



European
Crohn's and Colitis
Organisation

Interviews with N-ECCO National Representatives



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1. Interview – Ireland

Name & Date: Denise Keegan, May 2015

Country: Ireland (St. Vincent's University Hospital, Dublin)

Job Title: Clinical Nurse Specialist in Inflammatory Bowel Disease

1.1 What influenced your decision to apply for the role of N-ECCO National Representative for your country?

A: I have been a member of N-ECCO since 2009. The following year I, along with two other Irish IBD nurses, had the opportunity to attend the first N-ECCO School in Prague which was an excellent opportunity for us to network, gain further knowledge and share best practice with other nurses from around Europe. Since then I have been very fortunate to attend the N-ECCO Network Meeting on an annual basis. In September 2014 the N-ECCO Representative for Ireland, Yvonne Bailey, announced she was resigning her position and was looking for a replacement. I was delighted to be proposed and accepted for this position as I think the role of the N-ECCO Representative is an important one as it provides a link for IBD nurses or those have an interest in IBD in Ireland to the N-ECCO Committee.

1.2 What nursing initiatives or developments in IBD care are happening in your country?

A: The number of IBD nurses in Ireland has been increasing over the last number of years. Currently there are 20 IBD nurses in Ireland so last year it was decided to formalise the group and set up our own IBD nurse organisation. In May 2014 the IBD Nurse Association of Ireland (IBDNAI) was formed and the first AGM was held. The aim of the IBDNAI is to provide support and a forum for exchange of information for all nurses involved in the care of IBD patients to ensure the highest standards of care for patients with IBD. In addition we want to promote Inflammatory Bowel Disease Nursing in Ireland as a speciality by adding to research and literature in the area and to establish and maintain links with national and international organisations having similar objectives and we are now developing a website for our group.

1.3 What plans do you have in your role as National Representative to promote ECCO to other nurses in your country (including the N-ECCO School, Research Forum and Network Meeting)?

A: Following the N-ECCO Network Meeting in Barcelona this year (2015) I sent a newsletter by email to all the IBD nurses in Ireland to update them on the meeting and provide information on upcoming events.

With the development of the website for the IBDNAI, there will be a N-ECCO page, which I as the N-ECCO National Representative, will update on a regular basis to inform all members of the activities in ECCO and N-ECCO. It will encourage Irish IBD nurses to join N-ECCO and become involved in N-ECCO initiatives. It will also provide a valuable forum for promoting the N-ECCO School, the N-ECCO Research Forum and the N-ECCO Network Meetings. IBD nurses will be encouraged to apply for the Travel Award each year and new IBD nurses will be encouraged to apply to attend the N-ECCO School.

1.4 What barriers or problems do you perceive in doing this?

A: None at present.

1.5 What IBD nursing and N-ECCO networking opportunities do you currently have or plan to develop?

A: As the number of IBD nurses in Ireland is relatively small we are fortunate that many of the nurses are given the opportunity to travel to the N-ECCO Network Meeting each year to present their work, network and share best practice with other nurses from Europe. Each September there is an IBD nurse education meeting held in one of the hospitals; at this meeting the N-ECCO Representative provides an update for all the IBD nurses. In addition the IBD nurse who attended the N-ECCO School that year gives a presentation on her experience there.

1.6 The N-ECCO Travel Award is an excellent opportunity for nurses in your country to learn and share best practice. How do you plan to promote this to nurses in your country?

A: I intend to encourage all IBD nurses in Ireland to apply for the travels grant as this is a wonderful opportunity for nurses to travel within or to another country, to visit and observe an established IBD centre. The closing date for applications is on September 1st 2015 and I shall be contacting and encouraging all IBD nurses in Ireland to apply for this valuable opportunity.

1.7 How can N-ECCO help you to fulfil your role as National Representative?

A: I would be happy to receive regular updates about upcoming events in ECCO and N-ECCO by email. These can then be easily circulated to all the IBD nurses in my country and posted on our new website.

1.8 Do you use the N-ECCO Consensus Statements in your country? If 'yes', how do you use them? If 'no' why don't you use them? Are you planning to translate the Statements into your own language (if appropriate)?

A: The N-ECCO consensus statements are used within our country. Following their publication in 2013 they were presented at our annual nurse education meeting and we had an opportunity to discuss them at length. All IBD nurses in Ireland are encouraged to use them within their own hospitals with the aim of improving knowledge and education of nurses who may be involved in the care of IBD patients thereby improving the standards of care for all IBD patients.

2. Interview – Sweden

Name & Date: Ann Tornberg, August 2015

Country: Sweden (Skanes University Hospital, Lund)

Job Title: IBD nurse & Clinical research nurse

2.1 What influenced your decision to apply for the role of N-ECCO National Representative for your country?

A: I have been a member of N-ECCO since the beginning 2006-2007. I was asked at that time from the Swedish National Representative for ECCO to be the N-ECCO National Representative. The first meeting in Innsbruck, as well as the meeting in Lyon was a hallelujah moment for IBD nurses in Europe! That was the start! The role of the N-ECCO Representative is to be a link between the IBD nurses in Sweden and the N-ECCO Committee.

2.2 What nursing initiatives or developments in IBD care are happening in your country?

A: It's common that hospitals have IBD nurses at the day care unit. IBD nurses in Sweden work like specialist nurses. They work more or less as autonomous practitioners, side by side with the multidisciplinary team. They practice this within their own competency and accountability, supported by gastroenterologists and/or protocol/guidelines. Their tasks include face to face advice in clinics or over the telephone, nurse-led follow-up, day care unit for patients receiving treatment with biologics, iron supply etc., blood draws, laboratory tests/biomarkers etc. There is no education in Sweden to become an IBD specialist nurse. An IBD nurse in Sweden is a nurse with a lot of experience, supported by gastroenterologists and/or protocol/guidelines. The number of IBD nurses in Sweden has been increasing over the last couple of years. We don't know the exact number of IBD nurses in Sweden, but there are approximately 20-40 IBD nurses.

In Sweden we have two organisations, the Association of Nurses in Gastroenterology in Sweden (FSGS), who provides support and a forum for exchange of information for all nurses involved in gastroenterology, including research and literature (www.fsgs.se) and the Association of Nurses and other staff in Endoscopy and Gastroenterology in Sweden (SEGP) (www.segp.se).

Each September we have a one-day nurse education meeting for IBD together with Tillotts Pharma AB. In October we have a two-day education for the entire IBD-team (AbbVie AB). The aim of this education is to improve the management of IBD patients. In November we have a one-day nurse education meeting called *Highlights*, where we invite different speakers to talk about the highlights during the year of IBD, IBS, Hepatology, Endoscopy, Nutrition and Nursing (AbbVie AB).

The Swedish Association of Gastroenterology (SGF) has the journal *Gastrokuriren* where FSGS and SEGP can contribute some pages. In the journal *Gastrokuriren* we update all nurses about what has happened during the year. Here we present and update all members about ECCO, N-ECCO School, N-ECCO Research Forum and the N-ECCO Network Meeting. *Gastrokuriren* is published five times per year.

2.3 What plans do you have in your role as National Representative to promote ECCO to other nurses in your country (including the N-ECCO School, Research Forum and Network Meeting)?

A: I promote ECCO through my involvement in the Association of Nurses in Gastroenterology in Sweden (FSGS), through articles in the journal *Gastrokuriren* and through our education-days. I also help to search for scholarships for IBD nurses.

