Joint ESIP and AIM Position Statement on Information to Patients on Diseases and Treatment Options

ESIP and AIM cannot support this progress report of the Working Group on Information to Patients on diseases and treatment options for the following reasons:

1. Although progress has been made concerning the quality criteria, the currently proposed definition of "unbiased" does not reflect the AIM-ESIP definition submitted to the Steering Committee in May.

2. ESIP and AIM object to the use of the word "partnership" to describe the procedures followed so far in the working group and also any procedures to develop the results of the working group until a common understanding has been reached on the meaning of the term. Public Private Partnerships (PPP) are assigned major importance in the mission statement and ESIP and AIM have serious reservations about the establishment of PPPs in the context of information to patients.

3. ESIP and AIM see no added value in pursuing the model information package on diabetes. This is also confirmed by the results of the public consultation. ESIP and AIM recommend that the future work of the WG aims to look at existing models of good practices and ways to promote and draw awareness to the several existing sources of independent high quality information in the EU.

4. ESIP and AIM can only consider a "validation process" which is *Ex anteriori*. We do not support Co-regulation based on *a posteriori* controls or Self-regulation (according to an agreed code of practice).

5. ESIP and AIM fully support the EU ban on Direct-to-consumer-advertising and strongly resist to any direct or indirect processes aimed at relaxing the existing ban on DTCA.

6. ESIP and AIM still have concerns about the lack of transparency of the processes, procedures and methodologies in the Forum, in particular in the Working Group on information to patients.

7. ESIP and AIM strongly regret that their constructive proposals made during this process, in particular the request for a survey of existing patient information practices and the use of an EU quality label to identify high quality information, have not been taken up for further discussion. ESIP and AIM are convinced that developing synergies at EU-level and reinforcing collaboration among existing national bodies involved in issuing independent patient information already represents a high added value for all Member States, EU citizens and patients.

8. ESIP and AIM support further constructive dialogue with all participants on this important issue.