makes it easier for patients who do not have to measure the right dosage themselves.

Approximately 40% (12 respondents) did not think that medical packaging could help patients in taking their prescribed medicinal treatment. Their main argument was that the information indicated on the package was often contradictory to their doctor's instructions. A second argument was that it is very subjective and depends on many situational factors if a certain packaging is functional for the individual patient.

3.) Do you or your patient colleagues experience difficulties with the packaging of medication? If so, why?

Approximately 43% (13 respondents) experienced either themselves difficulties with the packaging of their medicines or knew of patient colleagues who had problems with the packaging. Main problems concerning the packaging were:

- The similar design of different medicines lead to confusion and mixing up of different medicines

- Some of the medicines are packed in a fragile way and are easily broken or damaged
- Instructions and information on and inside the packaging are written too small
- Instructions and information are incomprehensible
- Too much information or information that is not clear enough or misleading
- Information on side-effects is too concentrated on physical side-effects. Many medicines have however a strong psychological impact on the patient
- Instructions and information are contradictory to what the doctor has said and prescribed.
- Some packages are very difficult to open
- Liquid medicine in particular is difficult to measure
- It is often difficult to verify if the medicine was taken nor not (if pills are in a big bottle for example)
- Medicines for children are often very hard to use. Sprays and inhalers for example are not easy on children
- In some cases the medicine is difficult to take – injections for example. Training with doctors or nurses is needed
- Packages are too big and too expensive

Approximately 56% (17 respondents) had not experienced themselves or heard from their patient colleagues of any particular difficulties due to packaging in using their medicines so far.

4.) What do you expect from the packaging of your medication?

Approximately 69% (21 respondents) had some ideas and wishes about how medical packaging could be made more convenient and usable for them:

- Colours should be used in a standardised and very clear manner as to make the distinction between different medicines easier. For example, flashy colours for more dangerous medicines
- Universal symbols could be used
- The strength of the medication has to be clearly indicated
- Information on side-effects, long-term side-effects and interaction with other medicines has to be made more comprehensive
- To prevent patients (especially older ones) from getting scared by the list of possible side-effects, it should be mentioned very clearly that the doctor's instructions are more important than what is written on the package and should be followed
- A dedicated area on the package should be available for the doctor to note his instructions
- The same was said for dosage: the right dosage for self-medication should be clearly stated while emphasising that the doctor decides upon the right dosage for patients in treatment
- A majority of respondents thought the information included in the packages are too complicated while not being informative enough. They want more information relevant to

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their individual needs. They recognised that the inclusion of a lot of this information is stipulated by law and regulations. However, many expressed the wish for a simple summary, listing the most important points. One respondent suggested having this summary attached to the information leaflet with a perforated line, so that patients could easily take the summary with them to have at all times.

- Most respondents thought the information in the packages should be written bigger
- The consequences of discontinuing or interrupting the medication should be clearly explained
- Information in or on medical packages should be updated on a regular basis and should take into account new findings and developments
- Medicines should be packed in amounts that fit the cycle of treatment that is usual for the disease they are treating
- Different pre-packed dosages for different kind of treatments should be available
- The packaging is often difficult to open for patients. Many wish for a special tool that would come with the package that makes opening the package easier (like a can opener)
- The medicine should be easy to remove from the package and fit into reminder boxes, which most of the respondents use for their medication
- The packages should be different in shape to make distinction easy but somehow fit together (like a Tetris system) for easy storage
- Tablets which often have to be split in half should have a perforation line for easy dividing
- Some wished for an external review of packaging, an independent body that would control and regulate medical packaging so that patients could have more confidence in the packaging
- More medicines should be packed like the oral contraceptive pill with clear indication of what dosage should be taken on each day. This makes remembering and verifying if the medicine has been taken easier
- Less material should be used. Little medicine and big packaging was not found to be a good combination
- Besides name and trademark of the medicine, the active agent or active substance should be clearly noted
- Additional equipment for easy usage of the medicine should be offered (e.g. puffers for asthma)
- An electric alarm could be included for reminding patients to take the medicine on time.
- Packages should in general be smaller
- Special packages for travel should be available. Multiple Sclerosis patients stated that they pack extra medication for vacation and business trips. They also observed a positive evolution of information and explanations included in the medical packages over the last years

- Packages should in general be convenient for the patients to take the medicines with them. Many patients go to work, have a busy schedule and have to bring their medicine every day
- Packages should be more robust. Paper or carton packages, for example, get easily squashed when transported in a handbag
- Additional material needed for taking the medicine should be interoperable. For instance the injections device to take Interferon can only be used with Interferon but not with any other medicine
- Packages should have a reminder point. When the point is reached, the patient knows that he/she has to refill his/her prescription
- Packages should not only be easy to open but also easy to close
- The expiration date should be bigger and easy to read at first glance
- Different medicines for one treatment should be packed for the same period of treatment (not one for one month and the other for only one week)

Approximately 30% (9 respondents) did not have any particular expectations regarding the packaging of their medicine.

Respondents of the survey included patients with: Osteoporosis, Parkinson disease, Breast cancer, Mental Health, Multiple Sclerosis, Asthma, Liver disease, Thalassaemia, Kidney disease, Alzheimer's, Haemophilia, and patients who underwent transplants.

One respondent pointed out that in regard to medical packaging a distinction has to be made between mental health patients and other patients as well as between temporary illness and chronic disease patients. These different patient groups have different needs and respond to different stimuli for concordance.

The findings of our survey reflect of course the particular socio-economic reality of patients in Eastern and South Eastern European countries. Especially patients from Bulgaria and Romania emphasised repeatedly that their first and most important concern was the supply of medicine and that everything else ranked second.

One of the interesting factors in our survey was the age group. The respondents were between 28 and 70 years old, with a majority being in their 30s. Academic research about patients' attitude towards medical packaging was so far concentrated on the generation of 60+ or 70+. Therefore the findings of our survey, although informal, make a valuable contribution, giving insight into what patients under 60 years old think about and the difficulties they face in regards to medical packaging.