2.4 What barriers or problems do you perceive in doing this?

A: The problem in Sweden is that we no longer have the support from the pharmaceutical industry. The nurses do not have the financial resources to join a meeting abroad. The employer does not always pay. Today we have trouble getting nurses to participate in the N-ECCO School. The nurses who want to participate in the N-ECCO School also want to participate in the N-ECCO Network Meeting and at the ECCO Congress. That's too expensive for a nurse! Last year no Swedish nurse could participate

in the N-ECCO School and I'm afraid that it will be the same this year. As the N-ECCO National Representative, I help to search for scholarships for nurses.

2.5 What IBD nursing and N-ECCO networking opportunities do you currently have or plan to develop?

A: Please see answers to questions above.

2.6 The N-ECCO Travel Award is an excellent opportunity for nurses in your country to learn and share best practice. How do you plan to promote this to nurses in your country?

A: I intend to encourage all IBD nurses in Sweden to apply for the N-ECCO Travel Award!

2.7 How can N-ECCO help you to fulfil your role as National Representative?

A: I would be happy to receive regular updates about upcoming events of ECCO and N-ECCO via email. These emails can easily circulate to all IBD nurses and be posted on the FSGS website. We also wish for more travel grants. Nurses need financial help to visit the Congress of ECCO/N-ECCO.

2.8 How would you like to see N-ECCO develop?

A: I would like to see a closer cooperation within ECCO. One advantage of collaboration among professionals is that it promotes collaboration both within the academy and the clinic. The risk of separating N-ECCO too much from ECCO is that we find our own ways to work. There is the same risk with nurses' clinical research, as an example nurses' abstracts. No one, except nurses, looks at these abstracts. We are working as a team and this should be done within ECCO as a whole as well.

2.9 Do you use the N-ECCO Consensus Statements in your country? If 'yes', how do you use them? If 'no' why don't you use them? Are you planning to translate the Statements into your own language (if appropriate)?

A: The N-ECCO Consensus Statements are used within our country. We always refer to the N-ECCO Consensus Statements when lecturing/teaching. All IBD nurses are encouraged to use them. I don't think we need to translate them.

3. Interview – Czech Republic

Name & Date: Ludmila Procházková, August 2015

Country: Czech Republic (IBD Clinical Research Center ISCARE, Prague)

Job Title: Head nurse

3.1 What influenced your decision to apply for the role of N-ECCO National Representative for your country?

A: First, I work at IBD centre ISCARE, one of the biggest centres for IBD patients in the country with more than 3.500 IBD patients. Second, it was my interest to communicate with nurses from other countries, and to compare situations in the Czech Republic and abroad.

3.2 What nursing initiatives or developments in IBD care are happening in your country?

A: The most important initiative is the nurse section of the Intensive IBD course organized annually by the IBD working group of the Czech Society of Gastroenterology. There are also several other educational activities during the National Congress of Gastroenterology, specialised courses for IBD nurses organized by our IBD centre ISCARE, etc. IBD nurses also closely cooperate with the Czech IBD Patients Organisation. Among others, IBD patients organise elections for the „Best IBD nurse“.

3.3 What plans do you have in your role as National Representative to promote ECCO to other nurses in your country (including the N-ECCO School, Research Forum and Network Meeting)?

A: My plans include discussions with colleagues – nurses from all around the country during the above mentioned events – about ECCO and N-ECCO, about their roles and options that they offer us. Other ways how to let every nurse know about ECCO is the journal of the Czech Gastroenterological Society, patient’s organisation, cooperating with the pharmaceutical industry, etc.

3.4 What barriers or problems do you perceive in doing this?

A: For a lot of Czech nurses barriers include insufficient English skills and their limited time for any extra work.

3.5 What IBD nursing and N-ECCO networking opportunities do you currently have or plan to develop?

A: I plan additional courses for nurses interested in IBD. These courses are free of charge for all participants and are sponsored by pharmaceutical companies.

3.6 The N-ECCO Travel Award is an excellent opportunity for nurses in your country to learn and share best practice. How do you plan to promote this to nurses in your country?

A: I plan to share this information using emails, using our closed network with Czech IBD Working Group, and also using a close relationship with the pharmaceutical industry.

3.7 How can N-ECCO help you to fulfil your role as National Representative?

A: To be honest, my role as National Representative is approaching the end, so I hope that my successor will have the opportunity to answer this question.

3.8 How would you like to see N-ECCO develop?

A: I think that N-ECCO should help a bit more nurses from eastern parts of Europe to become a true part of this organisation. Language, money, general level of gastroenterology in each single country – all of these factors play a role. I’d strongly recommend creating a grant aimed to specifically help IBD nurses from Eastern Europe.



3.9 Do you use the N-ECCO Consensus Statements in your country? If 'yes', how do you use them? If 'no' why don't you use them? Are you planning to translate the Statements into your own language (if appropriate)?

A: Self critically said – no. A missing Czech version is maybe the most important barrier. Translating this document could be one of the first tasks for the above mentioned grant.

4. Interview – Denmark

Name & Date: Else Kjær Mikkelsen, August 2015

Country: Denmark (Regional Hospital Herning, Herning)

Job Title: IBD nurse

4.1 What influenced your decision to apply for the role of N-ECCO National Representative for your country?

A: The former National Representative retired as a nurse and I was asked if I was interested in taking over as a N-ECCO National Representative. I have been an ECCO Member for about 9 years and think that the work that ECCO/N-ECCO does is very important for improving IBD care. After having talked to my leaders I accepted because it was a chance to be a part of that and maybe help getting a better sense of connection between N-ECCO and the clinical IBD nurses – also in smaller hospitals – who see the patients every day and do a great job and help IBD nursing in Denmark benefit more from ECCO/N-ECCO and also contribute with what Denmark has to offer.

4.2 What nursing initiatives or developments in IBD care are happening in your country?

A: In Denmark we don't have a National IBD nursing group but many different groups. We have a large organisation connected to our union but that also includes all areas of gastroenterology and hepatology. Then we have a Nordic Network (mainly Danish) sponsored by a medical company. They organise one day of teaching each year and send out newsletters. They also sponsor our participants for the N-ECCO School. Finally Denmark – though a small country – is divided into regions and in each region the IBD nurses meet twice a year for one afternoon discussing different subjects and taking turns in planning the meetings. These meetings are also sponsored by a medical company. So many different things are going on but there is not much connection or contact between them.

4.3 What plans do you have in your role as National Representative to promote ECCO to other nurses in your country (including the N-ECCO School, Research Forum and Network Meeting)?

A: On the webpage for our gastro/hepatology organisation N-ECCO has a place where we try to keep everyone informed about N-ECCO activities. For the N-ECCO School I have worked with the company that sponsors the participants and used their email list in order to contact as many nurses as possible. We have also made a pamphlet about it. But not having one single IBD group makes it difficult to reach all nurses.

4.4 What barriers or problems do you perceive in doing this?

A: As mentioned above, it is difficult because I don't have an overview of all IBD nurses in the country.

4.5 What IBD nursing and N-ECCO networking opportunities do you currently have or plan to develop?

A: I am in contact with one of the doctor's ECCO National Representatives to try to establish some kind of national IBD forum for both doctors and nurses as IBD is a field driven very much in collaboration. I think that would be a chance to have a group focusing only on IBD and making the most out of the possibilities and input from ECCO/N-ECCO.

4.6 The N-ECCO Travel Award is an excellent opportunity for nurses in your country to learn and share best practice. How do you plan to promote this to nurses in your country?

A: It is announced on the webpage mentioned earlier and I encourage nurses at the events that I take part in.

