
Digitalisation of Healthcare - Ecosystem End-user Co-Creation

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European Federation
of Nurses Associations





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INTRODUCTION

2020 is a special year for the nurses and the nursing profession, since it is the “*Year of the Nurse and Midwife*”, in honour of the bicentenary of Florence Nightingale’s birth. On this occasion all over the world, this year will be dedicated to highlighting the tremendous work and contribution nurses and midwives can achieve at all levels if they have the support to do so.

At European level, the EFN, as Nursing Now European regional leadership group, focuses on Research & Innovation, particularly on the digitalisation of the healthcare sector. The need of patients and citizens to be able to access their health data is therefore high on nurses’ political agenda as part of designing people-centred care.

To deepen Europe’s innovation capability, Horizon Europe needs to keep the EU at the forefront of global research and innovation and will support European Partnerships to deliver on global challenges and industrial modernisation through concerted Research & Innovation effort with the EU Member States, private sector, foundations and other stakeholders. For the K4I community and partnership, the further negotiations until the adoption and the implementation of Horizon Europe, are of major concern.

In this context, and under the scope of Knowledge4Innovation 11th European Innovation Summit, which programme was closely linked to the work of the European Partnerships and Missions under the headings of ‘Digital Transformation’, ‘Greening’ and ‘Innovation’, the European Federation of Nurses Associations (EFN) and Nursing Now Europe organised this European Parliament event on digitalisation, with a special focus on the European Electronic Health Records, providing a state of art on two H2020 projects, Smart4Health and InteropEHRate,

developing formats for European Electronic Health Records in co-creation with the EFN, representing 3 million EU frontline nurses and end-users.

This meeting was an opportunity to exchange views with MEPs, the European Commission, civil society representatives and industry/SMEs, on the policies and steps to be undertaken to co-design the European Electronic Health Records, knowing that having a European Electronic Health Records’ exchange format is a growing priority of the EU Institutions, as pointed out in the Council Conclusions on Health in the Digital Society - making progress in data-driven innovation in the field of health (2017/C440/05) and the European Commission Recommendation on a European Electronic Health Record exchange format (C(2019)800).

In preparation for Horizon Europe, keeping the EU at the forefront of global research and innovation, European Partnerships are key to deliver on fit-for-purpose solutions, co-created with the end-user. Making sure the end-user is central to the design of the ‘Digital Transformation of the healthcare ecosystems’ becomes part of strengthening innovation ecosystems and making Horizon Europe a success.

Hope you enjoy reading this report.

Regards,



Paul De Raeve
EFN Secretary General



EXECUTIVE SUMMARY

The European Federation of Nurses Associations (EFN), the united voice of 3 million EU nurses and 6 million European nurses, organised on 5 February 2020 a high-level meeting at the European Parliament with two sessions – one in the afternoon, and a dinner-debate in the evening, to celebrate the hard work of nurses globally, under the scope of Nursing Now and Knowledge4Innovation 11th Summit, and within the context of the “2020 Year of the Nurse and Midwife”.

The afternoon session was a good opportunity to present the audience what the Nursing Now campaign is doing (of which the EFN is the European Lead), and to debate the health challenges we are currently facing, namely in terms of innovation. Invited as keynote speakers, MEP Maria Manuel Leitão reminded that Health is not an EU policy yet but should be soon, while MEP Nicolás González Casares, a politician who has more than 18 years of experience as an emergency nurse, explained that there are many health innovations that are based on data, reason for which we should advocate for a common European Data Space. Nevertheless, it is important to keep in mind that “*we can digitalise health data, but we cannot digitalise the human side of nursing*”.

For Thibaut Kleiner, European Commission’s DG Connect, one of the drivers of innovation is in fact budget – without money, innovation cannot be developed nor applied. Therefore, nurses and EU health stakeholders should focus on two upcoming EU research funds – Horizon Europe¹ and Digital Europe², with the latter programme focusing on upscaling and deploying research that is already out there, ensuring that it does have an impact for the end-user. Saila Rinne, European Commission senior policy officer, added that it is key to break down silos by pushing developers and researchers to ask the end-user what their needs are before starting to develop any

“Nursing is not only a European but a global force for good”

Elizabeth Adams, EFN President

“Nurses are at the frontline, together with patients, always enhancing patient’s trust. They play a central role in our healthcare systems. They should be empowered”

Juozas Olekas – MEP

innovation. MEP Maria da Graca Carvalho, also invited as keynote speaker, explained that one of the innovations of Horizon Europe, as opposed to H2020, is that it is more flexible and that it will be co-created and re-designed as it goes (it is designed to last seven years). Co-creation will go beyond the “Brussels bubble”.

When talking about innovation, we need to take into account digitalisation, and in specific ‘digitalisation of healthcare’ and nurses’ contribution as end-users to new tools such as Electronic Health Records. From a more practical point of view, Eva-Stina Slotte, Association of Finnish Local and Regional Affairs, gave the example of healthcare digitalisation in Finland, which is now an obligatory municipal strategy. Overall, the country is moving towards an integrated e-Government; a change motivated by the expectation it will reduce the administrative burden and improve patients’ satisfaction.

