

**EPF FINAL RESPONSE APPROVED BY THE EPF BOARD 3 MAY 2007,
FOLLOWING CONSULTATION WITH THE EPF MEMBERSHIP**

The European Patients' Forum response to the Commission consultation on the Diabetes Information Package.

1. How useful is it to have this kind of concrete information at the European level on a disease and its related treatment options? If useful, what other diseases would benefit from this approach?

In principle it is very useful to have a model at European Union level, that illustrates very literally good practice in relation to information to patients in specific disease areas, that can be used as a stand-alone tool, but also to inspire and nurture national information packages of the highest quality in specific disease areas for specific population groups.

Such a model could be replicated in all disease areas, in close consultation with all stakeholders concerned, including representative patients' organisations.

In EPF's reference document on information to patients, we have highlighted that the contents of such a model should include information on:

- Disease (symptoms, life-cycle/development of the disease, risk factors, health related quality of life)
- European treatment guidelines
- Prevention information (diet, exercise, environment and treatments)

- Diagnosis information (including questions to ask your doctor) tests,early signs
 - Treatment information (choices, risks, benefits, side-effects, cost, written self-management plan, follow up, emergencies and concordance, adherence information)
- Patient resources throughout the patient's journey (government, patient groups, services)

2. Which elements of this diabetes information package are the most/least useful? Which elements are missing and should be included?

EPF supports the response of its forthcoming member, the **International Diabetes Federation – Europe** on the specific input and details on information needs relating to patients affected by diabetes per se.

From a general patients' perspective, we would however wish to stress the following issues.

- Consistency of terminology

This document has been referred to as an 'information model', 'information package', direct-to-patient tool, and 'fact sheet'. This leads to confusion and belies perhaps some of the debate leading to the consultation.

It is important for both clarity and credibility that terms are used consistently.

- Patient-centred

Despite being entitled ' a direct-to-patient tool,' the model as it stands addresses frequently the patient in the third person, and its tone at times alternates between being sanctimonious and accusatory of the patient. Terms like ' make sure' and ' needs to play his/ her role' illustrate this and should be avoided.

The overall impression of the document is one of negativity. Nowhere is it stated that an empowered patient, who has the opportunities to manage his/ her disease/ condition should be able to reach and maintain a high health- related quality of life and continue to contribute actively to society.

With regard to choice, it would be important to at least trace some of the pros and cons of different treatment options. For example, the section on different approaches to insulin intake offer little information to the reader on the relative strengths and weaknesses of these approaches, to encourage informed choice, in consultation with medical professionals.

- Holistic Approach

EPF is of the view that the document needs to be strengthened with regard to the fundamental importance of a holistic approach to disease management. A good example of this is under the section on treatment where it would be particularly relevant for example to refer also to psychological and peer support options.

- Accessibility

In order to be as accessible and as user friendly as possible, significant work is needed on the presentation of the document, to make it attractive, appealing and engaging to read and to ensure that information is digestible and manageable.

This could be achieved by imaginative design and layout, use of graphics, bullet points and numbering.

As a concrete example, it would be helpful to differentiate between medical causes of diabetes and risk factors (2.2.1 and 2.2.2).

The document also needs to be made accessible to disabled people (Braille,

large print, easy to read etc)

A glossary would be useful to explain complex medical terms in layperson's language. This would be preferable and less distracting than brackets.

- One size does not fit all

EPF believes strongly that whilst there are universal principles linked to information to patients, in addition to being disease specific, information needs very often to be age, gender group specific and most importantly, accessible to the individual patient, in his or her cultural context. It is assumed that this will be addressed in depth in relation to information to be provided at national level. A good illustration of this is the Diabetes UK website with specific sections for teenagers, and older people for example.

- Participation in Society

The section titled participation in society is very technical and should be more user friendly. There should be reference to the basic premise of health-related quality of life.

The reference to non-discrimination is welcome, and could be enlarged upon in the context of equal citizenship. It would be perhaps of relevance to refer to EU level legislation in this regard, for instance the framework Directive on Equal Treatment in the Work Place.

It should be noted that inter-action with doctor, insurer etc, as referred to in this section is a means to an end, and does not in itself represent participation in society per se. The text should be clearer in this regard.

The implication in this section is that Information Technology is the only source of

information to build skills and knowledge around disease management. Whilst this is one way of dealing with European level information, it is not the case generally.

A key principle for EPF is that the Internet is not perceived as a sole information source for patients but rather in concert with other information resources and support as part of an overall self management education programme.

An essential component of such a programme is training to empower patients and carers to pose the appropriate critical, reflective questions in relation to information provided or not provided in accordance with his or her own individual situation and circumstances, and to develop the confidence to challenge and query this as necessary and seek more information.

This section should stress that information to patients should be a two way process and include contact information to enable feedback and obtain additional details / pose further questions.

3. Which elements of information in the diabetes information package should be provided at the national level (by national authorities for example)?

- Access to different forms of treatments and therapies
- Availability of and Insulin intake approaches
- Pricing and Reimbursement issues
- Age / Gender in cultural contexts / language
- Redress and patient safety
- Specific links with national regional and local patient organisations/ patient groups
- Social support/ other services available

4. How should this kind of information package be developed further at

national or European level?

Please see earlier suggestions under point 1 and point 2.