4.7 How can N-ECCO help you to fulfil your role as National Representative?

A: It is important to feel that you are a part of N-ECCO. The meeting in December 2014 in Vienna with all the different National Reps was really good. A big help would be if N-ECCO could make a refund of the costs for taking part in the ECCO Congress. It is

the only time in a year that we meet – and I think that meeting is important if N-ECCO takes us seriously – and as a National Representative it is important to be at the congress if you want to bring something to your country. However the financial resources are very limited for nurses (I am sure that this is not only the case in Denmark) and when your clinic has to pay for it all it blocks your colleagues from participating and you end up feeling guilty for taking opportunities away from others. This is not something that encourages you to be a National Representative...

4.8 How would you like to see N-ECCO develop?

A: I would like to see a closer connection between N-ECCO and the clinical nurse meaning that N-ECCO should be a part of all IBD nurses' working life. I would like to see National Representatives from every country that is a member of ECCO. I know that this was discussed at the National Representatives meeting in Vienna but I think it is important to find out individually for each country what could help their nurses in the best way. Then I also often hear from colleagues that they would like the structure of N-ECCO to be more transparent – for example: Who are these people? How and why are they in the committee? Were they elected? Elected by whom? etc.

4.9 Do you use the N-ECCO Consensus Statements in your country? If 'yes', how do you use them? If 'no' why don't you use them? Are you planning to translate the Statements into your own language (if appropriate)?

A: The Consensus Statements have been presented in different ways – mainly thanks to Palle Bager – and I think every IBD nurse in Denmark has heard about them, but it is not my impression that they are actively used. A national IBD group would make it easier to discuss and implement them. We would like to translate them to make them easier to access and have also found someone interested in helping us financially with that, but so far it seems that there have been too many complications concerning copyright, approval etc., so things are a bit unsure at the moment. But a translation would definitely help a lot.

5. Interview – Austria

Name & Date: Anita Beyer, Tobias Kasa

Country: Austria

Job Title: IBD nurse

5.1 What influenced your decision to apply for the role of N-ECCO National Representative for your country?

A: During our daily business we face all the difficulties of dealing with IBD patients. The huge amount of necessities of those people led us to the decision of applying for the role of N-ECCO National Representatives. Moreover, we have been influenced by our desire to optimize our professional practice and to help structure the job description with all its tasks.

5.2 What nursing initiatives or developments in IBD care are happening in your country?

A: Actually there are not many initiatives in Austria. Therefore, we wanted to be proactive and established an association called “CED Nursing Austria” (CED – engl. IBD). This association has evolved out of the Austrian IBD working group. Some of the major tasks are to organise, twice a year, advanced educational programmes and national nursing congresses for IBD. Additionally, we want to support networking opportunities for nurses in Austria. Currently we are in negotiation with the ÖGKV (Österreichischer Gesundheits- und Krankenpflegeverband), the Austrian union for nurses, to improve networking for IBD nurses.

5.3 What plans do you have in your role as National Representative to promote ECCO to other nurses in your country (including the N-ECCO School, Research Forum and Network Meeting)?

A: We use the (N-) ECCO Consensus as our background as much as possible due to our national circumstances. To promote ECCO, we refer it to the participants of our congresses and educational programmes. Additionally, we want to reference it on the homepage and newsletter of our association (currently under construction – <http://ced-nursing.at>).

5.4 What barriers or problems do you perceive in doing this?

A: Actually we do not have a registry for nurses in Austria. Hence it is quite difficult to evaluate the number of IBD nurses in our country. Therefore, the major problem in the country is that of networking and to get in touch with those who could benefit from more information regarding IBD nursing.

5.5 What IBD nursing and N-ECCO networking opportunities do you currently have or plan to develop?

A: First of all, we want to use “CED Nursing Austria” to reach out to all the IBD nurses nationwide. Furthermore, we use other occasions like gastroenterological meetings and medical congresses in Austria to promote our purposes. However, as we are also glad to be able to attend (N-) ECCO, we use this opportunity to get informed about developments in other countries.

5.6 The N-ECCO Travel Award is an excellent opportunity for nurses in your country to learn and share best practice. How do you plan to promote this to nurses in your country?

A: We plan to promote this award during our national nursing congresses. During these occasions we will be able to provide further information to those who are interested.

5.7 How can N-ECCO help you to fulfil your role as National Representative?

A: Our most valuable resource is time. As we have to fulfil our tasks additionally to our daily business, this resource is always insufficient. Therefore, we would appreciate updated news regarding N-ECCO which should be promoted in a straightforward manner and that can easily be shared.

5.8 How would you like to see N-ECCO develop?

A: As we were in a discussion about this question we came to the conclusion that we would like to see more exchange between nurses, doctors, dietitians and other professional caregivers. This means that we look forward to up to date information from scientific knowledge of other professions and how this influences nursing tasks. For example, challenging duties such as the transition from childhood to adolescence, surgical topics, etc.

As previously mentioned we would like to see and participate in interdisciplinary workshops to get a better insight in the decisions from other professional groups and explore ways in which this cooperation can further be improved.

5.9 Do you use the N-ECCO Consensus Statements in your country? If 'yes', how do you use them? If 'no' why don't you use them? Are you planning to translate the Statements into your own language (if appropriate)?

A: Let's start with the last question: Yes, we would love to translate the Consensus into our language. But as time is always short, we currently don't have sufficient to do that and this indeed is the biggest issue in using the Consensus. Not only the translation of the language, but also adapting it to the national circumstances, as they may differ quite much from other European countries regarding regulations by law and institutions.

6. Interview – United Kingdom

Name & Date: Lynn Gray, June 2016

Country: United Kingdom

Job Title: IBD specialist nurse

6.1 What influenced your decision to apply for the role of N-ECCO National Representative for your country?

A: I have three young children and as a result, in order to balance home and work, I have not become involved with any extra work. Now that my youngest child is in full-time education I feel I have the time and drive to take on more IBD activities outside of my normal work. I have attended the ECCO Congress for several years now and find the whole conference, content, atmosphere and networking invaluable. When the vacancy was advertised for this position I felt this would suit my professional and personal needs to give me a career challenge.

I have been a National Representative for just under a year and have found the opportunity a wonderful experience in which I have developed a network of international contacts and felt great satisfaction at having been involved with such an excellent programme.

6.2 What nursing initiatives or developments in IBD care are happening in your country?

A: A campaign led by Crohn's & Colitis UK for more IBD nurses. This campaign is being led by a very experienced nurse consultant, so I am confident this will be effective and beneficial in achieving its goal.

A closed Facebook group titled "Royal College of Nursing Gastrointestinal Nursing Forum" is about to be launched. This will be used to network and share information about all IBD-related issues. This could be an excellent forum to highlight N-ECCO information.

We have an Immunology annual conference involving dermatology, rheumatology and gastroenterology nurses. There is a day spent on issues concerning all three groups and a day spent discussing gastroenterology-specific issues.

Several, although not all, areas are moving towards using an IBD registry. There are obvious benefits to this service and it is anticipated more trusts will register in the future.

There have been several Twitter discussion groups at scheduled dates and times with an advanced topic / title. These discussions have been very informative and useful, and involved several members of the multi-disciplinary team, not just IBD nurses.

6.3 What plans do you have in your role as National Representative to promote ECCO to other nurses in your country (including the N-ECCO School, Research Forum and Network Meeting)?

A: A summary of the ECCO Congress and Press Conference will be sent to all members of IBD forums in all areas of the UK via the secretary. This allows them all to access the information, developments and updates that are available.

Several reminders to be sent to all members of the IBD forum (not just ECCO Members) promoting the N-ECCO School, Research Forum and Travel Awards. The reminders will discuss the benefits of each, the closing date and advice on how to apply, as well as how to get involved and the encouraging benefits of ECCO Membership.

