

30th Meeting

Paediatric Nursing Associations of Europe

Reykjavik, Iceland Notes 19th October 2017

Attendees

Guðrún Kristjánsdóttir, Eirberg, Faculty of Nursing, University of Iceland, Iceland [Host] [GK]
Karitas Gunnarsdóttir, Chair Paediatric workgroup of the Icelandic Nurses Association (PWINA) [KG]
Jane Coad, Coventry University, United Kingdom [JC]
Katrín De Winter, Paediatric Nurses Association, Belgium [KDW]
Karen Vansteenkiste, Paediatric Nurses Association, Belgium [KV]
Jorunn Tunby, Norwegian Paediatric Nurses Association [JT]
Helena Wigert, Swedish Paediatric Nurses Association, Sweden [HW]
Karin Bundgaard, Paediatric Nursing Association, Denmark [KB]
Conni Andersen, Paediatric Nursing Association, Denmark [CA]
Ingrid Hanks Drielsma, Dutch Association of Paediatric Nurses, Netherlands [IHD]
Catherine Sheridan, Irish Nursing Organisation, Ireland [CS]
Maria Brenner, MOCHA project, Ireland [MB]
Kristina Kuznik, Croatian Nurses Association of Paediatric Nursing Society [KK]
Dragica Beštak, Croatian Nurses Association of Paediatric Nursing Society [DB]
Sofia Abreu, Secretary of the Professional Specialty College of Infant Health and Paediatrics Nursing, Ordem dos Enfermeiros, Portugal [SA]
Filipa Barbosa, Professional Specialty College of Infant Health and Paediatrics Nursing, Ordem dos Enfermeiros, Portugal [FB]
Frauke Leupold, Berufsverband Kinderkrankenpflege, Germany [FL]
Jitka Voříšková, Head of the Paediatric section of the Czech Nurses Association [JV]
Ivona Mikulenkova, Vice President, Paediatric section of the Czech Nurses Association [IM]
Caoralie Cadene Pereira, Association Nationale des Puéricultrices Diplômées et des Etudiants, France [CCP]

Apologies

Vasiliki Matziou, Greece [VM]
Barbara Boutopoulou, Greece [BB]
Ayse Ferda Ocakci, Turkey [AFO]
Caroline Roberts-Quast, Dutch Association of Paediatric Nurses, Netherlands [CRQ]
Corry van den Hoed-Heerschop, Dutch Association of Paediatric Nurses, Netherlands [CvH]
Orsola Gawroski on behalf of Italian Nurses Association [OG]
Immacolata Dall'Oglio on behalf of Italian Nurses Association [IDO]
Fiona Smith, Royal College of Nursing, United Kingdom [FS]
Eleni Kyritsi-Koukoulari, President Hellenic National Nurses Association (HNNA) & Advisor Paediatric Nurses Sector [EKK]
Fragkoula Efstratiou, President of Paediatric Nurses Sector of HNNA [FE]

1. Welcome/introductions

IHD welcomed attendees to the meeting. Attendees agreed that IHD and IM chair the meeting and FL to take notes. IHD thanked colleagues in Iceland and in Reykjavik for hosting and organizing the PNAE meeting.

Prof Guðrún Kristjánsdóttir (GK), professor of children's nursing, welcomed attendees to Iceland and Eirberg University. The university has one of the oldest academic nursing education programmes in Europe. Children's nursing is taught separately but alongside medical paediatrics. Community paediatrics is central to the philosophy. There is a strong link between theory and practice with the Landspítali University Hospital Barnspítali (Children's hospital) and other facilities to care for children in Iceland, e.g. for handicapped children and palliative care. Students have a 4 year programme where all students are required to do a block of bedside nursing of 7 days / 75 hrs to get experience in caring for children in the hospital as well as in the community. This includes rehabilitation work and hospice experience. At the end they receive a nursing license.

