3rd EU Health Programme
Framework Partnership Agreement 2015-2017

External Evaluation

Operational Work Programme 2015
European Patients' Forum

Mark Delmartino
MDM CONSULTANCY bvba

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Chapter 1. Introduction

This document constitutes the third, main and final deliverable of the external evaluation assessing the effectiveness of the Work Programme implemented in 2015 (WP 2015) by the European Patients' Forum (EPF) under the three-year framework partnership 2015-2017 co-funded by the 3rd EU Health programme.

According to its Terms of Reference, the external evaluation has two purposes: to evaluate EPF's WP 2015 with particular attention to effectiveness and impact of its work; and to provide a 360° degree view of the organisation as it has evolved, manages its current tasks and faces the future. Between September 2015 and January 2016, Antwerp-based MDM CONSULTANCY bvba, who were selected further to a competitive tender process, performed several evaluation activities, in line with the external evaluation methodology (the first deliverable) designed and validated during summer. Given that WP 2015 is too comprehensive for a complete external evaluation, it was agreed that the evaluator would focus on four key areas thereof. The evaluation addresses EPF's actions in 2015 with regard to the activities in the area of Cross-Border Health Care, EPF Working Group on Empowerment, the Youth Group, and the Regional Advocacy Seminar (RAS) focused on Nordic countries.

The evaluator gathered information speaking to all EPF staff, by interviewing 11 patient leaders and 2 board members, through two online surveys and one e-mail questionnaire to which a total of 65 participants responded, and on the basis of desktop review of deliverables and materials. An overview of the persons contacted and the materials consulted is provided in annex. In order to 'live the life of the network', the evaluator attended a quarterly review meeting of the EPF team and the Regional Advocacy Seminar in Lund, Sweden.

The evaluation outcomes were compiled in a performance note mid-December. This second deliverable was discussed with EPF staff in January 2016 in order to contextualise the findings, considerations and recommendations from the evaluation exercise. The performance note and the feedback from EPF staff have guided the evaluator in drafting this report, which features two more sections in addition to the introduction: the next chapter presents the key findings and considerations on the four focus areas under evaluation; the final chapter contains conclusions and recommendations that are applicable to the entire organisation. The report was submitted to EPF early February 2016 and - after a review by the team - finalised at the end of February 2016.

Throughout the exercise, the evaluator had access to all information required for a comprehensive review of the WP. He thanks Walter Atzori for the smooth cooperation when implementing the assignment, as well as Kaisa Immonen-Charalambous, Camille Bullot and Valentina Strammiello for their active support in facilitating the evaluation on "their" focus areas. Finally, the evaluator wants to express his gratitude to all EPF staff, management and board for their interest in and constructive feedback to the evaluation.

Chapter 2. Evaluation of EPF's Work Programme 2015

This chapter addresses the first objective of EPF's external evaluation assignment: to assess the effectiveness and impact of EPF's work as delivered in the framework of its 2015 Operational Work Programme, which is co-funded through an Operating Grant under the 3rd EU Public Health Programme. Given that the 2015 WP is too comprehensive for a complete external evaluation, it was agreed that the evaluation would focus on four areas that together form a representative sample of EPF's work in 2015.

The chapter consists of four sections, one per focus area. Each section is built around the following components: a short description of the topic and its envisaged coverage by EPF in 2015, the evaluation methodology adopted for this specific focus area by the evaluator, the findings from the evaluation exercise, and the considerations by the evaluator and by EPF on the outcomes of the evaluation.

2A. Cross-Border Health Care

For some years now EPF has been addressing the **issue of cross-border healthcare** (CBHC) in line with its strategic goals 'healthcare access and quality' and 'non-discrimination'. CBHC, moreover, fits neatly in EPF's multi-annual work programme objective of strengthening the patient perspective and impact on EU health policy, programmes and decision-making, and its WP purpose to promote the development and implementation of policies, strategies and healthcare services that maximise access and reduce health inequality across the EU. According to the WP description, EPF was expected to continue in 2015 to monitor the implementation of EU Directive 24/2011 and contribute the patients' perspective to the European Commission's first report, which was expected in October 2015. As planned, EPF held workshops on the topic in several countries, and a European conference for patient leaders and National Contact Points (NCP) from EU member states to discuss meaningful patient involvement with the NCPs.