A survey to be sent to members (as above) asking what they want from their National Representative and promoting ECCO through questions emphasising the benefits of N-ECCO Travel Awards, using Guidelines, sharing information and attending the ECCO Congress, N-ECCO School and N-ECCO Research Forum. Details of how they would like the information to be cascaded – such as a local meeting, email, social media – will also be asked.

6.4 What barriers or problems do you perceive in doing this?

A: Time is the only barrier, but that can be overcome. Various non face-to-face options are suggested, as taking leave for study and meetings is becoming increasingly difficult.

6.5 What IBD nursing and N-ECCO networking opportunities do you currently have or plan to develop?

A: At present there are local meetings several times per year (frequency differs between regions). It is at these meetings that the N-ECCO updates are given either face-to-face from the National Representative or via an emailed summary. There are plans to improve the current situation, as detailed in question three.

6.6 The N-ECCO Travel Award is an excellent opportunity for nurses in your country to learn and share best practice. How do you plan to promote this to nurses in your country?

A: As mentioned above, several reminders are planned to be emailed to all members of the IBD group in the country. The emails will discuss the benefits and encourage people to apply or to pass the information on to others who would benefit from this wonderful opportunity.

6.7 How can N-ECCO help you to fulfil your role as National Representative?

A: Updated emails are very useful in keeping National Representatives informed and making the cascading of information easier and more up-to-date. There is a fast response to email queries and instructions are clear with deadlines for work. At present I do not feel I require any more help but am confident that if I should then someone would help address my needs.

6.8 How would you like to see N-ECCO develop?

A: Study leave is becoming more difficult to secure in the current NHS and therefore the amount of nurses getting the opportunity to travel to the ECCO Congress may reduce. Therefore, the sessions from N-ECCO need to be available to those unable to attend. In the next few years, the cascading of information is going to become more important. As well as information being given by National Representatives, an online summary with (may be difficult I know) a Q&A opportunity to ensure each nurse fulfils their individual needs for the sessions.

I feel it would be useful for all countries involved to take it in turn each year to discuss innovations, research, audit or changes to IBD management going on in their country. It could be the responsibility of the National Representative for each country to approach a speaker to showcase the good work they have done and how this was undertaken. This will bring a different session to the ECCO Congress each year and also help the Committee Members, who are very busy, since they can find one less speaker.

6.9 Do you use the N-ECCO Consensus Statements in your country? If 'yes', how do you use them? If 'no', why don't you use them?

A: In the UK, IBD care is influenced by the N-ECCO Consensus Statements and the BSG (British Society of Gastroenterology) Guidelines and IBD Standards. There is also some local slant on the above, but in general the UK are using N-ECCO Consensus Statements as a benchmark for the standard of care that IBD service users should expect from the people looking after them. All IBD nurses are encouraged to use them within their local hospital.

7. Interview – Romania

Name & Date: Nicoleta Dragomir, July 2016

Country: Romania

Job Title: Specialist nurse

7.1 What influenced your decision to apply for the role of N-ECCO National Representative for your country?

A: I have been a nurse member of ECCO since 2013. I was asked at that time from the Romanian National Representative of ECCO, to be the N-ECCO National Representative.

7.2 What nursing initiatives or developments in IBD care are happening in your country?

A: There is no education in Romania to become an IBD specialist nurse and we don't have a National IBD nursing group. Nurses work as specialist nurses with the multidisciplinary team. Our tasks include the care unit for patients receiving treatment with biologics, iron supply, etc. blood draws, laboratory tests/ biomarkers etc. A nurse in Romania is a nurse with a lot of experience supported by gastroenterologists.

7.3 What plans do you have in your role as National Representative to promote ECCO to other nurses in your country (including the N-ECCO School, Research Forum and Network Meeting)?

A: I would like to promote ECCO through my involvement in the OAMR (Organization of Nurses in Romania). My plans include discussion with colleagues, who are nurses from all around the country during the above mentioned events, about ECCO and N-ECCO, about the roles and options that are offered.

7.4 What barriers or problems do you perceive in doing this?

A: Problems that are being perceived are limited English skills and enough time for any additional activity.

7.5 What IBD nursing and N-ECCO networking opportunities do you currently have or plan to develop?

A: I am in contact with one of the (physician) ECCO National Representatives of Romania who try to establish a national IBD forum for both doctors and nurses. That would be an opportunity to have a group focusing only on IBD.

7.6 The N-ECCO Travel Award is an excellent opportunity for nurses in your country to learn and share best practice. How do you plan to promote this to nurses in your country?

A: I may promote this kind of award at National Congresses of Nurses, but the problem is that nurses do not have financial resources to join a meeting abroad. The employers don't always offer financial support.

7.7 How can N-ECCO help you to fulfil your role as National Representative?

A: I wish that ECCO could give me financial support for my participation at ECCO Congresses.

7.8 How would you like to see N-ECCO develop?

A: N-ECCO should increase helping nurses from eastern parts of Europe.



7.9 Do you use the N-ECCO Consensus Statements in your country? If 'yes', how do you use them? If 'no', why don't you use them?

A: In our country we use the N-ECCO Consensus as a guideline to approach the patients. IBD patients need special attention and the nurse is the most important specialist who is able to provide this care. All nurses who take care of this type of patients apply the statements from the N-ECCO Consensus.

At our meeting we discussed the possibility to translate the N-ECCO Statements and the general opinion was that a translation of the statements would be needed.

8. Interview – Germany

Name & Date: Janette Tattersall-Wong (Berlin), Susann Wienecke (Lüneburg), Oct 2016

Country: Germany

Job Title: Nurse / IBD Nurse / Study-Nurse

8.1 What influenced your decision to apply for the role of N-ECCO National Representative for your country?

A: We have been members of ECCO/N-ECCO since we began working as IBD specialist nurses. In 2015 we were approached by the former N-ECCO National Representative of Germany, Petra Hartmann, whether we would consider taking over her duties. It is a matter in which we are greatly interested and welcomed the opportunity to become more involved in the development of IBD nursing.

8.2 What nursing initiatives or developments in IBD care are happening in your country?

A: IBD nursing is an area that is relatively young in Germany and has yet to fully develop. There is an increase in the number of courses being offered and recruitment is in progress. The courses are supported either by the pharmaceutical industry or the German IBD Centre of Excellence and the German FA-CED (IBD nurses interest community), which was founded a few years ago.

8.3 What plans do you have in your role as National Representative to promote ECCO to other nurses in your country (including the N-ECCO School, Research Forum and Network Meeting)?

A: We have a considerable network of people in the IBD nursing scene. We have no hesitations in addressing the subject with newcomers and experienced nurses. We have personally recommended a nurse and a dietician to the N-ECCO school for 2017.

For the past two years we have been engaged in organising and promoting an annual post-N-ECCO for IBD Nurses in order to enable the professional exchange of ECCO/N-ECCO at a local level, which is conducted by the FA-CED.

8.4 What barriers or problems do you perceive in doing this?

A: The language problem is very apparent. Although most nurses have a basic knowledge of English, they are very apprehensive whether or not it is sufficient.

The financial aspect of attending congresses' etc. is also a problem for nurses, i.e. the travel expenses, hotel costs and the time off from work.

8.5 What IBD nursing and N-ECCO networking opportunities do you currently have or plan to develop?

A: As previously mentioned we have a good network of people and we look forward to a growing IBD Nurses' interest community.

8.6 The N-ECCO Travel Award is an excellent opportunity for nurses in your country to learn and share best practice. How do you plan to promote this to nurses in your country?

A: The idea of the N-ECCO travel award is truly excellent, however in Germany we are lacking nurses with sufficient experience to benefit from the program. We are expecting this problem to dissolve in the next years.

