

The question for this conference call is what scope is there for collaboration between EPAAC (European Partnership for Action Against Cancer) and EJA (European Committee of Experts on Rare Diseases Joint Action)?

Context

This issue was raised to ensure that the work currently going on with national cancer plans complements the work of EUCERD/EUCERD Joint Action in raising awareness of rare diseases (RD), particularly via the process of implementing national plans/strategies for RD. The question really is how well rare cancers (RC) are represented in both sets of planning activities. Gemma Gatta's team and the Patient Organisations are very keen to make sure rare cancers do not fall between the gaps in the two sets of plans. The EJA is very happy to consider developing systematic communication between the two joint actions, to ensure integration and cohesion of the two initiatives.

National Cancer Plans Update

National cancer plans are being instituted to develop policies for managing cancers, and this should include rare cancers. Due to the nature of the development of cancer plans, the main focus is adherence to screening guidelines, where these exist. What was noticed via questionnaires to the Member States (MS) was that the topic of investment in cancer management hasn't yet been dealt with very comprehensively. From surveys carried out on national cancer plans, only a small number of MS had clear amounts of money allocated to cancer and even fewer MS had clear answers as to how much they would *invest* in cancer management.

Harmonising National Plan Guidance: collaboration with EPAAC WP 10

The national plan process is going on in parallel in the RD field, and the EJA (WP 4 in particular) is supporting this. In order to harmonise the two processes and avoid duplicating effort (or even worse, providing conflicting advice) the prospect was raised of the two Joint Actions agreeing on a statement concerning RC, to be included in both sets of planning guidelines. EJA pointed out that in the RD field people have struggled even to compose decent lists of who is working on national plans in each MS; therefore, sharing experiences could be very valuable, to determine how much overlap there is (i.e. are the same people involved in formulating both sets of national plans?). It was agreed that the JAs should harmonise their guidance to the MS concerning national planning in the two areas, and also aim to ensure those involved in each process are aware of each other's activities.

The EJA explained that national conferences/meetings are being set-up in the RD field, to help MS elaborate and implement their national plans. EURORDIS is instrumental in the organisation of these events and can ensure that the right people are invited. The EJA suggested an invitation be extended to experts in each MS working on the cancer plans, to raise awareness. The EPAAC/EJA agreed statement could be presented and progress in individual MS relating to the cancer planning process could also be shared. As EPAAC wishes to share its draft guidelines for national cancer plans with the EJA for feedback, the latter would need these by April, to actively participate. Similarly, as the RD national plans conferences are already underway it is necessary to get people on invitation lists soon (even whilst EPAAC is still drafting its guidelines). EPAAC suggested that cancer plans should emphasise the concepts of Centres of Expertise (CEs) and European Reference Networks (ERNs), and in these respects the important work ongoing in the RD field could be reflected and developed.

Collaboration with EPAAC WP 7 and WP 9

Collaboration was proposed with EPAAC WP 7 (on healthcare). The team are assessing the feasibility of harmonising guidelines pertaining to care for RC - the specific cancer type selected here is sarcoma (Paolo Cassali, based in Milan, is leading this work on sarcomas). The sharing of best practice guidelines between MS is a concept of particular interest to the EJA, and it enquired about EPAAC's experiences with sarcoma in this respect. WP 7 explained that the idea is to see if it is feasible to make guidelines truly compatible i.e. is it possible to have EU guidelines for RC care? They reported that there *have* been objections from certain MS to such a centralised approach. It was agreed that it would be very helpful if an EJA representative could join relevant discussions in the near future. EJA added that EUnetHTA have managed to share health technology assessments across MS, which is an interesting model to explore further. The problem is that guidelines are generally so poorly evidence-based for RD and rare tumours that people tend not to adopt them and instead make their own. EJA pointed out that RARE-Bestpractices is going to look at whether guidelines for RD can be shared and adopted formally, so the results should be interesting to both sides.