In order to assess the performance of EPF with regard to CBHC in 2015, the **evaluator** first of all was briefed by EPF staff in charge of the topic. He then reviewed the reports from six national workshops and the European conference, held telephone interviews with five patient leaders across Europe who attended the workshop and/or conference and analysed the conference evaluation survey completed by 34 respondents out of 80 participants.

All interviewees indicated that the **workshops** they attended in Bulgaria, Ireland, Romania and Spain had met their expectations: they had been well organised and offered a good mixture of plenary sessions and workshops. The meetings had been very informative and provided a good opportunity to encounter not only fellow patient leaders but also representatives from the ministry and the NCPs. All interviewees indicated they made several new contacts during the workshops and met patient representatives they had never encountered before. Some interviewees knew hardly anything about CBHC before the workshop and felt that the event had provided clear information and compelling arguments for their organisation to look into CBHC in future. On the basis of the workshop reports, the evaluator understands that a much work has gone into the preparation of these events, which in turn explains the positive feedback of the interviewees. Following a similar structure, each workshop offered significant opportunities for information gathering and exchange among patient leaders, health authorities and NCP representatives, whilst EPF representatives delivered up-to-date information on CBHC. The respective participants' lists indicate that the workshops attracted the envisaged audience of health authorities and patient leaders, including many local patient organisations.

Interviewees had a similar appreciation of the European **conference**: well organised, informative and attended by different stakeholders at national and European level, including the EU Commissioner for Health, Andriukaitis. Moreover, they liked the presentation of concrete cases, in particular on the organisation of national healthcare systems and the respective position of the NCPs. Following the conference, 34 participants completed an online evaluation survey which confirms the appreciation of the interviewees. On a scale from 1 (poor) to 5 (excellent), almost all items are rated above 4 (good): this applies to the conference objectives, the participants' expectations, the professional relevance, the background information, and the facilities. Only two conference sessions get a score between average and good, a judgement the EPF staff fully understands. According to the evaluator, the conference report provides not only a detailed account of the conference programme but also a good state of play on the CBHC directive from the patient perspective.

The interviewees had been selected by the evaluator among those **patient leaders** that attended both the national workshop and the European conference. Whilst assuming that such individuals would be particularly knowledgeable on the patient movement in general and CBHC in particular, it turned out that several interviewees had limited knowledge of the topic and were not familiar with EPF. According to the EPF staff, this is due to the fact that these workshops were targeted at local disease-specific organisations whose representatives are less knowledgeable about healthcare developments and patient networks at European level. Furthermore, several interviewees and survey respondents indicated they require more and accessible information on CBHC. EPF had been sending information on CBHC prior to both workshops and conference, materials that were highly appreciated by the participants.

In terms of **impact**, several interviewees indicated that their participation in the workshop and/or conference had boosted their (organisation's) interest in CBHC as well as in EPF: one patient leader mentioned that she is now trying to apply the information she received about CBHC because the system in her country is not yet working as health authorities, including NCP, are not implementing the CBHC provisions adequately. Another patient leader indicated that her involvement at European level gives an additional perspective and allows her organisation to move forward at national level. The authorities are not opposing civil society but have little experience working with patient organisations. The representative of a European disease-specific organisation mentioned that the way EPF is addressing CBHC demonstrates that her umbrella organisation should offer more opportunities for its members to give their opinion on CBHC and other topics and then pass this opinion to EPF. One interviewee plainly stated that following participation in CBHC, his organisation wanted to be more actively involved in EPF. One of the survey respondents indicated that EPF is a very professional organisation that should not only address abstract issues such as CBHC but also deal with concrete problems that have a real impact on patients’ lives. With regard to the latter point, EPF staff commented that the directive had just begun to be implemented and there were not many concrete success cases to provide to the participants. EPF is currently collecting stories from patients who tried to go abroad whether this attempt was successful or not, and their feedback. EPF, however, also indicated very clearly that they are not equipped to respond to individual cases. EPF has an educational mission and despite its efforts to focus the conversation on policy, there seems to be a confusion among several participants who expect EPF to solve personal issues rather than advocate for systemic change at European level.