8.7 How can N-ECCO help you to fulfil your role as National Representative?

A: It would be a great help if especially the N-ECCO website would provide a local language section with relevant information about N-ECCO activities and application procedures.



8.8 How would you like to see N-ECCO develop?

A: I would like to see the N-ECCO community grow and an increase in the variety of opportunities tailored to meet the requirements of the IBD nurses in Europe.

8.9 Do you use the N-ECCO Consensus Statements in your country? If 'yes', how do you use them? If 'no' why don't you use them? Are you planning to translate the Statements into your own language (if appropriate)?

A: At the present time we are not using them. The IBD Nurse in Germany does not yet have a professional profile.

In the moment there are no plans for translation because there are no means. A simplified version would be an advantage and an aim for the not too distant future.

9. Interview – Norway

Name & Date: Beathe Nesvåg, December 2016

Country: Norway

Job Title: Nurse

9.1 What influenced your decision to apply for the role of N-ECCO National Representative for your country?

A: I have worked with IBD patients for 10 years as a nurse in a small hospital in the south of Norway. Early on I participated in local, regional and national meetings to learn more and made good connections with other nurses working with IBD patients. As the former N-ECCO National Representative had to step down she asked me if I wanted to be the next representative. The formal election was done in a board meeting of the national group of gastroenterology nurses who voted me to be the next N-ECCO National Representative.

9.2 What nursing initiatives or developments in IBD care are happening in your country?

A: Norway is a small country but stretches over 250 kilometres long. Small steps are made by nurses who are working hard to start nurse clinics and advisory lines on each hospital. We have come a long way since I first started working with IBD. More hospitals open telephone lines and most hospitals have at least one nurse who works with biologics and nurse day care clinic. Nurses are more involved in the planning of treatment and the function as a link between patient and doctor.

9.3 What plans do you have in your role as National Representative to promote ECCO to other nurses in your country (including the N-ECCO School, Research Forum and Network Meeting)?

A: I hold a national meeting every year in the fall with nurses from all over the country. We had a record this year with over 60 nurses from north to south. This meeting has an agenda to teach and discuss every part of the IBD patient problems, but also to facilitate networking between nurses. It is a two-day meeting with dinner in the evening on the first day and we have received remarkable feedback from participants. They are mostly satisfied with the content of the meeting. We also ask for feedback on themes for next year's meeting. It is important to know what nurses need and want to learn more about. Nurses who graduate from the university with a degree in gastroenterology nursing are invited to lecture from their examinations. This meeting also picks out two participants for the N-ECCO School. I also give a summary of the N-ECCO Network Meeting so that those who were not able to attend the ECCO Congress will get some information and news from the Congress. I also encourage nurses to attend the Congress and advertise the funding that N-ECCO has for those who have problems with funding in their own hospital.

9.4 What barriers or problems do you perceive in doing this?

A: The national nurses meeting is hard work and is done on my free time. Lots of meetings are held with the program committee and it is a challenge to get good lecturers. But for now we have been blessed with eager doctors and nurses and most say yes. It is not easy to get off work for the meeting. This role is voluntary, but I enjoy doing this very much.

9.5 What IBD nursing and N-ECCO networking opportunities do you currently have or plan to develop?

A: As you read above I hold a national meeting every year for IBD nurses. We already have a closed Facebook community for members of the national gastroenterology nurses where news from research, patient organisations and global meetings are shared. I want to start a networking Facebook community for IBD nurses. Here I can share information about the Congress and get nurses in contact with ECCO. I believe it will be good for recruiting members as well. We have many hospitals in Norway but the nurses work more or less alone because they work in small hospitals. I believe that networking is important for those nurses. The Facebook community is an easy thing to start up but I believe monitoring it will create a lot of work. And I guess that I will have to be prepared for whatever happens when I start it up.

9.6 The N-ECCO Travel Award is an excellent opportunity for nurses in your country to learn and share best practice. How do you plan to promote this to nurses in your country?

A: I already do every year on the national IBD nurses meeting.

9.7 How can N-ECCO help you to fulfil your role as National Representative?

A: I believe there is only so much you can do. I work full time as a nurse and do this voluntary. I do not see what more I am capable of doing now. I was not able to attend the National Representatives Meeting in Vienna because I could not get off work. I attend one congress and two national meetings a year. If I wanted to do more I would have to work less and that is not an option.

9.8 How would you like to see N-ECCO develop?

A: I do not know how to answer that. I think you do a great job with the N-ECCO Network Meeting, the N-ECCO School and the N-ECCO Research Forum. I am just sorry that many of these meetings are held simultaneously. But I guess there is no other way to do it.

9.9 Do you use the N-ECCO Consensus Statements in your country? If 'yes', how do you use them? If 'no' why don't you use them? Are you planning to translate the Statements into your own language (if appropriate)?

A: In Norway we do use the Guidelines. Doctors have been using them for years and nurses try to as well. All treatment planning and follow-ups are done according to the Guidelines. I held a small lecture on the N-ECCO Consensus Statements at the national meeting in 2015 in Norwegian, but I have not translated it yet. I believe it is not that important because we are used to reading English in Norway and research that we read is in English. Publications are mostly in English as well.

10. Interview – Israel

Name & Date: Revital Barkan, January 2017

Country: Israel

Job Title: IBD Nurse

10.1 What influenced your decision to apply for the role of N-ECCO National Representative for your country?

A: I am a certified nurse since 2000, with 12 years of experience in a large emergency room in a tertiary centre in Israel. Since 2012 I am practicing as an IBD nurse at the IBD centre of the TLVMC, and joined N-ECCO as a National Representative in 2013.

The IBD nurse profession in Israel is relatively new and not accredited yet. The IBD nurse is a pivot in the multidisciplinary team that manage and care for IBD patients. N-ECCO is the optimal platform to promote the position of IBD nurses. Thus, taking a role in N-ECCO will serve in the endorsement of integrative patient care in Israel.

10.2 What nursing initiatives or developments in IBD care are happening in your country?

A: In 2012 we established an IBD nurses' forum for nursing staff from IBD centres and infusion centres from all over the country. The forum conducts 6 business meetings per year (supported by pharmaceutical companies). Our goal is to create a collaborative network of nurses who will consult patients admitted for in-house care around the country and liaison with the main case manager. We also have academic programmes covering different aspect of IBD care such as: emotional support for chronic illness, updates in the research, clinical trials, endoscopic procedures, surgery, paediatrics, pregnancy in IBD, etc.

10.3 What plans do you have in your role as National Representative to promote ECCO to other nurses in your country (including the N-ECCO School, Research Forum and Network Meeting)?

A: My main personal aim is to promote the positioning of the IBD nurse within the Israeli health care system. This will be first done through accreditation by ministry of health, and later by the different health care providers in the country (insurance). I aim to implement the ECCO Guidelines, relevant formats, and recommendations in the everyday practice in order to achieve high quality care.

In our meeting I'm in charge of the professional updates from ECCO. I have created a mentoring programme in which new IBD nurses are mentored by experienced IBD nurses. I recommend all new IBD nurses to travel to the N-ECCO School as it is an important educational activity and I ensure 2 new nurses take part in the N-ECCO School every year. I encourage the development of new tools to help the IBD nurses in the treatment of IBD patients and promote cooperation between the various care centres.

10.4 What barriers or problems do you perceive in doing this?

A: Right now there are no barriers.

10.5 What IBD nursing and N-ECCO networking opportunities do you currently have or plan to develop?

A: I have joined the Israeli gastroenterology association (IGA) as a representative of the IBD nurses. In the January 2017 IGA meeting I became a faculty member, my role was to plan and orchestrate the academic activity of the entire gastroenterology nurses' community. I also chaired the nurses' satellite symposium in which 200 nurses took part, the session addressed aspects on innovation in IBD care and management, IBS, endoscopy, surgery and nutrition.

