



EPAP

European
Patient
Ambassador
Programme

Face to face meeting for EPAP PAG at ELF office in Sheffield on 23 March 2017

Participants:

Kjeld Hansen, Matt Cullen, Tessa Jelen, Betty Frankemölle

Emma Rooney, Toni Latimer-Simpson, Joanna Robazewska (via skype)

Kerstin Morrison ELF, Courtney Coleman ELF, Jeanette Boyd ELF

Agenda

- 10:30-11:00** Arrivals & greetings
- 11:00-11:30** Introductions/ice breaker
- 11:30-12:45** Session 1: How to better engage ambassadors and potential ambassadors
- 12:45-13:30** Lunch with ELF staff
- 13:30-14:30** Session 2: Vision for EPAP, Patients at all levels of involvement
- 14:30-15:30** Session 3: Newsletter/social media – PAG responsibilities/involvement
- 15:30-16:00** Coffee & departures

Summary/minutes of the day

It was a real achievement for us to have our first PAG face to face meeting and it was a wonderful and exciting opportunity to meet each other in person and be able to interact directly, rather than just on the phone. I would like to thank you all for taking part.

Big thanks to Emma and Toni, who gave up their day to join via skype. This is much more difficult than people think and it requires a great effort to keep engaged and follow what is going on, when you can perhaps not see everything, or the people present do not always include you at all times. So very special thanks for this great effort and investment into the meeting.

A big thank you also to all of you who travelled to Sheffield. We appreciate that travel can be difficult and exhausting when you have a health condition. And on top of all that you need the stamina to sit through a whole day of meetings and contribute.

I feel this has been a huge success – one that we can build on.

Session 1 - How to better engage ambassadors and potential ambassadors

1. Background

How do people come to EPAP?

Most people have accessed EPAP on recommendation of their patient organisation. Asthma UK and Longfonds are two organisations for example who actively promote EPAP to their members. Also the Biomedical Research Centre Patient Involvement Group.

Quite a few people have come through ELF. When asked to be a patient speaker for instance or to take part in Task Forces as well as through involvement in EU projects.

Why do people sign up for EPAP?

- To receive training and inform themselves
- To help promote the patient perspective
- To be better informed and get empowered
- To get a European perspective
- It fitted with interests, for instance being retired and looking for opportunities in volunteering
- Saw EPAP as meaningful and useful
- To encourage especially HCPs to think outside the box
- To help change the healthcare system for others

How did people get on with EPAP?

- People saw the value of EPAP and wanted to promote it to others
- Found it very useful and an excellent resource and wanted to share it with others
- Having been involved with the pilot, they wanted to see what it was all about and find out more

2. How to get more people involved in EPAP

Target individuals we already have contact with in support groups and patient organisations:

- Stronger dissemination through existing contacts with patient organisations, cascading information
- Using the examples of the Netherlands, where we have the national organisation for all lung conditions (the Dutch Lung Foundation) and a national patient organisation training organisation (who helped with the Dutch translation) both actively promoting EPAP, we should try and establish such contacts in other countries and roll out EPAP that way.



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- Any PAG member attending meeting or events should ask Kerstin for flyers to take. People are already doing this, Tessa and Betty especially.
- GPs would be ideal as people passing EPAP on to their patients, but this is quite unrealistic as their workloads are huge, they rarely recommend things from outside their own health systems and we could not possibly reach a good number of GPs in each country.
- Promote more opportunities as a way to “sell” EPAP to people, who want to put their knowledge and skills into practice. This too can be tricky. More opportunities have been coming through and Kerstin has disseminated them.
- There should be a PowerPoint slide that PAG members can take with them when giving presentations and that can be sent out to organisations who may agree to promote EPAP.
- Flyers can also be sent as PDF email attachments.
- There was a discussion about tracking any flyers, but at this stage we did not feel that this information would be useful enough to justify the effort setting this up.

3. How to keep people signed up on EPAP engaged?

- Use direct email to communicate with people who have started on a module to promote the other modules
- Use direct email to keep in touch with people registered
- Use direct email to send opportunities
- Develop a game or quiz app to send out to see how people are doing, what they are up to, have they done more modules, have they used their skills and knowledge
- Current FB group has potential to become more of a mutual exchange forum, but we need to look at the demographics of people doing EPAP and whether this coincides with the usual FB demographic
- Most e-learning programmes have an in-programme forum, where learners can communicate with each other. This may or may not be something to look into, although it is not possible at present on the IT platform we are using.

Session 2: Vision for EPAP, Patients at all levels of involvement

1. Barriers to engaging ambassadors

- We need to define the EPAP audience more clearly to find out how to better engage and what barriers there are to engagement (see discussion below).
- People don't necessarily get to know about EPAP when they need it, e.g. when in crisis (after a diagnosis) or afterwards, when dealing with a (new) condition.
- It was agreed that the registration process is not a barrier.
- 'Getting started' can be confusing for people, as it does not follow the regular pattern and you don't get a certificate for it.
- More thinking needed around how to keep less engaged people engaged.