Attendees express thanks to all involved in the visit to the Landspítali University Hospital Barnaspítali (Children's hospital) and to Sólrún W. Kamban, Elísabet Konráðsdóttir, Vigdís H. Viggósdóttir and Rakel B. Jónsdóttir who made presentations on the previous day.

The research presentations (see attached) covered the following topics and were lively discussed with the audience:

• **The effectiveness of advanced paediatric family nursing practice**

Sólrún W. Kamban og Elísabet Konráðsdóttir

Elisabeth -> works with children with diabetes in outpatient clinic, also educates colleagues and does research (about 15-20 newly diagnosed children in Iceland per year)

Solrun -> works with children with idiopathic arthritis and also epilepsy

- Sample: all newly diagnosed children, all ages / 38 parents, mostly mothers
- FAM-SOTC -> therapeutic conversation
- Research on the effects on parents, children, families ...
- Cognitive and emotional support significant after the intervention
- Parents have more facilitating illness beliefs after the interventions (positive changes)
- Better quality of life for parents, better communication in the family

📖 L.M. Wright / M. Leahey: Nurses and Families. A Guide to Family Assessment and Intervention. 5th ed. 2009

• **Childhood cancer survivors - new follow-up clinic in Iceland**

Vigdís H. Viggósdóttir

- 10-12 children each year newly diagnosed, rising numbers of survivors
- several effects of cancer therapy
- research on late-effects of childhood cancer survivors, treatment from 1981 and later (there is a database in the hospital from then on)
- Survivorship passport (digital form in hospital, printed for the patients - in future possible for patients to log in from all over the world to their digital information)

• **Neonatal clinic - outpatient part of the NICU**

Rakel B. Jónsdóttir.

- ECMO care -> children are sent to Karolinska, Stockholm
- transport team is important because the country is large, there have to be transports to Sweden e.g. for heart surgery, Iceland is also responsible for Greenland.
- 99% of the mothers in Iceland breastfeed
- there is no breastmilk bank because of economic reasons
- in winter there is no possibility to go to parents who live in the southwest of Iceland because of weather conditions - if needed, the child must be admitted and the parents have to stay (in a hotel) in Reykjavik
- more children are discharged early, with feeding tubes and are cared for by the outpatient clinic. This decreases the stay in the NICU which is cost effective and the parents are happy with it
- private company for paediatric home care, rarely used for neonates, mostly for children with chronic conditions

K G., chair of the Paediatric workgroup of the Icelandic Nurses Association (PWINA) welcomed attendees to Reykjavik the previous day.

2. Apologies

Apologies FS discussed. The RCN sent a message (email) that was read for all attendees, because it had not been cascaded prior to the meeting:

“Dear all,

The RCN recognizes the work that the PNAE has been involved with to support and share work by paediatric nursing associations across Europe. From its inception, we have supported the group and Fiona Smith has actively contributed and co-ordinated the groups activity over many years.

We are currently reviewing our international work and alliances to ensure that we are appropriately representing our members in a wide variety of national and international forums. We are unable to continue to provide the level of resource to PNAE that we have for the last 10 years, but also believe that the current model is not sustainable in the long term nor does it facilitate success planning for the long term future of PNAE.

Going forward, we will continue to be represented at PNAE through member attendance and Fiona will continue to be the RCN’s point of contact for PNAE.

Kind regards,

Wendy Preston

RGN BSC(hons) MSc Pgcert HE

Head of Nursing Practice

Nursing Department,

Royal College of Nursing“

IHD suggested that the deputy coordinator of PNAE should respond. IHD will contact Corry van den Hoed-Heerschop on returning to the Netherlands. All attendees agreed. Corry will take necessary actions.

Attendees hope that Fiona Smith can attend the PNAE meeting in Athens as she is in the organizing committee for the PNAE congress. It will make it possible for the PNAE delegates to thank Fiona for the fantastic job she has done as coordinator for the past 15 years and for all she has achieved for the PNAE and paediatric nursing in Europe and beyond.

At the next meeting it will also be necessary to discuss how work can be organized going forward. Attendees were convinced that the PNAE network is crucial for the further development and enhancement of paediatric nursing in Europe.