10.6 The N-ECCO Travel Award is an excellent opportunity for nurses in your country to learn and share best practice. How do you plan to promote this to nurses in your country?

A: The importance of IBD nurses is growing in Israel, there is a high awareness to the importance of quality knowledge and to need to work according to universal standards based on ECCO Guidelines.

We apply to the pharmaceutical companies to assist in financing national conventions and to finance the participation of nurses in international conventions. We explain to the companies that the nurses are those who are in constant contact with the IBD patients and are an integrative and crucial part of patient care and we need their support to be able to educate more nurses and have knowledge on the international level in between the countries in the ECCO.

10.7 How can N-ECCO help you to fulfil your role as National Representative?

A: N-ECCO can help us by including Israel as a travel destination for nurses, this will enable them to learn our methods of treatment.

10.8 How would you like to see N-ECCO develop?

A: By promoting multicentre research on the subject of nursing. By creating working groups that meet more often and will focus on more efficient methods of treatments.

10.9 Do you use the N-ECCO Consensus Statements in your country? If 'yes', how do you use them? If 'no' why don't you use them? Are you planning to translate the Statements into your own language (if appropriate)?

A: We use the N-ECCO consensus statements.

I supply every new nurse with a list of important articles that will help her in her new job.

The main paper is the N-ECCO Consensus Statements on the European nursing roles in caring for patients with Crohn's Disease or Ulcerative Colitis.

Since we are not recognised by the ministry of health as IBD nurses we depend solely on the ECCO Guidelines in order to keep high working standards.

11. Interview – Poland

Name & Date: Marzena Kurek, February 2017

Country: Poland

Job Title: Ward Nurse in Clinical Department of Internal Medicine and Gastroenterology

11.1 What influenced your decision to apply for the role of N-ECCO National Representative for your country?

A: I'm a Ward Nurse in the Clinical Department of Internal Medicine and Gastroenterology with Inflammatory Bowel Disease Unit in the Central Clinical Hospital of the Ministry of the Interior and Administration in Warsaw.

It is the leading centre in the field of multidisciplinary care of patients with IBD in Poland. We realise programmes of biological treatment refunded by the National Health Fund, as well as numerous of clinical trials.

I have dealt with the coordination of all these activities for many years, so I have a lot of experience in the care of patients with IBD.

I see many of the problems associated with specialised training of nurses in the care of patients with IBD. It is these problems, as well as awareness of the need for better education of patients, which encouraged me to accept the proposal of being a N-ECCO National Representative.

Moreover, our Deputy Director, Prof. Grażyna Rydzewska (MD, PhD), is now Chair of the Polish Society of Gastroenterology.

The Polish Society of Gastroenterology has been supporting the initiative of nursing and patronised regularly organised conferences devoted to multidisciplinary, mainly nursing care of patients with IBD.

11.2 What nursing initiatives or developments in IBD care are happening in your country?

A: For several years we have organised annual conferences and scientific training dedicated to important problems in the care of patients with IBD. The conferences were attended by around 60 nurses from gastroenterology, paediatrics and surgical centres from all over Poland, and moreover specialists on clinical nutrition, clinical pharmacy and invited doctors, specialists in the field of IBD.

Apart from lectures, we analyse the clinical cases, as well as discuss and implement research projects.

There are also special "training days" conducted by nurses most experienced in the treatment of patients with IBD in the centres which need such assistance.

Nurses are also involved in the activities of Society of Patients with Inflammatory Bowel Diseases, help in the organisation of educational meetings, give lectures and consultations concerning everyday problems of patients with IBD.

11.3 What plans do you have in your role as National Representative to promote ECCO to other nurses in your country (including the N-ECCO School, Research Forum and Network Meeting)?

A: For many years we have been trying to extend our cooperation with N-ECCO. The main problems arise from difficulties in the financing of travel and accommodation; they are often also associated with obtaining delegation from the workplace. This is due to the fact that nurses have a variety of responsibilities, far beyond the care of patients with IBD.

11.4 What barriers or problems do you perceive in doing this?

A: In our country, nurses deepen their professional knowledge under different specialisations. Completion of a specialisation programme and passing the exam is combined with career advancement and improvement of salaries. Unfortunately, despite the effort we failed so far to create a specialisation in the care of patients with IBD. Thus, the advancement of knowledge in this area is only motivated by nurses' own interests and ambitions. It is difficult because of the high load of various professional responsibilities and very often with the need to undertake additional work in order to improve the financial situation of families.

11.5 What IBD nursing and N-ECCO networking opportunities do you currently have or plan to develop?

A: For two years we have been strengthening international cooperation mainly with a team from the United Kingdom. We are realising the project of translating and validating the IBD-fatigue questionnaire. Wladzia Czuber-Dochan (Dr Wladzia Czuber-Dochan PhD MSc, Lecturer at Florence Nightingale Faculty of Nursing & Midwifery, London) and her team were successful with their application for funding from ECCO to translate the IBD-Fatigue Scale to 3 European languages and to do preliminary testing. Poland will act as the advisory team as we are already in the final stage of the IBD-Fatigue Scale translation and validation.

This project involved a dozen nurses from several centres in Poland.

11.6 The N-ECCO Travel Award is an excellent opportunity for nurses in your country to learn and share best practice. How do you plan to promote this to nurses in your country?

A: We talk about these possibilities and present such opportunities during our annual conferences, so I hope that in the next few years more Polish nurses will participate in the activities and projects of N-ECCO.

11.7 How can N-ECCO help you to fulfil your role as National Representative?

A: Probably some additional materials (from ECCO and N-ECCO) would be useful, especially those which in a simple and understandable manner present a variety of opportunities to deepen medical knowledge and exchange professional experiences in the field of IBD.

11.8 How would you like to see N-ECCO develop?

A: I think the most valuable development would be international research projects on various aspects of IBD. It would be important that such projects incorporate representatives of many countries, as is happening now with the project of translating and validating the IBD-Fatigue Scale.

11.9 Do you use the N-ECCO Consensus Statements in your country? If 'yes', how do you use them? If 'no' why don't you use them? Are you planning to translate the Statements into your own language (if appropriate)?

A: Yes, we have used the N-ECCO Consensus Statements in daily practice for many years. In 2014, Working Group Guidelines on the Nursing Roles in Caring for Patients with Crohn's Disease and Ulcerative Colitis in Poland, compliant with the European Guidelines published by N-ECCO, adjusted to the current situation in Poland have been published in the Gastroenterology Review (2014; 9 (4): 179–193 DOI: <https://doi.org/10.5114/pg.2014.45098>).

They were probably the first national guidelines based on the N-ECCO Consensus Statements, extended and amended, taking into account the major problems in the care of patients with IBD in Poland.

12. Interview – Spain

Name & Date: Ester Navarro

Country: Spain

Job Title: IBD Nurse

12.1 What influenced your decision to apply for the role of N-ECCO National Representative for your country?

A: I have been working as an IBD nurse for 5 years, and since the first year I have been a member of N-ECCO. During all this time, I have been actively involved in several projects at the national level related to IBD patient care.

Two years ago, the N-ECCO National Representative proposed to me that I replace him and I accepted. I did it thinking that having a representative in N-ECCO is a good way to connect the nurses from Spain with the rest of the world.

On a personal level I think it allows you to get to know other realities and ways of working, which allows one to improve overall.

12.2 What nursing initiatives or developments in IBD care are happening in your country?

A: In Spain there is GETEII, a nursing group working in IBD, which currently comprises about 70 nurses. There is a considerable amount of nurses who are highly motivated and wish to raise the role of the IBD nurse to more prominence.