Invited to present the EU project he is coordinating, Smart4Health³, Ricardo Gonçalves, from UNINOVA, explained that the project is developing an online health platform together with a system of cross-operable Electronic Health Records that will “enable citizens to manage and bridge their own health data throughout the EU and beyond, advancing own and societal health and wellbeing”. In this context of Electronic Health Records, another similar H2020 EU project is being developed – InteropEHRate⁴. Marc Lange, from EHTEL and lead of the dissemination work package, gave an overview on the project and its latest developments. These presentations were followed by Marc

Taverner, INATBA’s CEO, who reinforced the importance of adding an extra layer of security to these developments by using blockchain ledger technology. Finally, Jacqueline Bowman-Busato, Policy Lead of the European Association for the Study of Obesity (EASO), highlighted the great

¹ https://ec.europa.eu/info/horizon-europe-next-research-and-innovation-framework-programme_en

² <https://ec.europa.eu/digital-single-market/en/news/digital-europe-programme-proposed-eu92-billion-funding-2021-2027>

³ <https://www.smart4health.eu/>

⁴ <https://www.interopehrate.eu/>

job these two projects are doing: fostering co-creation with end-users, to ensure right deployment and impact.

To close the session, Dame Donna Kinnair, EFN Executive Committee Member, reminded the key importance of nurses for the well-functioning of our healthcare systems and the wellbeing of citizens. All sessions were actively engaged by MEPs, Commission representatives of DG research and DG Connect, Industry/SMEs and Civil Society, all reinforcing the importance of fostering end-user co-design in digital health, especially the frontline nurses.

Following the afternoon session, the EFN organised a high-level dinner allowing MEPs, Commission Representatives, Industry/SMEs and Civil Society to continue debating on co-creation, digitalization, and healthcare innovation. This was an opportunity taken by the EFN Executive Committee Members present to share the latest EFN policy work on the digital agenda, the European pillar of social rights, quality/safety and workforce policy initiatives at EU level, and the importance of fostering nurses' end-user co-design in the EU policies. It became clear how successful nurses are in developing evidence-based EU policies, benefitting the people within the EU and Europe.

“Nursing is the finest profession on Earth. The planet is in need, and nurses can make a very valuable contribution to planetary health”

Roland Strauss – K4I Director

Anne Marie Rafferty, Founding Director of the European Nursing Research Foundation, then explained that when it comes to nurses co-designing, it brings the added value of developing human-centred tools and values into quality improvement approaches in healthcare organisations –

“Nursing save lives and nurses will save health systems!”. For Elizabeth Kuiper, EFPIA, the role of nurses is often overlooked. Nurses are the closest to the patients, and this is very important. We should further engage in the nursing profession when we talk about the transformation of healthcare systems. For Usman Khan, from the

European Patients' Forum, what nurses are good at is empowering others to engage in the political discussions, leading to policies that impact on the citizens we represent! Patients' trust in nurses is huge – and we should build on this trust!

The meeting was closed by Elizabeth Adams, who thanked everyone for their participation and encouraged all to not only celebrate 2020 as the Year of the Nurse and the Midwife, but think and act in the long-term, taking into account the nurses frontline voice in co-creation of policies, procedures, standards, tools, and whatever supports the citizens' health.



EFN & ENRF – United EU Nurses’ Voice

Europe is facing unprecedented challenges to guarantee sustainable and accessible healthcare solutions for its citizens. Research and Innovation is instrumental to upscale system level developments and engage frontline knowledge, understanding and know-how through Life-Long learning.

The EFN members welcome the progress made by the European Parliament and the EU Member States in defining the strategic priorities of the EU’s new framework programme for research & innovation ‘Horizon Europe’ and its aim to elevate research and innovation in the European Union. However, too much research and innovation are done in the “cloud”, hardly reaching frontline change. The key reason for this lack of deployment is the way end-users and stakeholders are engaged in co-creation and codesign. Whatever research topic, we tend to talk ‘about’ the challenge, and not ‘with’ the challenge. Horizon Europe’s focus on unleashing the potential of new tools, technologies and digital solutions in healthcare is key, but not without impactful end-user engagement. The nursing profession can contribute significantly to the areas of intervention laid out in existing and future EU research programmes.

Advanced application of health data and artificial intelligence in nursing care can support clinical decision-making by improving clinical pathways interpretation and enabling more effective care processes and outcomes. The nursing research and profession can successfully integrate innovative solutions and artificial intelligence into the discipline to offer interoperable and cost-effective solutions to healthcare

ecosystems to boost personalised healthcare. We believe that nursing care research, such as *‘missed nursing care’*, could be a strong driver to inform EU policies impacting European Citizens and as such accelerate integrated and person-centred approaches and improve the health outcomes. A comprehensive research agenda, considering external factors affecting people’s health, is central to developing targeted research for personalised approaches.

Policy and political discussion on the co-creation of a digital healthcare sector, with a diverse group of key stakeholders from different industry sectors, including MEPs, patient



representatives, policymakers, being fundamental principle of the Nursing Now Campaign to engage other stakeholders in a dialogue on nursing issues. The Horizon Europe Research agenda and the digitalisation of healthcare ecosystem are two important dialogue themes, between the IT designers, the end-users, and the legislators, the European Commission, the European Parliament and the Council of the European Union.

Considering forthcoming decisions defining research priorities in Europe, the EFN, together with the European Nursing Research Foundation⁵ (ENRF), is ready to substantially engage the end-users, the health stakeholders and industry, the EU Institutions and the EU Member States to shape Horizon Europe Excellence and Impact. Only through a partnership between all healthcare providers/professionals, academia and the Citizens/patient community, Europe can uphold the sustainability of healthcare systems and guide the transition to personalised and patient-centred healthcare.

⁵ <https://www.enrf.eu/>

Nursing Now!



Officially launched in London in February 2018, by the Duchess of Cambridge, Nursing

Now⁶, is a programme of the Burdett Trust for Nursing⁷, aiming at improving health by raising the status and profile of nursing globally and maximise the contribution that nursing makes to Universal Health Coverage, women's empowerment and economic development, and ensuring that everyone everywhere has access to health and healthcare. This three-year campaign, being run in collaboration with the International Council of Nurses⁸ and the World Health Organization⁹, is at European level led by the European Federation of Nurses Associations¹⁰.