Asked which conference components could be improved, **suggestions** include a Question and Answers session on CBHC, more time for workshops and more attention to exchange of experiences and practical concrete cases. These recommendations reflect the limited level of knowledge on CBHC of some participants. According to EPF staff, these needs are genuine but at the same time exceed the capacity of EPF staff who cannot build up know-how on the particularities of all national/regional/local healthcare systems. What EPF is doing – and will continue to do in future – is to involve members / patient leaders to identify relevant practical cases and explain how things are going on the ground. In this respect, EPF will try to activate its informal network even more next year. Some respondents, moreover, noticed that there were hardly any representatives from the medical profession, from hospital management or research institutions at the conference. According to EPF, this was a conscious choice because the conference was meant to focus on the relationship between patient leaders and NCPs. The next conference on CBHC will feature a wider variety of stakeholders.

2B. Working Group Empowerment

In 2014, EPF introduced the concept of thematic policy working groups where a cluster of appointed and dedicated members meet and work together. One group looks into issues of access; the Working Group Empowerment (WGE) informs EPF’s policy development on empowerment from both a strategic and a contents perspective. Whereas the actions on CBHC for instance seek to maximise access and reduce health inequality, EPF’s attention to the **issue of empowerment** aims to promote the development and implementation of policies, strategies and healthcare services that foster the effective empowerment of patients. In this respect, the WGE contributes to EPF’s strategic goals ‘health literacy’, ‘healthcare access and quality’ and ‘non-discrimination’. According to the WP description, the WGE would meet twice in Brussels in 2015, develop a consensus definition on patient empowerment and clarify concepts such as patient involvement and health literacy. Moreover, EPF would start developing a toolkit for patient organisations to support empowerment. Finally, EPF would launch its thematic campaign on empowerment at a European conference.

In order to assess the performance of EPF with regard to WGE in 2015, the **evaluator** was briefed by the EPF staff in charge of the topic. Having reviewed the WGE Terms of Reference and 2015 Action Plan, the evaluator then drafted a questionnaire which served as a basis for interviews with four WGE members after the second WG meeting in Brussels.

All **interviewees** had joined the WGE because of the importance of the topic and its particular relevance for their own organisation. The interviews showed that the WG members are well aware of the terms of reference of the WGE and its action programme for 2015. They agree to the topics addressed and the internal task division: whilst EPF proposes the topics and the EPF secretariat facilitates the discussions, it is in the end the WG who takes decisions and approves positions. Moreover, interviewees are satisfied with the size of the group, the expertise among its members and above all with the professionalism of the EPF staff, which interviewees consider to be very knowledgeable and particularly strong in organisational and intercultural issues. Finally, some interviewees indicated that their involvement in EPF and the WGE has strengthened their own capacity and that of their member organisations, which in turn enhanced their status as patient leader with decision-makers and stakeholders at home.

Asked about **suggestions** to improve the effectiveness of the WGE, some interviewees indicate the current WG meetings are very long (and exhausting) and would prefer somewhat shorter meetings with less items on the agenda which are discussed in more depth. Such approach would then require the group to make more and better use of online meetings throughout the year. If possible, they would also like to increase somehow the representation of patient organisations from Western Europe as the group currently features mainly patient leaders from Central, Eastern and Southern Europe. One interviewee suggested that WG members could be informed more systematically about the follow-up that is given to their work in the EPF Board and that a closer link could be installed with the Access WG. Whilst one of the WGE members is the dedicated liaison with the Board and the Access WG, the information reportedly does not reach the other members.

From a contents point of view, some interviewees suggest the WGE should also focus on concrete things, not only the abstract definition of empowerment. One interviewee suggested the WGE could disseminate (more/better) the meaning of patient empowerment at all levels. Communication is key to empowerment: notwithstanding the well appreciated efforts to implement an empowerment campaign, one interviewee emphasised that in order for such a campaign to be effective locally, the concept of empowerment should first of all be translated (both literally and figuratively) in some national languages.

In a first **reaction** to these findings, the dedicated EPF staff member indicated she would take on board the members’ feedback in the organisation of the 2016 WGE activities. Starting with a discussion on this year’s priorities with the WGE Steering Group, it would require a more active involvement of the entire WGE in the preparation of the programme and the meetings. If the WGE wants to focus more on concrete things, which is perfectly understandable and feasible, then the WG members should take the lead in defining the concrete topics and the WGE agenda.

