

SUMMARY NOTES OF THE 'ACCESS AND EQUITY'

Stakeholders Meeting, 27th November 2013

Participants: BATCHELOR, Laura (FIPRA); BEDLINGTON, Nicola (European Patients' Forum); BEGER, Birgit (Standing Committee of European Doctors); BERTOZZI, Elena (Burson-Marsteller); BRENNAN, John (EUCOMED); CARVALHO, Artur (DG Health and Consumer Policy at EC), CHAZE, Nathalie (DG Health and Consumer Policy at EC); CLAY, Vincent (Pfizer); CRAWLEY, Grainne (Eli Lilly); DEDES, Nikos (Positive Voice); DE RAEVE, Paul (European Federation of Nurses Association); DIMITROVA, Rostislava (Healthcare consultant); DYSON, Andy (Advocacy Aligned, on behalf of MSD); FEHERVARY, Andras (Novartis); GAREL, Pascal (HOPE); GIACOMUZZI, Giovanna (Pharmaceutical Group of the European Union); HASARDZHIEV, Stanimir (National Patients' Organization – Bulgaria); HOGAN, Stephen (Janssen Pharmaceuticals, Inc); KOVATCHEV, Andrey MEP; MARSCHANG, Sascha (European Public Health Alliance); OLAUSON, Anders (European Patients' Forum); RICHTER, Milena (Sanofi); VAN DEN HOVEN, Adrien (European Generic Medicines Association); VAN HOOFF, Paul (GlaxoSmithKline); ZACHMANN, Clara (European Generic Medicines Association)

Anders Olauson, EPF President welcomed warmly all participants to the meeting and led the discussions.

I. Background and Context

Stanimir Hasardzhiev, Chair of the National Patients' Organisation in Bulgaria and EPF Board Member, made a brief presentation on the idea behind the Access Partnership and the progress that has been made since the last informal stakeholder meeting on 25 June (see attached presentation)

It was agreed that we work under the Chatham House Rule

The subsequent discussion confirmed the dramatic and unacceptable situation confronting patients in many parts of the EU, and the imperative to act, in a spirit of solidarity. The following notes 'cluster' the key ideas expressed during the discussion.

II. Creating the 'Access' Partnership and its added value

It was reiterated several times that no one individual stakeholder can tackle the issue of access alone. It requires a multi-layered, multi-stakeholder approach that involves all players. This is the novelty of this Partnership, in that it brings together the patients' movement, the medical community, the payers, the industry, the policy shapers and implementers, and the politicians to move forward on solutions and approaches to access that really work for patients and address the current barriers and inequities. A further role of the Partnership is to create 'noise' about access across Europe and the human, political and economic damage we are creating by not addressing it collectively.

One issue is information and knowledge transfer- an example given was the need for basic info to the Member States on the functioning of the European Medicines Agency

Identifying innovative ways of encouraging Member States to cooperate on access issues, through for example 'twinning schemes' to enhance technical capacity was also explored.

The need to utilise to maximum effect existing instruments and mechanisms, such as the Cross Border Healthcare Directive, and HTA cooperation was stressed.

Another area requiring thorough investigation is the new structural and investment funds.

Crucially, the Partnership should involve people on the ground, and not be another 'Brussels talking to Brussels' exercise. We should learn from previous experiences re. both process and outcome.

The focus should not only be on the new member states but rather the entire EU – we should not accentuate any divide between the member states.

III. How do we conceptualise 'Access' in the context of the Partnership

It was acknowledged that 'access' is not be simply about pricing and reimbursement of medicines, it is about healthcare more broadly, screening, waiting times, quality of services, co-payments and many other aspects.

It was agreed that a working definition of 'Access' for the Partnership should be formulated and agreed

IV. The Importance of bringing on board the Member States

The Partnership must seek the buy-in from the Member States, new and old, large and small. The current debate on differential pricing is a good illustration of the major challenge this presents. Whilst understanding the sensitivities and some resistance to act, this should not inhibit the Partnership from advancing its work.

Our messaging should be positive and constructive, not alienating.

V. Why a legal entity needed

It was acknowledged that a legal non-profit making entity is needed purely to ensure that the Partnership is able to receive funding from both public and private sources in a transparent way, to be able to carry out its work.

EPF had explored some possibilities regarding legal status in Belgium and it was recommended that an ASBL would be the most appropriate construct. Lawyers will now work on a proposal to be shared with the stakeholders as soon as possible. Two participants from the health professionals' arena offered to support this process.

It was clarified that this would not entail participants 'joining another association'. The Partnership itself will function as a network with a simple governance structure. This should be kept as lean and as responsive as possible, whilst respecting good governance and accountability practices. The

Partnership will nominate a 'steering group' at the next meeting to lead the work and specific thematic areas will be dealt with by working groups.

It was agreed to look at examples of good practice in this area and the 'APOLLO' example from the Netherlands will be explored

The legal entity is simply to ensure that funding can be sought and managed appropriately.

VI. The European Parliament Informal Group

This group, announced in June, will meet for the first time at the end of January (28 January 2014 is the proposed date, invitations are forthcoming). Concrete activity that can be anticipated in advance of the EP elections includes: raising awareness about the Access Partnership during this period and securing a balanced representation across political parties and countries, encouraging the Commission to support the Partnership through a written question, and organising a one hour debate in Plenary.

It was stressed that MEPs who are part of this Group will have a key role at national level.

The EP 'Access' Group will also be active in relation to the new Commission and specifically in the context of the new Commissioner for Health's Public Hearing

The Co – Chairs of this Group will be represented in the Access Partnership.

VII. The EPF Election Campaign and Manifesto

One of the core pillars of EPF's election campaign is the 'Access Partnership', and the Campaign's 'roll out' is happening now. Participants at the meeting were encouraged to mobilise their networks to support the EPF campaign and inter alia the Partnership <http://www.eu-patient.eu/whatwedo/EPFCampaign2014Elections/>

VIII. A mapping exercise on current activities in the area of Access

It was acknowledged that many different activities are taking place on access, in a somewhat ad hoc and piecemeal way. A mapping exercise is needed to understand who, among the stakeholders, is doing what and to identify gaps, opportunities and synergies. It was suggested that this be the focal point of the next 'Partnership' meeting that will take place in Athens, Greece, during the EU Presidency. The date for this meeting will be conveyed as soon as possible, and the methodology for this mapping exercise shared with the participants for their comments.

IX. Tool for measuring access and monitoring equity of access to healthcare

The importance of developing a tool to measure access and monitor equity of access on an on-going basis, was highlighted. A concept paper on this should be presented at the next meeting with a view to seeking funding for this in 2014.

X. A work plan for 2014

It was stressed that the work plan should be as realistic and achievable as possible.

It will comprise the following elements

- Setting up a legal entity (January 2014)
A draft document from lawyers will be circulated to the participants of the meeting for comment
- European Parliament Informal Meeting (January 2014)
- Discussion with the European Commission regarding linking the Partnership with a Commission structure such as the European Health Policy Forum(on-going) and how the outcomes of the Partnership can be used to the optimum
- Stakeholder Meeting under the Greek EU Presidency to undertake mapping exercise, explore monitoring tool and set up steering group for the Partnership (March 2014)
- Establishment of a link with the EU Member States through the relevant Council Working Group, via the support of the Greek EU Presidency (next six months)
- Development of a strategy for the next legislative period (autumn 2014)
- Presentation of the Partnership at the Gastein Health Policy Forum (October 2014)

Call for support

Given the volume of work identified in the meeting, and given the relative urgency, EPF appealed to participants for their support to advance specific pieces of work.