

EPF Training Module on Transparency Concept Note

1. Background

Because of the intrinsic nature of patient organisations, the complex external environment with potential and/or perceived conflict of interests demanding a high degree of integrity and accountability, ethics and transparency are therefore an absolute priority for them.

This need for transparency applies across all of the organisation's activities, from membership criteria and governance rules, to their cooperation agreements, through their financial resources. But what are the formal rules you need to fulfil, and what are the processes to implement and monitor them in your organisation? All patient organisations can benefit from a code of ethics and conduct that systematically identifies ethical practices and acceptable standards. The adoption and internal enforcement of a suitable code not only provides an ethical check for an organisation; it also serves as a statement to beneficiaries, donors and the public that the organisation takes seriously the importance of maintaining high standards.

This training module aims at reviewing transparency and ethics guidelines for patient organisations, through the exchange and building of good practices. It will also be the opportunity to initiate a collective reflection within EPF on the ways for patient organisations to increase their credibility and strengthen their position on the public health scene.

2. Objectives of the module

- To develop a common understanding of what constitutes an ethically sound patient organisation and the legitimacy criteria patient organisations should fulfil;
- To reflect on the accountability of patient organisations, and how to demonstrate it;
- To establish guidelines and principles for cooperating with other stakeholders, with a focus on donors

3. Training outputs

- Definition of legitimacy criteria for patient organisations;
- Development of a code of conduct and/or transparency guidelines model to be adapted to each participating organisation;

4. Training outcomes

- Improved understanding of what constitutes good governance and accountability for patient organisations;
- Awareness and knowledge of ethical principles and how these can be applied in the organisations;
- On the longer-term, improved reputation for patient organisations.

5. Methodology

5.1 BASELINE ASSESSMENT

A baseline assessment will be conducted by the trainers to understand where the participating organisations stand and adapt the face-to-face training accordingly.

5.2 FACE-TO-FACE TRAINING

The training will be structure around 3 main building blocks:

- Module 1 - Enhancing the legitimacy and integrity of patient organisations;
- Module 2 - Cooperating with the private and public sector: putting ethics first;
- Module 3 - transparency: communicating who you are and how you work;

MODULE 1 - ENHANCING THE LEGITIMACY AND INTEGRITY OF PATIENT ORGANISATIONS

Format: Short presentations, guided discussion, interactive workshop

- Integrity: the importance of having clear guiding principles, mission and vision; ensuring integrity and independence in pursuing the mission
- Governance structure: clear roles and responsibilities, transparent and democratic decision-making processes, identification and management of conflicts of interest, confidentiality;
- Truthfulness and Transparency:
 - Consistency of activities and expenditures with the mission
 - Effectiveness and efficiency
- Membership-based organisations: monitoring and encouraging compliance with membership criteria, fostering openness and inclusiveness,
- Importance and benefits of internal and external evaluation: being able to demonstrate impact and added value of the organisation

MODULE 2 - COOPERATING WITH THE PRIVATE AND PUBLIC SECTOR: PUTTING ETHICS FIRST

Format: Workshop and roundtable with external stakeholders

- Building sustainable partnerships with external stakeholders: it's not all about money (the value of cooperation, acceptable practices...)
- Fundraising principles
- Guaranteeing independence: good practices and safeguard mechanisms (diversification of funding sources and cooperation);
- The importance of feedback with sponsors
- Establishing guidelines for cooperating with other stakeholders: codes of conduct

MODULE 3 - TRANSPARENCY: COMMUNICATING WHO YOU ARE AND HOW YOU WORK

Format: Presentations, workshop

- The importance of accurate reporting (annual reports, website...)
- Public trust, disclosure of bias, accuracy and in context information
- Dealing with the media: curating your image, responding to questions and allegations
- Promotion/Proactive communication of your organisation's values

5.3 REPORT ON IMPLEMENTATION STRATEGY OF KEY LEARNINGS

Each participating organisation will produce a report on how they intend to implement key learnings in their own organisation.

6. Evaluation

The Capacity Building Programme module on Transparency will be subject to a two phase evaluation. Evaluation will be performed at the end of the training to capture short-term outcomes in terms of satisfaction, learning, and willingness/ability to apply the learning in the organisation.

A second evaluation round will take place six months after the training to assess the extent to which have the participants and the organisations they are affiliated with applied the learning in terms of strengthening their legitimacy and transparency. The baseline assessment will be used as a reference.

7. Timeline

- March 2016: finalisation of concept note, first communication to members
- March – May 2016: call for tender and selection of consultants

- April-June 2016: recruitment of participants (Target: 12)
- July-August 2016: Baseline assessment
- September 2016: Face-to-face training (Provisional dates: 19-21 September)
- December 2016: Report from each participating organisation on how they intend to implement key learnings in their own organisation

8. ELIGIBILITY CRITERIA

Organisation:

- EPF membership: the organisation should be a member of EPF;
- Commitment: The organisation must commit to complying with the highest standards of transparency and accountability. The organisation shall ensure that learning, outputs, and outcomes of this training programme are effectively upheld by the governing body of the organisation.

Participant:

- Endorsement by the organisation: the participant must be nominated by an organisation member of EPF;
- Profile: the participant must have responsibilities related to either: governance of their organisation or fundraising;
- Availability: the organisation's representative must be available for the proposed training date (19-21 September, to be confirmed);
- Active participation: the participant must commit to fulfilling all requirements arising from the participation in this training programme which shall include:
 - A) providing information to contribute to the baseline assessment as requested by the trainers,
 - B) attending the full face to face training,
 - C) applying learning acquired during the module within the organisation

9. How to apply?

To apply, please send the following documents to Camille Bullot, Membership & Stakeholder Relations Manager (camille.bullot@eu-patient.eu) by **17 June 2016 COB**.

Incomplete applications will not be considered.

- Application form duly completed;

- CV of the nominated participant;
- Motivation letter (included in the application form) indicating:
 - Your organisation's motivation to participate in this module;
 - Your expectations from the training;
 - How you intend to apply the learning within your organisation and cascade it down to your members;
- Commitment form filled in: Endorsement by the Board and political commitment to undertake work on ethics and transparency.

10. Selection Criteria

The selection of participants will be carried out by EPF according to an assessment of the following criteria:

- **Compliance with eligibility criteria.** In case the number of applications is higher than the available places for this training, preference will be given to organisations which comply with the Full membership criteria.
- **Profile of the nominated participant:** The organisations' representative has responsibilities related to either: governance of their organisation or fundraising (as per job description or Terms of Reference if applicable).
- **Availability and commitment:** the organisation's representative must be available for the proposed training date and committed to pursue and further develop the communication activity initiated during the training. The candidate will need to demonstrate how he/she intends to apply learning after the training.
- **The quality of the motivation letter**
- **Language requirement:** the organisation's representative has a good knowledge of English (written and spoken).

11. Contact

If you are interested in participating in this training module or if you wish to have more information, please send an email to Camille Bulot, EPF Membership & Stakeholder Relations Manager (camille.bulot@eu-patient.eu).