2C. Youth Group

In 2011, EPF launched its youth strategy and established a **Youth Group**. It currently involves a dozen young patients (aged 15-29) representing a wide range of chronic conditions and nationalities. The aim is to raise awareness about young patients' living conditions and address cross-cutting issues that affect their quality of life. The attention to young patients aligns with the multi-annual work programme aim to reinforce the capacity of patient organisations to contribute to better health and social care and with its specific objective to involve youth when strengthening the capacity of the patients' community. Three objectives are informing the youth group activities in 2015-2017: capacity development, transition to adult care, and discrimination. In 2015, the focus is on capacity development in order to evolve as a strong and sustainable community of young patients. The activities respond to governance issues and provide tools to help the Youth Group develop as self-managed entity within EPF. The group has two meetings per year; moreover, they exchange information and ideas regularly through conference calls and social networks.

In order to assess the performance of EPF with regard to the Youth Group activities in 2015, the **evaluator** was briefed by the EPF staff in charge of the topic. Having reviewed materials on the Youth Group, the evaluator drafted a questionnaire which all youth group member were invited to complete after their second meeting in Bucharest. Six members returned the survey; their responses formed the basis for telephone interviews in which two youth group members clarified their positions and put the overall findings in context.

The survey learned first and foremost that **Youth Group members** consider it very important and relevant to have a separate structure within EPF that pays attention to the specific position of young patients from a contents/policy point of view. From an organisational point of view, several interlocutors indicated it is rewarding to be together with peers in a setting where they can exchange personal experiences in a discrete environment. The young patients are satisfied with the support from the EPF secretariat, but at the same time consider that more can be done by EPF to make the group function as a proper entity within the network.

According to respondents and interviewees, the face-to-face meetings of the Youth Group are of good quality. The focus of the meetings so far is on capacity development and this aspect is addressed increasingly successfully. One interviewee strongly supported the EPF approach to first focus on developing the capacity of the Youth Group as an organisation before addressing policy issues. In this way the actions have most relevance for the young patient leaders, who are knowledgeable on their own specific health condition but need organisational skills. The online meetings so far are less successful because not all members feel committed to participate. It is difficult to take decisions at these online meetings and to follow-up on these when not everybody is present.

Overall, Youth Group members consider that the activities strive to meet the explicit goals of the Youth Group, i.e. to involve young patient leaders in patient organisations, to promote the rights of young patients and to strengthen the skills and the confidence of young patients. With regard to the latter, one interviewee confirmed that his involvement in EPF is increasing his reputation among fellow patients in his organisation at home.

Asked about **suggestions** to improve the effectiveness of the Youth Group, members see a need to enhance the visibility of the Youth Group as an independent structure within EPF. Currently, not a lot of people (including EPF members) know about the existence of the group. Another recommendation is to upgrade the status of the online meetings and use these as moments for practical administrative decision-making on the Youth Group organisation, leaving more time at face-to-face meetings for training and in-depth policy discussions. Moreover, the Youth Group should become more active than merely meeting twice per year. One way to do so is to get involved in projects. When discussing these findings, EPF staff indicated that, resources permitting, it should be feasible to explore funding opportunities for the Youth Group. In this regard, preliminary work is underway regarding an ERASMUS application.

Several interlocutors indicated that the Youth Group could be expanded involving members from more affluent parts of Europe; currently the group is not representative for all healthcare systems in Europe but mainly features young patients from Central, Eastern and Southern Europe. Furthermore, respondents suggested that - in line with the objectives of the Youth Group - there could be more contacts with EU decision-makers and other stakeholders, and that there is room for improvement in building relationship with adult patient leaders. In this context, an EPF staff suggested to bring the Youth Group in contact with the European Medical Students Association (EMSA), who have been very supportive of the patient empowerment campaign.

Finally, and very importantly, Youth Group members would like to get more support from the EPF Board, which they feel is only paying lip service to the cause of young patients. One interviewee complained that the Youth Group tries to come up with ideas which are then taken over by EPF without involving them in the implementation. EPF staff acknowledged that communication is an ongoing problem with the Youth Group and understood that members feel let down by the lack of follow-through. However, there are failed expectations from both sides: if the Youth Group wants to play a more prominent role, the individual members will have to become more active as well, dedicating more time to EPF in a more systematic way. The Youth Group would also like to be represented properly and visibly on the EPF Board, not necessarily by one of its own members but at least by a competent and dedicated representative. This in turn would raise the awareness and visibility of the Youth Group as an entity, and enhance their contacts with decision-makers at European level. Further to these findings on the position of the Youth Group within the network, the EPF Board decided early 2016 to support the Youth Group proposals for an intern and to attend future board meetings.