It is still unclear if FS can still make the agenda for the next meeting.

Members suggest writing a resume of PNAE work to cascade with in their country. This is seen as an important lobbying mechanism for PNAE by the attendees. JC is willing to help with this.

3. Update of Paediatric Nursing in Iceland

KG highlighted the key issues affecting paediatric nursing and gave more information about the Landspítali University Hospital Barnspítali (Children’s hospital) and about the work of the Paediatric workgroup of the Icelandic Nurses Association (PWINA) (see attached presentation).

- Barnspítali in Reykjavik for capital region (finished in 2003, planned in the 90s)
- Charity for building a hospital founded in 1942
- Hospital has the first ward in 1957, major problem then was tuberculosis.
- 1975 hospital was opened
- Children are sent also to Sweden and the USA for treatment/surgery, e.g. cardiac disease, bone marrow/organ transplants
- Unit for chronically ill and handicapped children not located in hospital, but in other building

- Trauma center located in another building of the hospital with about 26 000 visits/year in emergency department and trauma center
- NICU since 1976 – day visits, e.g. come daily for administering antibiotics
- No PICU in Iceland. Children older than 3 months go to adult ICU, where they are taken care of by their paediatric nurses with ICU experience.
- Nurses and doctors who specialize must be trained abroad, mostly in Sweden
- Rjodur (6 beds near the coastline) -> rehabilitation, respite care (chronically ill and disabled children for respite. Stable children. Ventilation care etc. 24 hour care for up to a week) -> run by the hospital, initiated by paediatric nurses association, is taking “a load from the inpatient unit”, is also sort of hospice
- Home healthcare nursing -> 9 nurses, attending 20-30 each time
- Outpatient clinics, research presentations on the previous day all from this unit
- Sleep disturbances – nurse led clinic – published a book (“Sweet dreams”), translated to many languages (Arna Skuladottir)
- Paediatric palliative care workgroup – multi professional team, good and easy communication between hospital and home care

- Sometimes more nurses are needed on children’s wards. Nurses work 9 hour shifts Monday thru Fridays and 12 hour shifts during the weekends. Every 3rd week they work 1 weekend
- Children’s ward Akureyi (north eastern region of Iceland): has 6 inpatient beds and 440 admissions per year.

4. Matters arising from notes of meeting April 2017

4.1 Written update for website – All

Action:

- Request to respond to website update. Please respond urgently if you have not done so – **All**
- Key contact to cascade information, agendas and papers within their own country/Association as required – **All**

4.2 Workforce and recruitment - All

Agreed to place issue on the agenda regularly

Belgium:

s.th. going on about levels of nursing and differentiating functions, s.th. will change because of 4 years education.

Denmark:

No specialized education for paediatric nursing -> big problem, association took action concerning this issue politically – want post-graduate education (post bachelor degree).

Norway:

Paediatric nursing 3 semester course, implemented to university 5 years ago. Hospitals give students salary because they want the students back at the hospital. 2 years ago a national survey (questionnaire for hospitals) on nursing education showed the most needed group is paediatric nursing. More than 50% of the leading nurses want more paediatric nurses.

France:

Rebuilding education for paediatric nursing. They want a master degree for paediatric nursing. General nurses can by law do the same as specialized nurses. In 2010 the general education changed and there is no paediatrics within the new curriculum. After

change of government with a new minister, association work can possibly work on rebuilding the education.

Ireland:

Post-graduate and under-graduate education for children's nurses is available in Ireland. Overall national problem of retention of nurses. The brand new children's hospital in Ireland being commenced this year with a children's workforce planning group in progress.

Croatia:

Good education for general nurses (bachelor degree & master degree) but not for children's nurses – no post-graduate education in paediatric nursing.

Sweden:

One year specialist programme for paediatric nursing (master degree) - only 30% of nurses in hospitals are paediatric nurses. In the community are paediatric nurses.