Advocating that the biggest thing we can do to improve health globally is to empower nurses, representing half the health workforce of the world, its main focus points are specifically around advocating for policy changes to make sure nurses are central to achieving universal health coverage, developing primary health care, and tackling non-communicable diseases. The Campaign calls for investment in the development of nurse-led clinics; primary and community care; prevention, promotion and health literacy; midwifery, child health and adolescent services; and development of more advanced nurses inside and outside hospitals. Its activities are linked with the global health workforce strategy and the five-year Action Plan of the Commission on Health Employment and Economic Growth.

Within this context, the EFN has been appointed as the Nursing Now European regional leader of the Campaign.



EFN Members – EFN General Assembly, October 2018, Slovakia

The campaign strategic goal is to position nursing to optimise the potential to fully contribute and make a real difference to the health of the global population, to support nurse leaders within and across countries to translate the vision into reality, and to improve perceptions of nurses, enhance their influence and maximise their contributions to ensuring that everyone everywhere has access to health and healthcare. As such, the EFN will ensure to position nursing more central to health policy and ensure that nurses can use their skills, education and training to their full capacity.

By the end of 2020, Nursing Now ambition is to have:

- Greater investment in improving education, professional development, standards, regulation and employment conditions for nurses.
- Increased and improved dissemination of effective and innovative practice in nursing.
- Greater influence for nurses and midwives on global and national health policy, as part of broader efforts to ensure health workforces are more involved in decision-making.
- More nurses in leadership positions and more opportunities for development at all levels.
- More evidence for policy and decision makers about where nursing can have the greatest impact, what is stopping nurses from reaching their full potential and how to address these obstacles.



At European level, the EFN as Nursing Now European regional leadership group, will focus on nurses' support to the current political policy driver across Europe – European Pillar of Social Rights¹¹ – building on 20 key principles (with a focus on those principles that EFN Members have committed to), and structured around three categories: equal

⁶ <http://www.nursingnow.com/>

⁷ <http://www.btfm.org.uk/>

⁸ <http://www.icn.ch/>

⁹ <http://www.who.int/>

¹⁰ <http://www.efnweb.eu/>

¹¹ https://ec.europa.eu/commission/priorities/deeper-and-fairer-economic-and-monetary-union/european-pillar-social-rights/european-pillar-social-rights-20-principles_en

opportunities and access to the labour market; fair working conditions, social protection and inclusion.

Promoting the right to affordable long-term care services of good quality, in particular home-care and community-based services, has become a key priority for policy-makers and politicians, with the nursing profession co-designing policies guarantying timely access to affordable, preventive and curative health and social care of high quality. The need of patients and citizens to be able to access their health data is high on the political agenda, leading to the design of people-centred health and social care policies. It is time for the National and EU political leaders to enact concrete policies supporting 3 million EU nurses in Europe, and 6 million in Europe.



There is a great opportunity to make advances in nursing, but nurses¹² need to be ambitious and go beyond small changes: “start small, think big, go fast!” Furthermore, building on the Campaign the World Health Assembly¹³ in 2020 will be centred on Nursing, which represents an important policy opportunity.

The European Pillar of Social Rights in 20 principles

Chapter I: Equal opportunities and access to the labour market

1. Education, training and life-long learning
2. Gender equality
3. Equal opportunities
4. Active support to employment

Chapter II: Fair working conditions

5. Secure and adaptable employment
6. Wages
7. Information about employment conditions and protection in case of dismissals
8. Social dialogue and involvement of workers
9. Work-life balance
10. Healthy, safe and well-adapted work environment and data protection

Chapter III: Social protection and inclusion

11. Childcare and support to children good quality
12. Social protection
13. Unemployment benefits
14. Minimum income
15. Old age income and pensions
16. Health care
17. Inclusion of people with disabilities
18. Long-term care
19. Housing and assistance for the homeless
20. Access to essential services.

Further information is available at:

https://ec.europa.eu/commission/priorities/deeper-and-fairer-economic-and-monetary-union/european-pillar-social-rights/european-pillar-social-rights-20-principles_en



¹² <https://www.nursingnow.org/category/country-page/>

¹³ <http://www.who.int/media/centre/events/governance/wha/en/>

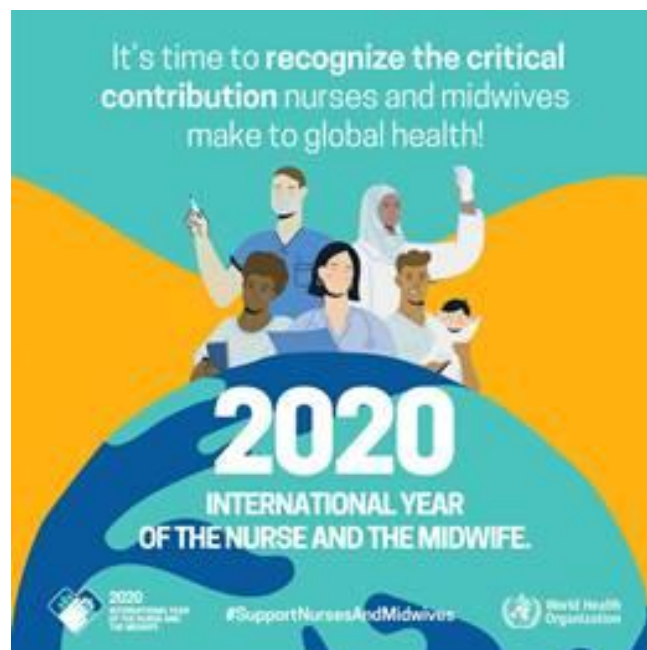
WHO Year of the Nurse and Midwife – Nurses Are The “Bridge” Of Healthcare

WHO has declared 2020 as the International Year of the Nurse and the Midwife¹⁴ to mark the bicentenary of the birth of the founder of modern nursing, Florence Nightingale and to recognize the critical contribution both professions make to global health. May is a key moment to catalyse high-level dialogue and collaborative engagements for moving forward the findings of The State of the World's Nursing Report, which will be launched on World Health Day, 7 April 2020, as part of the activities of the International Year of the Nurse and the Midwife.