2D. Regional Advocacy Seminar

For many years EPF has been organising **Regional Advocacy Seminars** (RAS) to improve the advocacy skills of patient organisations and their knowledge about the European political system. Through the seminars, which are often held in regions where EPF is less represented, EPF wants to inform members and local patient organisations how they can contribute to the health debate. The RAS aligns – just as the Youth Group actions - with the multi-annual work programme aim to reinforce the capacity of patient organisations to contribute to the health debate. Three seminars are foreseen in the period 2015-2017. In 2015, the seventh RAS is organised in Sweden targeting patient leaders from all Nordic countries because EPF's presence can be reinforced in Denmark, Finland, Iceland, Norway and Sweden. Following preliminary discussion with EPF members from the region, it was decided to focus during RAS on the topic of EU healthcare and research.

In order to assess the performance of EPF with regard to the RAS in 2015, the **evaluator** was briefed by the EPF staff in charge of the topic. Having reviewed preparatory materials on the seminar, as well as an evaluation report on the previous RAS in 2013, the evaluator drafted a questionnaire which all participants were invited to complete after the seminar. The evaluation findings are based on the responses from 25 participants (representing the five target countries) and on the personal experiences of the evaluator who attended the event.

The survey contained mainly closed questions: on a scale from 4 (very good) to 1 (very poor), **seminar participants** give a high score (well above 3, good) on almost all items. This applies to the programme sessions, the seminar logistics, the professional relevance of the seminar and its effectiveness in meeting the objectives of the event. The high scores are reflected in the positive feedback to open questions, which means that participants have completed the survey properly and thoughtfully.

When asked about **suggestions** for improving the organisation and effectiveness of RAS in future, participants referred first of all to issues that had received a somewhat lower score: a first recommendation is to get rid of the bring back sessions after the workshops and to use this time for other workshops or informal networking. Secondly, whilst appreciating the quality of both hotel and venue, they were too distant from each other which proved tiresome and not practical. Thirdly, participants would have appreciated more and better background information on the seminar and workshop topics prior to the event. Finally, some participants thought the RAS topic of health research was too abstract and did not bring sufficient tangible information on how patient organisations can play a role in shaping EU policies and legislation. Compared to the evaluation results of the previous RAS in 2013, the event in Sweden definitely improved in terms of involving the audience more actively. However, the background information remained one of the weaker components. Looking at the evaluation results, EPF staff indicated that the scores are very much in line with their own experiences on site. The several positive points are rewarding for the EPF staff who had worked very hard to make this RAS a success. The suggestions for improvement are valid and will certainly be taken into account when organising the next seminar.

Similar to the evaluation findings on CBHC, several **patient leaders** indicated they had not heard of EPF prior to the RAS and only a minority of them had been involved with EPF before. This, in turn, explains why respondents indicated that the presentations were interesting, but could have been more useful if EPF had focused more on concrete issues: for instance by showing the concrete path how a local patient organisation can benefit from the experience of EPF at European level, or by presenting good practice examples of Nordic cooperation, or by organising dedicated national workshops. Whilst EPF staff had announced to the evaluator before that it was explicitly not the aim of EPF to turn the RAS into an EPF promotion event, it seems that several participants would have appreciated more awareness raising on what EPF is doing. In a first reaction, EPF staff picked up on this indicating that an introductory session on EPF might be appropriate. Moreover, the ‘concrete path’ suggestion could be something to explore at the next RAS, including a more hands-on approach (e.g. through role play simulation) to make the abstract theme more digestible. Similar to its feedback on CBHC, EPF staff indicated it goes well beyond its own capacity to be knowledgeable on the particularities of national/regional/local healthcare systems. If participants want to reflect on national or regional good practices, the expert input will have to come from EPF members.

Chapter 3. Considerations on the Performance of EPF

This chapter addresses the second objective of EPF's external evaluation assignment: to provide a 360° degree view on the organisation. It consists of observations that were made under several focus areas and are therefore applicable beyond individual EPF actions. These considerations have been shared with EPF board and staff, and their feedback integrated.