EPAAC WP 9 focuses on disseminating information on RC and ensuring this will be available in new information systems. The efforts of EUCERD/EJA in promoting RD were highlighted here as a good model. There are two main RC projects involved: Rare Cancers Europe, concerned with promoting guidelines and increasing awareness of RC, and RARECARENet (Rare Cancers Information Network), tasked with identifying CEs for RC, updating epidemiological indicators etc. The importance of such projects was acknowledged, as promoting awareness of rare conditions is obviously crucial; however, in view of the numerous initiatives out there, the special value of Joint Actions was emphasised.

Centres of Expertise and European Reference Networks

The EJA was interested to learn whether CEs for rare cancers will be the same ones which deal with *other* cancers too (i.e. non-rare forms). EPAAC confirmed that this *is* the case, although recommendations for CEs dealing with rare cancers are still needed. Some large cancer centres won't be able to deal with individual RCs like sarcomas, for example. It will be necessary to put the experienced centres in RC into a network together. EJA noted that this is potentially an ideal set-up for a rare cancer ERN, because CEs for cancer are probably further on in their designation process than in other disease areas, and are better established; furthermore, the RC community *know* who is working on rare cancers, which speeds up the process. EJA suggested that the *EUCERD Recommendations on RD ERNs*, once finalised, may be of interest to EPAAC here. EJA also noted that the technicalities of dealing with rare cancers make them an interesting case study for the RD field. These are *common* conditions with *rare* subgroups that therefore "qualify" as rare diseases, a scenario which will become more frequent as medicine progresses. It's important we embrace the fact that the boundary between 'common' and 'rare' diseases is blurring, and that experts will need to become increasingly specialised (e.g. a lung cancer expert will need to know about all types of rare lung cancer, not just the more common presentations).

Conclusion:

Rare cancers are important. In fact, most cancers are technically rare anyway! In preparing a guide for high quality national cancer plans, RC require special attention. This initiative is therefore very welcome on both sides.

Action Points following EUCERD JA/EPAAC Teleconference

- 1) EJA will be added as an EPAAC collaborating partner, providing access to the Virtual Partnership and Open Forum events. (DG SANCO want collaboration **between the Joint Actions specifically.**) EJA should provide EPAAC Secretariat with details of a lead contact.
- 2) The topic of synergy between the two JAs will be included as an agenda point at the next EPAAC Steering Committee in Malta, May 2013.
- 3) The topic of synergy between the two JAs will be included as an agenda point at the next EJA Partner Meeting in early 2013. In addition, K. Bushby will present a summary of this call and its conclusions to the 6th EUCERD meeting in Luxembourg, 14-15th November 2012.
- 4) A possibility is to invite an EJA representative to the EPAAC Steering Committee meeting (or vice versa) in order to increase cooperation.
- 5) Concrete collaboration was envisaged as follows:
 - EJA and WP 10 (guides for National Cancer Plans)
 - o The WP 10 team will send the draft guidelines (anticipated April 2013) to EJA for comments **in order to coordinate a section on rare cancers.**
 - o It was suggested EURORDIS could help to invite national cancer plan people to the national RD conferences being organised under EJA WP4. (T. Albrecht can supply names of suitable individuals.)
 - o RARECARENet is happy to provide data on RC for these conferences and can discuss the similarities between RD and RC, to present at such meetings.
 - EJA and WP 7 (sarcomas and harmonisation of clinical guidelines):
 - o Josep Borrás will speak with Paolo Casali on this topic.
 - o The EJA will be informed of the progress made - particularly regarding experiences in sharing best practice guidelines for RC across MS - and will potentially attend working meetings on this topic.
 - EJA and WP 9 (European Cancer Information System):
 - o The RARECARENet team will confer with Milena Sant and other WP9 colleagues about how to ensure that RC will be properly considered in the European Cancer Information System (and then provide an update to all).
- 6) Regarding ongoing communications, the EPAAC and EJA Secretariats are happy to correspond. In particular, details of contact points between the JAs (including WP leaders) should be exchanged. Teleconferences on specific topics can be organised if the need arises, involving the relevant stakeholders.
- 7) RARECARENet plans to organise meetings to discuss the criteria for CEs for rare cancers – they are happy to invite representatives from EPAAC and EJA to attend these meetings and offer input. (For reference, EUCERD Recommendations on CEs can be found here: http://www.eucerd.eu/?post_type=document&p=1224)