Nurses and midwives play a vital role in providing health services. These are the people who devote their lives to caring for mothers and children; giving lifesaving immunizations and health advice; looking after older people and generally meeting everyday essential health needs. They are often, the first and only point of care in their communities. The world needs 9 million more nurses and midwives if it is to achieve universal health coverage by 2030. That's why the World Health Assembly has designated 2020 the International Year of the Nurse and the Midwife.

Join WHO and partners including, the International Confederation of Midwives (ICM), International Council of Nurses (ICN), Nursing Now and the United Nations Population Fund (UNFPA) in a year-long effort to celebrate the work of nurses and midwives, highlight the challenging conditions they often face, and advocate for increased investments in the nursing and midwifery workforce.

Dr. Ghebreyesus acknowledged that nurses are the "bridge" of healthcare, a crucial link between the people of the community and the complex healthcare system. Nurses are on the "frontlines" of healthcare, and because of this, they are the key factor in achieving universal health coverage, which is an initiative the WHO is spearheading for the sake of bringing adequate healthcare to humans across the globe.



¹⁴ <https://www.who.int/news-room/campaigns/year-of-the-nurse-and-the-midwife-2020>

Horizon Europe & the EU Digitalisation Agenda

A recent Communication¹⁵ from the European Commission on enabling the digital transformation of health and care in the Digital Single Market – empowering citizens and building a healthier society, is a key starting point for change.

The Commission's plan is to promote health, prevent and fight diseases, help respond to unmet patient needs and make it easier for citizens to have equal access to high-quality care through appropriate use of digital innovations and social economy.

Nurses engagement in the co-design of electronic health records (EHR), to make them fit-for-purpose, is key to move forward the ongoing digitalisation discussion. The need of patients and citizens to be able to access their own health data is becoming an important priority at EU level, however, it is central that such tools respond to real frontline needs and facilitate their daily work, allowing Healthcare Professions to spend more time frontline with the citizens/patients. As such, frontline nurses' input is crucial to develop EHR features able to smooth and boost continuity of care. Therefore, nurses need to be engaged in the co-development of EHR to ensure it responds to frontline and patients' needs.

It is important to remember that within the health and social care ecosystems, digitalisation needs to be viewed as a **supporting tool** and not the solution itself. Therefore, its integration needs to go hand in hand with changes in workflow and working methods, but also with the development of the e-capacity of health care professionals, informal carers and patients. The European Single Market and Digital agenda recognises the importance of upscaling the eSkills of providers and end-users to deliver high quality and safe services in the eHealth ecosystems in the EU and Europe.

Improving access to high quality and affordable long-term care services, in particular to preventive community-based actions, provided by a highly qualified and motivated

nursing workforce, is crucial to respond to the increasing unmet needs of citizens/patients.

One of the fundamental pillars to promote high quality healthcare is through a highly educated, dedicated and skilled nursing workforce. Specifically, the promotion of advanced roles for nurses is proven to boost quality, safety and cost-effectiveness of the healthcare delivered. These roles have made an enormous difference on the governance and management of healthcare, and improve efficiency, enhance patient care, improve health outcomes, contributing ultimately to the sustainability of health systems.



The most recent initiative of the European Commission, the 'White Paper on Artificial Intelligence (AI) – A European approach to excellence and trust'¹⁶, highlights the importance of creating a unique 'ecosystem of trust'. As rightly indicated, the use of AI systems can have a significant role in achieving the Sustainable Development Goals, and in supporting the democratic process and social rights. The Commission strongly supports a human-centric approach. Within this context, especially as end-users in the eco-systems, the

Digital Europe Programme, Horizon Europe as well as the European Structural and Investment Funds need to address the needs of the end-users.

Indeed, Europe needs a lighthouse centre of research, innovation and expertise that would coordinate efforts and be a world reference of excellence with the end-user central in the design and implementation. The involvement of social and civil society dialogue partners will be a crucial factor in ensuring that human-centred approach lead to change and social impact.

It is therefore key that coordinated action and end-user co-creation will need to guide EU digitalisation developments to make policies and IT solutions "fit-for-practice" in all EU Member States. The full potential of the EU EHR and AI will be exploited when different national systems of EHR become interoperable with each other, or when a cross-national EHR system gets implemented in the EU.

¹⁵ <https://ec.europa.eu/digital-single-market/en/news/communication-enabling-digital-transformation-health-and-care-digital-single-market-empowering>

¹⁶ https://ec.europa.eu/info/sites/info/files/commission-white-paper-artificial-intelligence-feb2020_en.pdf

The **InteropEHRate**¹⁷ H2020 project objective is to realise an open, standardized and unique European extended-EHR to preserve the European assets and professional ways of working, by addressing the current lack of standardization and security, defining a set of integrated protocols and conformance criteria for mobile apps, supporting secure and portable local storage and backup, released as open specifications.

The **Smart4Health**¹⁸ H2020 project is developing, testing and validating a platform prototype for a citizen-centred health record EU-EHR exchange. This will pave the way for the full deployment of citizen-centred solutions and services in a digital single market for wellbeing and healthcare, through an easy-to-use, secure, constantly accessible and portable health data and services prototype,

thus advancing citizens' health and wellbeing, and digital health innovation¹⁹.