A first observation gathered in all interviews and surveys is the **high-quality performance** of EPF staff. Survey respondents invariably give very high scores on the quality of the work and the professionalism with which events are organised. Interviewees applaud the know-how and dedication of EPF staff and, as it was shown in the case of CBHC, want to be involved more with EPF following a first encounter.

A second observation is that EPF addresses **topics that matter for patients**, irrespective of whether these issues are tabled proactively (empowerment) or as a response to EU initiatives (CBHC). Notwithstanding certain areas are more covered than others, it is obvious that EPF is representative for the patient movement in Europe, both disease-wise and geographically. Contrary to other European networks, EPF seems particularly strong in Central, Eastern and Southern Europe.

Thirdly, EPF offers a **platform for peer discussion**, which is much appreciated by members. Both young patient leaders and WGE members valued the fact that they can express their viewpoints, concerns and anxieties in a discrete environment to an audience of peers. In this respect, the evaluator understands perfectly that the RAS targets only patient leaders, not other stakeholders who could be relevant to the theme of the seminar.

A fourth observation is that members think highly of EPF's **expertise in building capacity** among patient leaders, both in terms of policy know-how and organisational skills. The interviewees and surveys indicate that there is still a lot of capacity to be built. According to the EPF president this is an important challenge for the future, which EPF is addressing through its ambitious plans for a patient academy.

A fifth observation is that EPF has a strong public image at European level and with those organisations and stakeholders who know them. However, many **local patient leaders do not know EPF** yet, as the evaluation of CBHC and RAS has shown. According to EPF staff this is not surprising as EPF first and foremost focuses on national patient coalitions and European umbrella organisations. Local patient organisations are not targeted systematically, but through training on specific topics.

Previous considerations lead to the final observation that there are many members, local organisations and patient leaders who have only limited know-how on the issues that EPF is addressing and therefore want / need basic information on these topics. The evaluation has shown that sometimes there is a **discrepancy between members' expectations and EPF's**

mission, for instance when emphasising the need for capacity building at national level, when suggesting to address the practical concrete dimension of topics that impact on the life of patients, or when issuing a request to advocate topics directly with national governments.

The final section of this chapter presents the main conclusions and recommendations from the evaluation exercise. It also features some suggestions for evaluation in future.

In so far as the four focus areas are concerned, the overall **conclusion** should be that **EPF has delivered its work programme for 2015 successfully**. The work undertaken by EPF on CBHC, WGE, Youth Group and RAS is much appreciated by the participants. The evaluator, moreover, is particularly impressed by the quality and consistency of the programme documents and by the level of supervision and follow-up of the individual actions. The focus group meeting learned that good progress had been made in programme management and delivery over the past few years and that similar efforts were undertaken with regard to monitoring and evaluation of the EPF strategy and work programme. On the basis of this evaluation exercise, the evaluator fully endorses the professionalism of the EPF staff.

This combination of professional staff and quality interventions and deliverables would never have reached such level of success were it not for the opportunities offered by DG Health through the **Operating Grant of the EC Public Health Programme**. Looking at the evaluation findings, the evaluator deducts that the EC grant is a tremendous support to advancing EPF’s policy-making and public affairs work at European level and – through its member network – at national and regional levels. The Operating Grant allows EPF to hire additional staff who in turn can cover more patient-related topics and develop these in more depth. As EPF has been receiving similar grants before, it now disposes of good quality and experienced staff who have been able to build up know-how and skills and managed to follow-up on health policy issues on a more long-term perspective. According to the evaluator, it is this combination of presence, quality, experience and long-term perspective that forms the key strength - and value added - of EPF’s work as patient movement at European level.

In terms of **effectiveness**, i.e. the quality of the action and the degree to which the expected results in 2015 are meeting the specific objectives of the three-year programme, the evaluator concludes that EPF is doing very well on all four accounts. In terms of **impact**, however, this one-year evaluation exercise is not yet conclusive. For most areas, the span of activities is too short to draw relevant conclusions. In the case of CBHC, some interviewees nevertheless reported impact at individual organisational level; moreover, the EC appreciated EPF’s work on CBHC inviting EPF to give a presentation at the meeting of the NCP network.

