ISSUE 1: DIABETES INFORMATION PACKAGE

This response does not comment on the specific content, of this package which is more appropriately the domain of clinicians and of patient groups. Rather, the issue is addressed more generically:

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?

i. It is useful to set a standard, which forms a template for countries and other information providers to follow. However, given the national competence for health services, such information has limits in that it can only indirectly signpost local service sources. Greater value will be yielded when it can contain country-specific links for citizens of all Member States.

ii. Citizens are more likely to look to European sources of advice when they are dissatisfied with local services. Therefore a link to rights and options for cross-border treatment outside the country of residence are highly relevant – a subject of consultation currently by the Commission.

iii. Many countries may have different treatment modalities and entitlements.

ISSUE 2: PATIENT INFORMATION QUALITY PRINCIPLES

1. Is a set of principles on good quality information on health-related information and treatments for patients and citizens useful at the EU level?

These cannot be disagreed with, but are far too abstract to be useful. There are no definitions, and the principles are not capable of being enforced.
2. Do these principles provide a clear basis on which to judge the quality of information at a European level?

No.

3. Should any of these principles be revised and if so, how? Are there any important principles missing?

First, there is no reference with regard to existing Commission policy on Quality of Health Related Internet Sites [1]. This policy, though useful, is itself of limited value, as it does not relate to verification of content.

Second, there is no allowance for patient choice of guidance, and of treatment. A citizen who knows little on a subject may well seek official sources of information. But a citizen already within the treatment system may well be looking for alternative information – guidance from other suffers’ experience; consideration of different treatment modalities; independent evidence about a particular drug and its possible side-effects, etc.. A single official source assists the first, but contravenes the second. Particularly when a citizen is distrustful (rightly or wrongly) of formal advice – such as local treatment policy, or pharmaceutical product statements – the important need is that they can look around at alternative views in order to become the truly informed citizen, but in so doing they need signposts as to the authentication and evidence basis of different information available.

Concurrent with this, citizens may seek guidance on the veracity of e-mail and Internet sources of guidance and the marketing of new products. Not least in the field of diabetes, there are currently waves of e-mails offering ‘better’ supplies and new ‘effective’ products. Are these justified or not? The citizen is left without a reliable source of evidence.

What is needed is the combination of plurality of guidance combined with robustly enforceable proof of authenticity, of authorship, and of source and strength of evidence.

In 1998/9, The European Commission funded a project to assess issues in the verification of quality of health informatics services generally, including web sites [2]. That project identified that citizens were being put at risk because of the lack of a simple yet robust means of independently verifying the authenticity and integrity of health internet sites, and recommended a system of third party seals. These seals would comprise:

- a set of principles and standards, such as location and nature of organisation, nature, and explanation of evidence;
- a prescribed format for labelling a site;
- and availability of a third party seal of verification.

The results were widely published [3,4], and informally welcomed by the Commission. Indeed, there was a provisional policy commitment to explore this solution. Unfortunately, subsequent submissions for a feasibility study have obtain
offers of no more than 60% funding from DG Sanco, which has proved not sufficient to enable progress. Top-up funding could not be obtained from a number of sources approached, including the European pharmaceutical industry body, as this issue was not seen as a priority.

However, the need for a system to enable European citizens to exercise the right to seek information freely, and to have choice based on sound alternative evidence, remains unmet. As a consequently citizens only can access official sites, where they may feel that not all alternatives are being offered to them; or else risk being misled by spurious, misleading or fraudulent sites which seek to offer ineffective or harmful products or services [3].

Thus, in the context of this consultation, the missing principles are those of robust and reliable third party verification and of citizen choice. Moreover, official sites, and those offered by responsible bodies such as pharmaceutical manufacturers, will stand to benefit if there is scope for their facts to be shown to be substantiated by independent sources, and if spurious sites are unable to obtain such independent verification.

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References


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