It is key for the frontline nurses that a co-creation environment is the starting base for change. Innovation in health should empower patients and frontline nurses, moving towards an integrated care system based on proactive/empowered health-aware patient/citizen. We need to ensure that the IT tools, and the data revolution support and facilitate the shift towards a resilient health and social care ecosystem, and support nurses to deliver frontline high quality and safe care.

Therefore, it is key to build trust: citizen and patient' trust is a central concept in developing digital tools. Due to the close relation nurses have with citizens (prevention), the patients (care and cure), families and informal carers (informal care), nurses are ideally placed to make digitalisation trustfulness.



¹⁷ <https://www.interopehrate.eu/>

¹⁸ <https://www.smart4health.eu/>



¹⁹ Both EU projects, Smart4Health & InteropEHRate, have received funding from the European Union's Horizon 2020 research and innovation programme under the grant agreements: No. 826117 (Smart4Health) & No. 826106 (InteropEHRate).



Afternoon session

“European Electronic Health Records - Digitalisation in the Healthcare sector”

1st Panel – Welcome & Introduction



Paul De Raeve – EFN Secretary General

“Engaging end-users in a process of co-design is a must to ensure excellence and impact.”

The EFN Secretary General, Paul De Raeve, started the meeting by easing the audience into the big lines of healthcare innovation, namely the digitalisation of citizens’ health, and how digital co-creation process is changing the healthcare ecosystems.

He considers that for innovation to “succeed” in healthcare, engaging end-users in a process of co-design is a must to ensure excellence and impact. For him, co-design means engaging with the end-users, in our case with nurses, the largest healthcare professional group, during all the stages of the IT tool’s development – from its conceptualisation to its deployment and upscaling, going through all the end-user requirements design phases. End-user engagement is not running a consultation asking for approval after everything has been done – this is a misconception of co-creation that stakeholders should reject.

Co-creation is about placing everybody at the same level, with clearly assigned roles: end-users enunciating their thoughts and needs, and developers looking for the best and most accurate ways to accommodate these requirements.



He then introduced the Nursing Now Campaign²⁰ and the reason why all this event was taking place. Nursing Now is a three-year global campaign (2018–2020) aiming to improve health by raising the profile and status of nursing worldwide, of which the EFN is the European lead – Nursing Now Europe²¹. It is run in collaboration with the World Health Organization (WHO)²² and the International Council of Nurses²³. The campaign seeks to empower nurses to take their place at the heart of tackling 21st Century health challenges and maximize their contribution to achieving Universal Health Coverage.

The campaign focuses on five core areas:

- » ensuring that nurses and midwives have a more prominent voice in health policy making;
- » encouraging greater investment in the nursing workforce;
- » recruiting more nurses into leadership positions;
- » conducting research that helps determine where nurses can have the greatest impact; and,
- » sharing of best nursing practices.

²⁰ <https://www.nursingnow.org/>

²¹ https://www.efnweb.be/?page_id=10720

²² <https://www.who.int/>

²³ <https://www.icn.ch/>

This last year of the Campaign, 2020, was declared by WHO as the “*Year of the Nurse and the Midwife*” in honour of the 200th birth anniversary of Florence Nightingale (1820–1910), the mother of modern nursing. It is the first time in history that the WHO dedicates one year to celebrate one healthcare profession, a nurse!



Maria Manuel Leitão – MEP

Maria Manuel Leitão is a MEP (Committee on Internal Market and Consumer Protection) as well as the former Minister of the Presidency and of Administrative Modernisation in Portugal (2015–2019). She reminded that, unfortunately, “health” is NOT YET a European policy, such as others are. The role of the EU in healthcare is not as she thinks it should. However, she thinks this situation will soon change – or at least some aspects of it. Health, and more concretely health research, both need to be developed at the EU level – this is what EU citizens are demanding.

“Health is NOT YET a European policy, but this will soon change!”

She reminded the audience how at least cancer is getting higher and higher on the EU agenda – including discussions on future steps currently going on at the European Commission and at the European Parliament. In the latter, there is even a special group of MEPs who are devoted to discussing cancer and the policies around it.

Finally, she stressed that there is a need for improving health services to every European citizen. For that, it is important that all the knowledge gathered by Artificial Intelligence and Big Data are put to an optimal use that would benefit the patients and the broader population. She supports the European Commission ambition to create a common European data space. **Trust between patients and healthcare professionals needs to be enhanced even more. Nurses are key positioned for this, as they are the most trusted healthcare professionals of all!**



Nicolás González Casares – MEP

Nicolás González Casares is a newly elected MEP (Committee on Industry, Research and Energy) who has more than 18 years of experience as an emergency nurse in Spain, his country of origin. He was grateful for having been invited to the event organised by the EFN, which he considers timely as taking place in 2020: “*Year of the Nurse and the Midwife*”. He is a personal admirer of Florence Nightingale (also known as “the lady with the lamp”), being inspired by her work, believing that her work and life are still shaping the reality of the nursing profession today.

“Florence Nightingale – the lady with the lamp – her work and life are still shaping the reality of the nursing profession today”



She was the first nurse statistician because she was the first who started collecting patient’s health data to foster better health research and outcomes. We should take over her legacy by creating a common European data space, which is already being demanded by citizens, healthcare professionals, and public administrators. It would benefit innovation in healthcare and medicines development, hence ultimately benefiting all. Nicolás closed his intervention by saying that “*we can digitalise health data, but we cannot digitalise the human side of nursing*”.