In addition to several very strong points, the evaluation has also shown a few areas for improvement. The evaluator therefore **recommends** EPF to consider following actions:

- enhance the internal follow-up of its actions and communicate better on the results of the follow-up, as was suggested by interviewees from both WGE and Youth Group;

- fine-tune the (level and amount of) information provided to patient leaders attending EPF events for the first time, as was demonstrated by CBHC and RAS participants;
- become a true ‘information broker’ using its knowledge of European issues to build the capacity of national members and pass on members’ viewpoints and concerns to European decision-makers;
- mainstream the youth dimension in all EPF activities and include the Youth Group as an integral yet self-standing part of EPF. This will require additional resources and statutory work (Terms of Reference, Work Programme) from EPF as well as a more explicit commitment from Youth Group members to be actively involved.

Taking as a basis the 2015 external evaluation approach, the evaluator suggests paying particular attention in **future evaluations** to:

- including also external viewpoints in the evaluation exercise, e.g. by gathering feedback among European decision makers how they perceive EPF’s performance and its value added as patient organisation operating at European level;
- addressing explicitly the impact dimension of some focus areas (in addition to a continued attention on quality and effectiveness of performance);
- identifying - together with EPF staff - measurable process, output and outcome indicators and integrate these into EPF’s existing monitoring and evaluation system.

Finally, the evaluator would like to draw attention to the human factor in delivering WP 2015. The overall positive appreciation on each of the assessment tasks is to a large extent due to the dedication of individual staff at the EPF secretariat. Receiving an operational grant is certainly beneficial for an organisation, but it is the people involved in the coordination and implementation of the activities that eventually determine the success of the grant and on the quality of the network’s performance.

Mark Delmartino
External evaluator
Antwerp, 29.02.2016

Annex – Sources: persons interviewed and materials consulted

European Patients Forum

- Briefing with Walter Atzori
- Focus group meeting with EPF staff: Walter Atzori, Nicola Bedlington, Camille Bullot, Danielle Flores, Kaisa Immonen-Charalambous, Anke Seidler, Valentina Strammiello, Valentina Stylianou, Véronique Tarasovici.
- Interviews with Anders Olausen (president) and Susana Palkonen (vice-president)
- Discussion with EPF staff on performance note: Walter Atzori, Danielle Flores, Zilvinas Gavenas, Laurent Louette, Laurène Souchet, Valentina Strammiello, Stefano Tironi.

Cross-Border Health Care

- Briefing by Kaisa Immonen-Charalambous
- Telephone interviews with Isabela Tudorache (RO, Muscular Dystrophy), Paddy Creedon (IE, Rise Foundation), Joke Devocht (BE, EFANET), Elsa Mateus (PT, Portuguese League Against Rheumatic Diseases) and Momchil Baev (BG, Centre Amalipe)
- Conference satisfaction survey completed online by 34 participants

Working Group Empowerment

- Briefing by Kaisa Immonen-Charalambous
- Telephone interviews with Georgia Orphanou (CY, PASYKAF), Guadelupe Morales (ES, Spanish Patients Forum), Tunde Koltai (HU, AOECS) and Jean-Denis Kahn (FR, EFAPH)

Youth Group

- Briefing by Valentina Strammiello
- Survey completed through email by 6 youth group members
- Telephone interviews with Polis Stavrou (CY) and Martha Carabott (MT)

Regional Advocacy Seminar

- Briefing by Camille Bullot
- Conference satisfaction survey completed online by 25 participants

Materials consulted

- Work Programme 2015-2017 for the Framework Partnership Agreement for an Operating Grant, EPF proposal to 3rd EU Health Programme
- Work Programme 2015 for the Specific Grant Agreement for an Operating Grant, EPF proposal to 3rd EU Health Programme
- A strong patients' voice to drive better health in Europe, EPF Annual Report 2014
- Centre for Community Policies, EPF Final Evaluation Report 2014
- Summary Report Cross-Border Healthcare, EPF Regional Conferences 2013-14
- EPF Meeting Reports on Cross-Border Healthcare Workshops in 2015
- EPF Conference Report Cross-Border Healthcare, July 2015

- Terms of Reference EPF Thematic Working Group on Empowerment
- EPF Working Group on Patient Empowerment, Draft work programme 2015
- EPF Youth Group leaflet
- 2015 Regional Advocacy Seminar Nordic Countries, EPF seminar report
- 2013 Regional Advocacy Seminar Zagreb, EPF seminar report
- Evaluation report 2013 Regional Advocacy Seminar
- Various promotion materials and internal documents
- EPF website: www.eu-patient.eu