Iceland:

No post-graduate programmes, only in NICU and PICU (abroad). All master degree programme if nurses want to.

Portugal:

General nurses all have practical (about 400 hrs) and theoretical part (about 300 hrs) on children within general nursing education. After two years of work experience in paediatrics nurses can go for the post-graduate programme for a master degree in paediatric nursing. Nurses have to finance the master education themselves and receive no financial benefit there after.

Czech Republic:

Bachelor level is general. They want to rebuild the paediatric nursing education. They want a 2 year post graduate specialized course where nurses work on paediatric ward. They also want a master degree in paediatric nursing – workforce shortage.

UK:

Changes in 2017, new guidelines, JC will cascade.

Germany:

Complicated situation. In 2020 a new law will be implemented. This entails the implementation of academic education and vocational training with a general part and special part. Several different certificates includes a bachelor degree. There's an overall workforce shortage in nursing, and places for education and an increasing, political demand for minimum nurse-patient ratio for all nurses. A minimum nurse-patient ratio for NICU's on different levels are requested by law. Otherwise beds are closed (with support from parent's association)

Netherlands

The government now requires that all children have be cared for by paediatric nurses. This includes paediatric nurses not only in hospitals but everywhere. (schools and at home for children with chronic conditions). This implementation asks for curriculum changes in postgraduate nursing education and extra education for earlier trained paediatric nurses. There is a master degree but this is not for specializing in paediatric nursing.

Action:

- To place workforce and recruitment on the agenda as a regular item – **FS**
- To consider review and update of nurse education for paediatric nursing position

across Europe in 2018.

4.3 Congress 1st and 2nd of June 2018 in Athens – VM (to join via Skype)

Skype meeting with Vasiliki Matziou and colleagues from Greece– (see presentation attached)

Results of the discussion:

- Greece has been in contact with all the invited speakers
- Main subjects on the round tables are defined, not all lectures are finished.
- Round tables “paediatric pain” and “neonatal care” will be put together with KdW and IHD.
- IHD will try to find and propose a speaker on paediatric pain.
- All attendees have visited the website and thank for the good work.
- All representatives have circulated the programme in their national networks.
- Greece hasn't got any numbers about registration at this moment.
- The website is open for abstract submission and registration.
- Some lack of communication between local committees and the PNAE members of the organizing and scientific committees. IHD suggests an improved plan of communication and abstract deadlines. Skype meetings of the committees are urgently needed.
- Discussion about possibly postponing the deadline in case there are not enough abstracts.
- - JC describes how she dealt with this in Glasgow. She gave an extension of one month.
- She also advises to use the criteria for abstracts that were cascaded by FS and were used in Glasgow and in Porto.
- There is no special registration for PNAE members. Only invited speakers, the organizing- and the scientific committee get special registration.
- IHD accentuates that the Greeks have to organize the PNAE meeting one day in advance of the conference. This is the 31st of May 2018. All needed information has to be sent to the PNAE members in due course.
- The planned trip to the islands the day after the conference is only one day. If attendees want to join they must stay one additional night in Athens after the tour.

Action

- Place information about accommodation on the congress website as soon as possible - **Congress organising company**
- PNAE representatives to promote the conference in their country and to highlight call for abstracts at periodic intervals – **all**
- PNAE representatives to advise VM of potential sources of sponsorship - **all**
- Send out regular updates to FS and those who register expressions of interest in receiving updates - **Congress organising company**

5. Palliative Care

Position statement discussed and agreed.

Action:

- Circulate position statement and covering letter to PNAE representatives – **FS**
- Translate and circulate to key stakeholders – **All**

6. Models of Child Health Appraised (MOCHA) project – Maria Brenner (MB)
(see attached presentation)

IHD thanked MB for coming to present the project with PNAE members.

MOCHA project includes 30 countries in Europe, 6.8 million Euro funded by EU, June 2015-Dec 2018. Principal investigator is Prof Mitch Blair. MB highlighted the aims and the work packages of the MOCHA project.