Elizabeth Adams – EFN President

The EFN President started by saying that “*nursing is not only a European but a global force for good*” and introduced the EFN and her work within the organisation – advocacy on behalf of 3 million EU nurses. Elizabeth explained how a big part of her advocacy activities within the EFN is advocating for the full and right implementation of the European Pillar of Social Right across Europe, in the benefit of all EU nurses. The European Pillar of Social Rights²⁴ is more perceived as an EU “soft law” initiative focusing on delivering new and more effective rights for citizens. All these rights are enshrined in 20 key principles. Out of those, the EFN is working very actively on the principles related to education (no. 1), wages (no. 6), healthcare (no. 16) and long-term care (no. 18). All these touches upon the nursing profession and hence are of importance for the EFN’s advocacy work. Co-designing and then implementing frontline the European Pillar of Social Rights commission initiatives is dependent on nurses and midwife’s engagement, expertise and leadership.

All this work is carried out in parallel to other EFN political priorities – which are the digitalisation of healthcare, nurses’ end-user input to Electronic Health Records, and nurses as co-designers of new digital health tools.

“Nursing and Midwifery interventions make it possible to design a cost-effective health system responsive to needs of the population.”

Elizabeth explained how nurses are the largest group of health professionals – harnessing their full capacity offering the best possibility for transforming the healthcare ecosystem. Practise to their full scope will accelerate innovation and better-quality patient care and outcomes. Moreover, nursing and midwifery interventions make it

possible to design a cost-effective health system responsive to the real needs (unmet needs) of the population. She then mentioned the nurse/midwife-led models of care which are: optimising health, improving access to care, reducing pain and suffering, and saving the health system millions.

“Nurses and midwives are the backbone of every health system: in 2020 we’re calling on all countries to invest in nurses and midwives as part of their commitment to health for all.”

Dr Tedros Adhanom Ghebreyesus, WHO
Director-General 2020

She then referred to the Nursing Now Campaign, and the 2020 “Year of the Nurse and the Midwife”, celebrating the 200th anniversary of the birth of Florence Nightingale. To celebrate 2020 as the Year of the Nurse and the Midwife, the EFN members support the Nightingale Challenge, which aims to equip and empower the next generation of nurses and midwives as leaders, practitioners and advocates in health. This challenge asks every health employer around the world to provide leadership and development training for a group of their young nurses and midwives during 2020, aiming to have at least 1,000 employers accepting the Challenge, benefiting over 20,000 nurses and midwives aged 35 and under during 2020. As of today, 662 employers’ worldwide and 204 employers in Europe have subscribed to it. In total, it is benefiting more than 30.000 nurses.

Finally, Elizabeth explained that the EFN is the European Lead of the Nursing Now Campaign, the reason for which it is organising this European Parliament event, with EU stakeholders that are not so familiar with nurses and nursing.

Worldwide Statistics



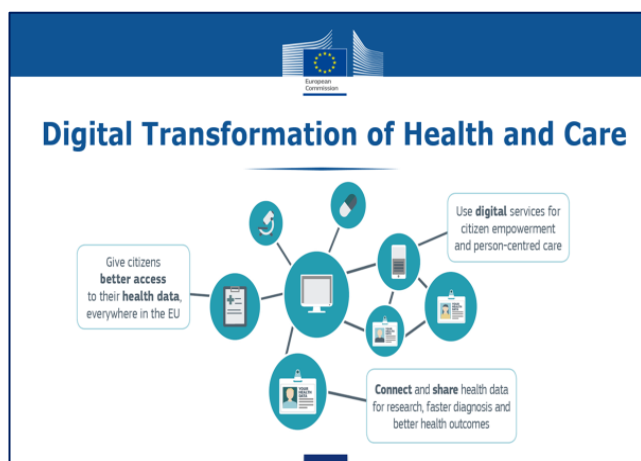
²⁴ https://ec.europa.eu/commission/priorities/deeper-and-fairer-economic-and-monetary-union/european-pillar-social-rights_en



Saira Rinne - European Commission

Saira Rinne is a senior policy officer the European Commission (DG Connect). She is very experienced on digitalisation and end-user co-design due to her high-level position within the institution. She is a firm believer that we should all break down silos by pushing developers and researchers to first go to the end-user and ask them what they need and then work on it, instead of only consulting them after the innovation has already been developed.

In this context, Saira was happy to share the European Commission's paper on the "Digital Transformation of Healthcare"²⁵, focussing on how to give EU citizens better access to their health data in the EU by using digital services that would empower them. It also advocates for person-centred care, fostering the use of shareable health data for research, enabling better diagnosis and better health outcomes.



In this context, efforts are being put in place by the EU Member States regarding the interoperability of Electronic Health Records²⁶ – something that is needed by the EU citizens, particularly by those living in cross-border regions and those who travel often. However, this is a daunting task – at national level, within each Member State, as well as at EU-level, across borders. A way of advancing interoperability would be a common European exchange format. In this regard, there is some important cross-cutting work going on, particularly on the sharing of health data.

Digital tools are already actively helping EU citizens to take care of their health data. And for healthcare professionals, these mean that they are much more precisely informed on the health of patients. All-in-all, this is contributing to the equal provision of healthcare within countries. There are many ways digital health tools can help fostering health equality and driving high-quality care, both within a country, as well as across European countries.

All these policies will be supported by the funding research programmes Digital Europe²⁷ and Horizon Europe²⁸.

Moreover, Horizon Europe will include a dedicated health cluster. Healthcare is a very important area in which to deploy digital innovation. We should contribute to the creation and development of the European Health Data Space.

The upcoming research fund Horizon Europe will aim at fostering Artificial Intelligence technologies as well as citizen's acceptance of these. She considers that we need highly focused, cost-effective and faster research.