- The lines of improvement in which the group are working are:
- Creation and publication of a guide to nursing in IBD with the aim of unifying our daily practice
- Encourage activities to create networks
- On-line and face-to-face continuing education courses
- Favour research projects in nursing care, through training and research grants
- Creation of a web page

12.3 What plans do you have in your role as National Representative to promote ECCO to other nurses in your country (including the N-ECCO School, Research Forum and Network Meeting)?

A: Each year we hold a roundtable at the annual meeting of GETEII to inform our colleagues about the content of N-ECCO. In this meeting, two nurses participate: one of them is the participant from the N-ECCO School, whilst the other of the attendees comes from the N-ECCO Network Meeting.

In the same forum, as a N-ECCO National Representative, I inform members and attendees about the possibility of accessing scholarships and about other ECCO and N-ECCO activities.

There is also a mailing throughout the year to publicize the various activities of ECCO and N-ECCO.

12.4 What barriers or problems do you perceive in doing this?

A: I do not think there are any barriers to promoting the activities of ECCO and N-ECCO. Where barriers arise, as in many other countries is the possibility of attending such meetings due to two factors, the difficulty of finding financial assistance to attend, and the difficulty in getting permits from the same hospitals to attend. This requires a personal effort, both economic and time-wise, that not all nurses can afford.

Additionally, specifically for Spanish nurses, the English language can sometimes be a significant barrier.

12.5 What IBD nursing and N-ECCO networking opportunities do you currently have or plan to develop?

A: I would like to refer to question 3 of this interview. Additionally, another goal that I would like to mark would be to favour the participation in studies of nursing research of a multicentric and international character.

12.6 The N-ECCO Travel Award is an excellent opportunity for nurses in your country to learn and share best practice. How do you plan to promote this to nurses in your country?

A: I believe this project is a wonderful opportunity, and in all the forums that I attend at the national level, I take the opportunity to make it known. Unfortunately the barriers mentioned above (the lack of time, economic funding, and especially the lack of English knowledge) mean that few nurses consider going to them.

12.7 How can N-ECCO help you to fulfil your role as National Representative?

A: I feel we are already well-informed through the updates that we receive periodically by email. However, I believe that it would also be good to work on creating a network among all the representatives through some platform that will facilitate the contact between all us, and thereby, we could also obtain a stronger feeling of group membership and unity.

12.8 How would you like to see N-ECCO develop?

A: I would like N-ECCO to continue evolving in updating the Consensus. Furthermore, aiding in training to countries like Spain in which there is no regulated academic training specialised in IBD would be quite valuable. I believe that promoting the realisation of international research projects should also be within the priorities of the future.

12.9 Do you use the N-ECCO Consensus Statements in your country? If 'yes', how do you use them? If 'no' why don't you use them? Are you planning to translate the Statements into your own language (if appropriate)?

A: The knowledge and use of the Consensus Statements are clearly widespread in Spain. I think I would not be wrong to say that 100% of IBD nurses utilise this document as a reference in their clinical practice. Fortunately, the Statements have already been translated into Spanish, which has clearly facilitated their disclosure. And I encourage all those non-English speaking countries to translate it.

13. Interview – The Netherlands

Name & Date: Maria de Jong and Laurence Duijsens, March 2017

Country: The Netherlands

Job Title: IBD Nurse Practitioner

13.1 What influenced your decision to apply for the role of N-ECCO National Representative for your country?

A: de Jong: I was asked to fill the role by the previous N-ECCO National Representative. I am a board member of the Dutch IBD nurses network and as a N-ECCO National Representative you can also get involved with the European policy and stay up-to-date.

Duijsens: In my case, it was similar. I was asked by the previous N-ECCO National Representative. A reason for me too, was that because I am living in the southern part of the Netherlands, most of the jobs at national organizations go to people living in the central part (people they know) so to me this was also a way to become involved in the Dutch nurses network.

13.2 What nursing initiatives or developments in IBD care are happening in your country?

- A:**
- IBD nurses network, a collaboration with the IBD network from gastroenterologists in the Netherlands dedicated to IBD
 - Development of protocols
 - Development of patient information
 - Development of the profile of an IBD nurse
 - Regional IBD education for nurses
 - Nationwide IBD education for nurses
 - 6-day course (school) for IBD nurses

13.3 What plans do you have in your role as National Representative to promote ECCO to other nurses in your country (including the N-ECCO School, Research Forum and Network Meeting)?

- A:**
- Promote the ECCO Congress and the N-ECCO activities
 - Promote the ECCO Website with protocols, etc.
 - Update the followers (nurses) about developments in the IBD world
 - Post N-ECCO
 - Promote the N-ECCO School
 - Promote the N-ECCO Travel Award and Research Grant

13.4 What barriers or problems do you perceive in doing this?

A: de Jong: None

Duijsens: I actually do not have real barriers, but it helps that Maria is a board member of the Dutch network, so she knows her way around how to reach the Dutch nurses. Otherwise it would be very difficult for me. On the other hand this is a way to become involved in the Dutch organization and I am grateful to have this opportunity, so I think it should not be required in becoming an N-ECCO National Representative.

13.5 What IBD nursing and N-ECCO networking opportunities do you currently have or plan to develop?

A: See answer 2.

Additionally, more attention to provide research done by nurses.

13.6 The N-ECCO Travel Award is an excellent opportunity for nurses in your country to learn and share best practice. How do you plan to promote this to nurses in your country?

A: Via a newsletter sent by our committee

13.7 How can N-ECCO help you to fulfil your role as National Representative?

A: de Jong: Provide a protocol in what ECCO expect from us and give a year programme with an overview of all the ECCO activities. Now you are getting a lot of emails, so you don't have an overview.

Duijsens: It would be nice to get an overview, especially since you don't know at start the content of the role (although you have defined and detailed them), but it helps in how to fulfil the roles, responsibilities and expectations.

13.8 How would you like to see N-ECCO develop?

A: de Jong: Maybe in future make a N-ECCO meeting with 2 programmes, one for inexperienced IBD nurses and one for more experienced nurses. Now you see the more experienced nurses not participating in the N-ECCO Network Meeting, they are going to the doctors' programme. So maybe a kind of a masterclass.

13.9 Do you use the N-ECCO Consensus Statements in your country? If 'yes', how do you use them? If 'no' why don't you use them? Are you planning to translate the Statements into your own language (if appropriate)?

A: de Jong: Yes, I use it sometimes. It is a good overview of activities done by an IBD nurse. For now, we are not planning to translate it.

14. Interview – Switzerland

Name & Date: Christina Knellwolf & Rosmarie Junker, March 2017

Country: Switzerland

Job Title: IBD Nurse

14.1 What influenced your decision to apply for the role of N-ECCO National Representative for your country?

A: After attending my first N-ECCO Network Meeting in Prague, I found out that Switzerland was a Country Member. Due to the fact that there are not that many IBD nurses in Switzerland, Rosmarie and I decided to apply for the role of N-ECCO National Representative.

14.2 What nursing initiatives or developments in IBD care are happening in your country?

A: We have in Switzerland the IBDnet, which is a network of doctors working in IBD. Within this network there is a platform for IBD nurse education, in which we will be hosting a Post N-ECCO in October.

14.3 What plans do you have in your role as National Representative to promote ECCO to other nurses in your country (including the N-ECCO School, Research Forum and Network Meeting)?

A: As already mentioned above, we will be hosting a yearly Post N-ECCO meeting. We have a waiting list for all nurses working in IBD that would like to attend the N-ECCO School.