Central aim is to look at models of child health across the 30 countries to review the 'best' primary care model, to find the answer for the question: What would an ideal model look like?

MB is responsible for Work package 2 with focus on the interface between acute care and community care.

- non-experimental descriptive study with a qualitative element - a pragmatic and pluralist approach
- adapted standards (Lucy Packard Standards for systems of Care, Boston, USA) for survey
- 3 vignettes (case descriptions) used, different ages (across the lifespan), developed with experts, three conditions included (LTV, intractable epilepsy, traumatic brain injury)
- every country agent got the vignettes with a questionnaire
- 30 plus questions in the questionnaire, asked about service delivery and policy directions
- interviews with children and parents
- key facilitators and barriers to care integration

MB will send final report for comments from PNAE members

7. The health of child immigrants

See questions posed in previous meeting notes for discussion

Sweden:

Problems and discussion concerning unaccompanied minors – tests for age (x-ray ...) of the refugees – school nurses -> vaccinations – children are alone in hospitals, staff from shelters cannot come with them

Czech Republic:

Survey not necessary

Portugal:

No issue, children don't stay in Portugal

Iceland:

Few immigrants, don't come alone to hospital

Croatia:

No issue, children don't stay in Croatia

Ireland:

Few immigrants, survey not necessary

France:

Lots of immigrants, focus on answers that can be given to colleagues concerning the support of parents to focus more on their child, survey not necessary

Norway:
Survey not necessary

Denmark:
Survey not necessary

Belgium:
Survey not necessary – good care in a special situation, no special needs, “adapt what you have”

Netherlands:
Survey not necessary

Germany:
Survey not necessary

UK:
Survey not necessary

Attendees discussed a potential survey but did not identify the need. It was noted that nursing can adapt existing guidelines to ensure good care for immigrants / refugees.

Action:

- To consider review of the situation in future

8. Advanced Nursing Practice

IHD highlighted the situation:
Different countries, different systems and different roles. There is a need for very specific questions. FS sent suggestions prior to the meeting. Suggest including the role and education of “Physician assistants”.

Attendees gave a description of their national situation and discussed potential questions for a possible survey on the topic.

There is a need for a clear definition to be able to compare our systems. Language is complicated and the same role maybe named differently. There is to distinguish between qualification and role.

CNS = clinical nurse specialist
ANP = advanced nursing practice

Belgium:
At this time the situation is changing. Discussions are taking place.

Denmark:
CNS at Master degree level, don't have ANP, have special role for nurses called “Treatment nurses” with additional training to support medical physician (similar role like “Physician assistants”).

Norway:
Master degree level at many universities - Nurse specialist role.

France:

Want ANP on Master degree level for paediatric nurses. Are building the master degree at the moment. No financial remuneration for higher qualification, role and responsibilities.

Ireland:

ANP on Master degree level with defined roles (prescribing etc.). Community nursing also examined and likely remodeling. In difference CNS can be diploma level, e.g. diabetes in paediatrics.

Croatia:

No ANP, CNS (diploma level) helping the doctors.

Sweden:

No ANP, only a "specialist nurse" on master degree level. They do nursing research similar to ANP.

Iceland:

ANP.

Portugal:

No ANP system. They have clinical specialists but don't use this not name. No additional pay.

Czech Republic:

No ANP

UK:

ANP on master degree level, paid more for that. CNS: some have additional qualifications. Physician assistants are also developing. NMC now moving towards competencies (NMC review). Now moving towards more acceptance of 'advanced nursing' and levels. No additional payment. Clinical masters/PhD nurses also doing own clinical academic research.

Germany:

In paediatric nursing some ANP on master degree level, mostly in neonatal care and cancer care, needs to be extended. Do research, role is counselling and educating parents as well as colleagues Is not a physician assistant. Recently salary system is changed (by negotiations of the workers union) Higher qualification in nursing is recognized and from now on a higher post-graduate qualification is financially rewarded.