Finally, when it comes to the Digital Europe programme, the main upcoming priority actions are about connecting health data, interoperability's infrastructure, etc. They also aim at building trust for innovation in digital health and care. It would also be important to have a network of digital health hubs.

²⁵ <https://ec.europa.eu/digital-single-market/en/european-policy-health>

²⁶ <https://ec.europa.eu/digital-single-market/en/exchange-electronic-health-records-across-eu>

²⁷ <https://ec.europa.eu/digital-single-market/en/news/digital-europe-programme-proposed-eu92-billion-funding-2021-2027>

²⁸ https://ec.europa.eu/info/horizon-europe-next-research-and-innovation-framework-programme_en



Thibaut Kleiner - European Commission

Thibaut Kleiner is head of Unit at the European Commission (DG Connect). His first thought was that to create innovation, also in healthcare, we need the end-users. Take as example the elderly's demands of being able to live longer at home supported by new technologies. For that to become a reality, we need to invest in new digital technologies, research, infrastructures, and frontline support, with nurses in advanced positions coordinating the complexity of care.

“To create innovation, also in healthcare, we need the end-users.”

He is concerned that we, stakeholders, are putting the focus on priorities that are important, yes, but not forward-looking. EU leaders, he believes, should put the focus where it matters for the end-user's future – and that is end-user engagement in digital programmes.

There will be opportunities for this in the upcoming research funds Horizon Europe and Digital Europe. Horizon Europe will be more open to the users of the research, through co-creation, that any other previous research fund. A greater focus will be given not only to the research areas but to their expected impact, the key performance indicators reflecting and responding to the end-user's unmet needs. The latter, Digital Europe, will not put the focus on financing new research but on upscaling and deploying research outcomes that are already out there.

Thibaut concluded by explaining that we need to listen to all stakeholders to achieve deployment solutions and cross-border impact. In a nutshell, we need the money, as well as a more holistic approach to where EU funding can ensure impact.



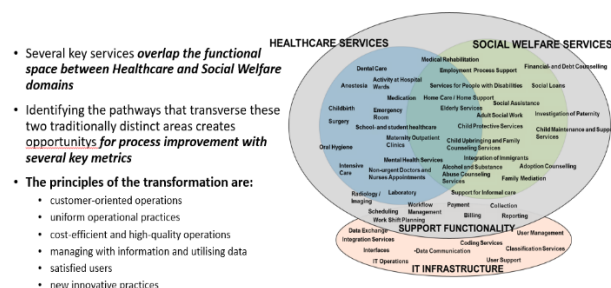
Eva-Stina Slotte - Association of Finnish Local and Regional Affairs

Eva-Stina Slotte, from the Association of Finnish Local and Regional Affairs, gave the local and regional perspective in co-creation. She talked about the healthcare digitalisation in Finland, which is now an obligatory municipal strategy. Finnish municipalities do not have to do this all alone, they can do it in cooperation or consortiums.

Overall, the whole country is moving towards an integrated e-Government. This change is motivated by the expectation it will reduce the administrative burden and improve patients' satisfaction.

Finnish authorities aim to provide equal health services across the whole of Finland. However, Finnish municipalities using different health management systems that do not “speak” to each other, all these have been integrated. Now they have a centralised data archive for citizen's health records and data. The new system contains e-prescriptions compatible with Croatia and Estonia's systems. The Electronic Health Record system available for patients, the electronic health record allows them to enter information on their health and wellbeing. Of course, the ongoing digitalisation of health in Finland is GDPR compliant.

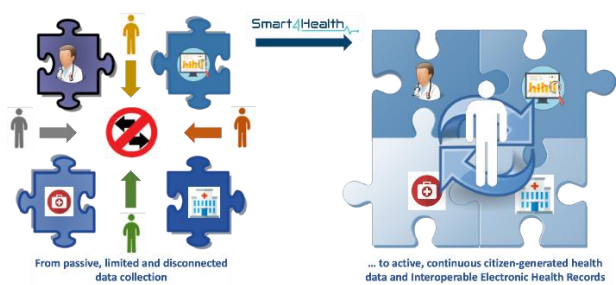
Apotti: Healthcare and Social Welfare



The main objective of the project is to prove three pillars:

- 1) citizen empowerment through co-creation;
- 2) provide a platform that can be interoperable for health data coming from different sources; and,
- 3) donating collected health data for research.

The expected impact of the project is to enable the citizen to use their own health data, and with whom to share it. The project relies on a true citizen-centred approach in which the user is involved at the different stages of the development. Users are adapted to each "Use Case" (i.e., the project scenarios) to ensure proper results.



Co-creation is a key part of the project. They want to use it for the citizen's engagement. End-users are being engaged in citizen discussion groups, individual citizen engagement exercises, and by collecting end-user input from some project partners, such as the EFN.

Smart4Health Co-creation process – Citizens engagement



Co-design is happening through eight CUCs (i.e., Citizen Use Cases) via diversified and adjusted engagement approaches specific to each citizen environment (Citizens from different EU countries and regions; Citizens with different working activities (e.g. nurses at hospital, workers

in industry); Citizen while at work; Citizens while performing daily life routines; Citizens traveling, on holidays, as a tourist). The impact expected coming out of this work is to make a difference for European citizens.

Smart4Health Citizen Use cases

Citizen engagement via Citizen Use Cases (CUC)

- Citizens from different EU countries and regions
- Citizens with different working activities (e.g. nurses at hospital, workers in industry)
- Citizen while at work
- Citizens while performing daily life routines
- Citizens traveling, on holidays, as a tourist



Smart4Health is funded by the European Commission under contract 101017011

Smart4Health

UNINOVA



Marc Lange – InteropEHRate Project

Marc Lange, Secretary General, EHTEL, and lead of the Dissemination Work Package of the InteropEHRate³¹ H2020 project, explained how both projects are working on different dimensions related to the EU Electronic Health Records (EHR), yet with the same objectives. Digital health will not succeed and will not be fully implemented unless it is done in co-creation with all stakeholders, in particular with the end-user.