14.4 What barriers or problems do you perceive in doing this?

A: Communication between the three national languages in Switzerland has always been a problem. We are hoping to resolve this through the IBDnet, which is set in all 3 languages.

14.5 What IBD nursing and N-ECCO networking opportunities do you currently have or plan to develop?

A: The IBDnet holds a seminar for nurses at least once a year. Some of the nurses working in endoscopy also attend the national convention for nurses in GI-endoscopy, which forms a network platform.

14.6 The N-ECCO Travel Award is an excellent opportunity for nurses in your country to learn and share best practice. How do you plan to promote this to nurses in your country?

A: This will be mentioned every year during our Post N-ECCO session.

14.7 How can N-ECCO help you to fulfil your role as National Representative?

A: A flyer with a summary of the most important topics of N-ECCO and ECCO.

14.8 How would you like to see N-ECCO develop?

A: Exactly how it is at the moment, growing and growing. The collaboration with N-ECCO will be very helpful for us in Switzerland to spread the information to all who are interested.

14.9 Do you use the N-ECCO Consensus Statements in your country? If 'yes', how do you use them? If 'no' why don't you use them? Are you planning to translate the Statements into your own language (if appropriate)?

A: Unfortunately, Switzerland is not that far yet in nursing to be able to use the N-ECCO Consensus Statements regularly. Most of the nurses, not only working in IBD, but also in other GI-areas, do not know about them...yet. We hope to change this in the future.

15. Interview – Turkey

Name & Date: Berna Nilgün Ozgursoy Uran, April 2017

Country: Turkey

Job Title: Lecturer in a university and IBD nurse in a hospital

15.1 What influenced your decision to apply for the role of N-ECCO National Representative for your country?

A: I am responsible for the training of IBD patients in Izmir. "What can I do for IBD patients and how can I be useful?" I got acquainted with ECCO and N-ECCO on the advice of our clinic chief, and then I attended congresses of ECCO and N-ECCO activities. I am constantly exchanging information with N-ECCO members on each subject. I get support from them on any issues of IBD. In addition, I also have the opportunity to follow up on the work of the world as a whole and keep up with current developments.

15.2 What nursing initiatives or developments in IBD care are happening in your country?

A: IBD nursing is a newly developing area in our country. Very few nurses work in this area. However, the single patient groups are not IBD, they have to look at other diseases in the clinic. In this regard, I make a special effort of IBD nursing, and I plan the training of the nurses in this field. I explain the principles of treatment in the clinic, nutrition, exercise, coming to regular checks, etc. I am planning and conduct disease education for patients. In IBD patient school, I train the patients. Since there are no nurses working for IBD like me, I recently provided training for the IBD nurses in our country. I intend to open "the IBD Nursing Association" in our country in the future.

15.3 What plans do you have in your role as National Representative to promote ECCO to other nurses in your country (including the N-ECCO School, Research Forum and Network Meeting)?

A: By opening the IBD Nursing Association, I will share with all nurses about N-ECCO's work: N-ECCO School, Research Forum, and Network Meeting. I will encourage more nurses to join the congresses held in the coming years with more work than Turkey. I will also work on opening certificates and graduate programmes for the specialisation of IBD nurses in our country.

15.4 What barriers or problems do you perceive in doing this?

A: There are no barriers or problems except that the low number of nurses working in clinics and the IBD specialist nurses. Also, the number of nurses who speak English at a sufficient level is too little.

15.5 The N-ECCO Travel Award is an excellent opportunity for nurses in your country to learn and share best practice. How do you plan to promote this to nurses in your country?

A: First of all I want to experience it myself. Because we can tell something that we have experienced to others more clearly and correctly. Our nurses need this support. They want to evaluate friends who I mentioned your travel award.

15.6 How can N-ECCO help you to fulfil your role as National Representative?

A: As my work speeds up I will need help. I will always be in touch with you at this point. Thank you.

15.7 How would you like to see N-ECCO develop?

A: I hope to reach bigger population. It is also very pleasing to have them in every country and always be in contact. I wish success and I appreciate N-ECCO.



15.8 Do you use the N-ECCO Consensus Statements in your country? If 'yes', how do you use them? If 'no' why don't you use them? Are you planning to translate the Statements into your own language (if appropriate)?

A: Yes, I use it and I translated these statements into Turkish. I tell these at every opportunity to use these for the nurses. I especially talk about these statements in my nurse trainings. I am organising these statements in a way that can be used for our recommended patients, and I am going through based on these evidence-based statements in my patient trainings.

16. Interview – Finland

Name & Date: Tanja Toivonen, April 2017

Country: Finland (Hatanpää Hospital)

Job Title: IBD Nurse

16.1 What influenced your decision to apply for the role of N-ECCO National Representative for your country?

A: I have been member since 2012, my first ECCO Congress was in Barcelona 2012. I was impressed by IBD nursing and since then I have been fortunate to take part in the Congress on an annual basis. I have met other Finnish IBD nurses in the meetings and I have wanted to be part of N-ECCO. When a former N-ECCO National Representative, Tuija Vilmunen, asked me to continue N-ECCO work I did not hesitate.

16.2 What nursing initiatives or developments in IBD care are happening in your country?

A: The number of IBD nurses in Finland has been increasing. There have been four courses of specialising education for IBD nursing. The courses have been held in two different university of applied sciences schools. So there about 50 nurses who have been educated as an IBD nurse. We have some kind of network, but there is still work to do. After this year's ECCO Congress we created a forum on Facebook. There has been conversation for years about the need for our own association or division under the Association of Nurses in Gastroenterology. Maybe this year something will happen.

Annually there have been one to two national IBD nurse meetings, as well as regional education which has been organised by medical companies.

16.3 What plans do you have in your role as National Representative to promote ECCO to other nurses in your country (including the N-ECCO School, Research Forum and Network Meeting)?

A: I have tried to promote N-ECCO and ECCO activities in our meetings. Through our IBD nurse network I have found participants for the N-ECCO School. During my first year there was one nurse who applied, this year there were over ten.

16.4 What barriers or problems do you perceive in doing this?

A: I do not think there are any barriers to do that. The barriers are to find financial assistance to attend. The interest is arising towards ECCO.

16.5 What IBD nursing and N-ECCO networking opportunities do you currently have or plan to develop?

A: The first virtual clinic is under work. There are four IBD nurses taking part in that project. There will be a survey held, which will give us more information about IBD nurses in Finland. Gastroenterologists will receive the survey as well. It tries to give us more information on how IBD nurse posts benefit hospitals and what IBD nurses are doing in Finland.

16.6 The N-ECCO Travel Award is an excellent opportunity for nurses in your country to learn and share best practice. How do you plan to promote this to nurses in your country?

A: I intend to encourage Finnish IBD nurses to apply for it. I have heard that one or two nurses intend to, let's hope they will.

16.7 How can N-ECCO help you to fulfil your role as National Representative?

A: I have been happy how it has worked until now. E-mails are good ways to communicate. It could be possible to create a website for the N-ECCO National Representatives, which we could use to communicate with each other.

16.8 How would you like to see N-ECCO develop?

A: I would like it if taking part in the N-ECCO Educational Activities could happen like a webinar. IBD nurses in Finland would gather here in one place and take part in the meeting like that. More nurses would have chance to take part and it could ease that. Nurses would experience the language and the big congress feeling.

16.9 Do you use the N-ECCO Consensus Statements in your country? If 'yes', how do you use them? If 'no' why don't you use them? Are you planning to translate the Statements into your own language (if appropriate)?

A: We lack our national statements, it would be good start to translate N-ECCO Consensus Statements. We could use it better and maybe create our own national statements using N-ECCO's.