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- Age? Working people will have less time to be engaged than retired people?
- There is also a whole stratum to patients, who think the doctor knows best and would not want to be involved.

2. Opportunities and how to reach more people

Here we discussed how we can reach more ambassadors and how to manage any opportunities:

- We should promote the message how easy EPAP is to do – easily accessible, online, so you can fit it around your routine, one module does not take much time etc.
- Promote it as a way of opening up other opportunities, that it can lead onto other things.
- Try and promote it through national structures, such as Healthwatch in the UK and the National patient Federation in the Netherlands.
- Recognise that anyone going through a health crisis will be too busy at that point, but after this they may want to know more – this would be the time to “catch” them and support them. Patient organisations are the best route for this.
- Ideally hospitals would have EPAP information in their clinics, but there is the same problem as mentioned earlier with the GPs.
- Young people could be engaged through a school’s programme, but again, there needs to be discussion on who our audience is.
- A “Hackathon” event, where out-of-the-box thinking to create something was mentioned.

Discussion on EPAP audience

We had a discussion as to who we are aiming at, who our audience is. Once we have decided this more specifically we then better plan for social media and for ways to keep people engaged:

- EPAP does not have to be for everyone, e.g. was not developed for young people and it is a great place for people who are less confident about using the internet.
- It may be time to revisit who the target audience for EPAP is. Many other training programmes have developed since EPAP was first launched. An in-depth discussion at the next teleconference around audience might help to clarify who we’re targeting and why.
- Premature to talk about local application of EPAP until we are clearer about what we offer and who it is for.
- Be realistic about what EPAP offers, e.g. it is a starting point, therefore our audience will be those patients not heavily engaged already.
- It’s ok if EPAP isn’t for everyone – it doesn’t have to target all audiences.
- For some people EPAP is a higher level of training than they may want. Some people might just want to do 1 module initially, but they could use that as an entry point to get more engaged.



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- Focus on people who firstly just looking for more information, e.g. just joined patient group. They have not decided they want to be so involved but would like more information on their journey. Or, do we want to be leading online training programme for patient ambassadors – they are different things. Time to re-think and clarify.
- The ‘Becoming Better Informed’ module recognised as good for all patients.
- Map other European patient training programmes and see where EPAP fits. A lot has changed in European advocacy since programme was first developed.
- Does it need a name change in future? Will ‘European’ become less relevant in future..? Name should link to audience once clearly defined. Lots of the content is relevant outside Europe but the name may inadvertently restrict our reach.
- As an example, if our target audience were 60+, is Facebook relevant? Newsletter may be more appropriate. May need to adapt our communication methods.
- Further discussion required on this at next meeting.

Session 3: Newsletter/social media – PAG responsibilities/involvement

1. EPAP newsletter

- The first newsletter will go out around 28 March.
- Any registered learner, who has agreed to be contacted has been signed up.
- The newsletter will appear quarterly.
- Kate Hill from the mesothelioma charity in the UK has recently run three patient group training sessions on EPAP – she will hopefully contribute to the July edition.
- It will be one of the main vehicles of to keep people engaged with EPAP.
- The EPAP website, where opportunities are posted, articles and resources - is not well used.
- There should be regular direct emails to ambassadors about further modules they can complete, opportunities and other interesting things, to keep engagement.

2. Social media engagement

- Overall there is less engagement with the EPAP social media platforms than hoped. The intention was for the social media platforms to be ‘patient-driven’ and it was suggested that a rota of PAG members to post opportunities and information may help to address this.
- Members of the group questioned whether opportunities needed to be open to patients across Europe, or whether local or national level opportunities could also be shared.
- At the moment, opportunities shared on EPAP social media need to be on a European level, however this could be reviewed with the PAG and ELF if it is no longer appropriate.
- For EPAP learners based outside Europe this is obviously a challenge to ongoing engagement as they only hear about opportunities which are not open to them.



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- Some of the PAG felt that they are aware of opportunities in their local or national area, but less so on a European level. They are not always in a position where they hear about opportunities via other networks and would therefore struggle to post opportunities on EPAP social media unless content was provided by ELF.
- For others, they are not aware of opportunities for patients to get involved in research or health influencing on any level, so would struggle to support this activity.
- PAG members reflected that they mainly get involved in opportunities on a local or national level and hear about these opportunities via other patient organisations or forums. When living with a condition, they often want to work on a more local level, especially if travel is required.
- Targeted emails to EPAP members who have already expressed an interest in a particular type of activity or who have experience of a particular health condition has helped to boost engagement with specific opportunities in the past.
- It was noted that not all EPAP ambassadors want to get involved in further opportunities. Some people may complete the programme to help inform their understanding and management of their own health and they don't want to get involved any further.
- On the other hand, some people complete EPAP and are eager to get involved in active projects, but struggle to identify opportunities. Understanding and targeting learners in a more individual way may help.
- It was noted that the Royal Brompton hospital provide patients involved in research with a good overview of research terminology, which may be useful for EPAP to consider.