Netherlands:

ANP roles are set on international standards. Physician assistants are there but education is paid for by doctors. You don't have to be a nurse to become a physician assistant. Doctors decide what they will do.

There are many national differences, with government and policies changing. Following discussion it was decided to postpone a survey until next year.

Action:

- To place ANP on the agenda for 2018 and then to discuss and agree potential questions for future survey - **FS**

9. Potential for Pan European standards of care/evidence based protocols

Agenda item to be delayed until 2018 as there is a workgroup on this issue in Europe. See website EFCNI.

10. Safeguarding children and young people

Attendees discussed the terms “safeguarding” and “protection” and the need for a survey. The majority identified that a survey is necessary. Information is relevant on the following issues:

- Which models are used?
- Role of nurses?
- Qualification?
- National standards? Differences in standards?
- Evaluation? Reports on it?

📖 Royal College of Paediatrics and Child Health: Safeguarding children and young people: roles and competences for health care staff. INTERCOLLEGIATE DOCUMENT Third edition: March 2014

Action

- Draft questions and circulate for comment within deadline – **FL**
- Respond to suggestions – **all**
- Place topic on the agenda for the next meeting – **FL**

11. School Nursing

Prepare topic for discussion at next meeting– see notes from Athens 2015

Action

- To prepare questions for the next meeting – **SA**
- To place topic on the agenda for the next meeting - **FS**

12. Shared record keeping between nurses and families

IDO not present, therefore topic delayed until next meeting.

Action

- To place topic on the agenda for the next meeting – **FS**

13. Any other business

KdW (see document of an abstract cascaded by email shortly before the meeting and apologies for translation) presented a document of transmural (outpatient) care for children in Belgium. The author has a project on home care for children, made clear the problems and bottlenecks, set up a vision, referred to PNAE position statement community nursing 2017 and is looking for partners to support the document. KdW asked whether PNAE can support this vision and give logo from PNAE. Attendees supported the idea and most attendees agreed directly, with Sweden, Ireland and Germany agreeing after the meeting because they had not read it in time for the meeting.

Agenda items for next meeting

- “Who is documenting how and when with whom?” – **Denmark**

Action

- Place topic on the agenda for the next meeting – **FS**

Please note: if you suggest an agenda item, please give more information in advance. Set the scene and identify what you wish to discuss. This gives PNAE members a chance to prepare this topic for the meeting - **ALL**

Notification and responding to emails within requested timeline

IHD reminds everyone that FS asked for all PNAE representatives to keep to set timelines for responses and notifications. This because information is required by hosts well in advance to be able to plan and prepare.

Action

PNAE members to respond to requests, notifications and to return information within set timeline – **All**

14. Future meeting dates/venues and locations

- 31st May (meeting) and 1st and 2nd June (2 day congress) 2018 – **Athens, Greece**
- 18th and 19th October 2018 – **Prague, Czech Republic**
- Spring 2019 – **Madeira set dates asap**
- 17th and 18th October 2019 – **Zadar, Croatia**
- **TBC** Spring 2020 including 2 day congress - **Estonia set dates asap**
- **TBC** Autumn/Winter 2020 – **Belgium**

Ireland would like to host a meeting, when the new planned children's hospital is opened

Action:

- Discuss venues and dates of future meetings at each meeting - **All**
- Advise FS of attendance at the next meeting- **All**

Please advise FS if you are interested in hosting a meeting - all

PNAE meetings are held in different venues/countries to enable as many representatives from Paediatric Nursing Associations/National Nursing Associations to attend and participate in activities. We appreciate that financial implications of travel and accommodation may prevent several members from attending PNAE meetings. If your country has not yet attended a PNAE meeting but you would be interested in hosting a meeting in your Nursing Association/Country please contact Fiona Smith – **Fiona.smith@rcn.org.uk** ASAP

16.00 Meeting closed.

NOTE

- If documents are circulated with request for comment/agreement and no response is received it will be assumed that there is agreement.
- ***Please ensure receipt of emails is confirmed***