The exchange of data, as part of electronic health records, normally happens with the authorisation of the patient but without its control. Moreover, this exchange is organised by a superior authority – namely governments or hospitals. The idea behind this project is to give data's control back to the citizens and patients, by empowering them.

³¹ InteropEHRate has received funding from the European Union's Horizon 2020 research and innovation programme under the grant agreement: No. 826106.

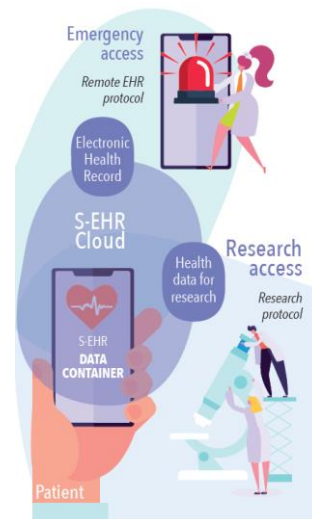
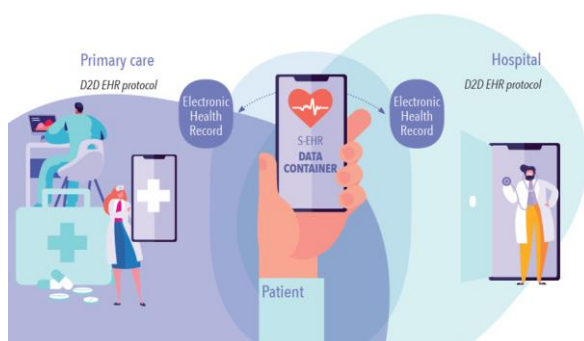


Hence, the InteropEHRate project will release an open specification to securely exchange health data using the InteropEHRate protocols between different persons' S-EHRs, and different applications of researchers and healthcare professionals of different countries.

The core functionalities of the project are:

- 1) patients are in control of all personal health data and can collect, see and share it with healthcare professionals, researchers or whoever they want;
- 2) people are hence mediators for health data exchange that can also be transferred privately and securely through device-to-device protocols;
- 3) the patient is not locked with one vendor and may change the S-EHR app or move data between cloud storages;
- 4) the S-EHR app and cloud vendors may be different;
- 5) the cloud storage can be used for emergencies, like a national EHR; and,
- 6) InteropEHRate will define vendor-independent protocols for direct communication with patients and vendor-independent criteria to be fulfilled by the apps and service providers for secure storage of health data on mobile and on cloud.

He then gave an overview on the three scenarios the project is working on: 1) device-to-device, 2) a patient in an emergency situation, and 3) donating data for research.



The end-users, namely healthcare professionals (in particular nurses and doctors) and patients, need to co-create with the developers of this EHR format to ensure that it delivers to their needs. Part of the co-creation, in this project, is testing the developed solution but also testing how it impacts the end-user organisation (i.e., the hospital).

In this context, we are all aiming at transforming/supporting the transformation of healthcare. To foster co-creation, focus groups are not enough – it should go beyond. Marc Lange considers that the digitalisation of healthcare will not succeed without businesses' engagement. The latter need to understand the added value of end-user engagement in co-creating new technologies and then deploy them frontline.



Jacqueline Bowman-Busato – EASO

“CO-CREATION = CO-OWNERSHIP”

For Jacqueline, EASO EU Policy Lead, “*co-creation is about building together, as equal partners*”. Hence, co-creation equals co-ownership. Co-creation is realistic in terms of actual and aspirational capacity to implement and take up.

She then explained that for her, co-creation is not a ‘One directional’ consultation where one party gathers others opinion, analyses and then produces a “push” solution. Co-creation means:

- ✓ Research methods that involve end-users in developing ideas and concepts for a community to implement (commercially or otherwise);
- ✓ A balance of actively engaging with the different stakeholders on an equal basis (facilitated by a trusted third-party);
- ✓ Identifying a shared value; and,
- ✓ Building the chosen solution (and related processes and ecosystem) around that shared value.

She concluded by stating that, ultimately, co-creation is not that difficult. It should be fun, establishing a shared value that meets the needs of everyone, and creating a pathway that engages all stakeholders and is piloted prior to major resource (re)allocation, building in the shared value and measurements for success from each stakeholder perspective.



Maria da Graça Carvalho – MEP

Even though professionally speaking Maria da Graça Carvalho does not come from the healthcare sector (being an engineer), she is very much into it. Being part of the European Parliament Committee on Industry, Research and Energy and K4I Forum Chair, she has special value and respect for the nursing profession.

She took this opportunity to ease the audience into the state of healthcare in her own country, Portugal, and on how it was improved by digitalisation. She also explained that she was a rapporteur of Horizon 2020 when they managed to increase the budget devoted to health in the programme.

As for the future, they are currently finalising Horizon Europe – they are waiting for the budget confirmation. They want to have a good budget for their next framework programme to finance all research fields, highlighting healthcare as one of the important ones.

One of the innovations of Horizon Europe, as opposed to H2020, is that it is more flexible and that it will be co-created and re-designed as it goes (it is designed to last seven years). Co-creation will go beyond the “Brussels bubble”.

There is plenty of work upcoming for the MEPs as regards to digitalisation, which she considers will have a very big and positive impact in healthcare.



Dame Donna Kinnair – EFN Executive Committee Member and Chief Executive and General Secretary of the Royal College of Nursing

Donna Kinnair closed the afternoon session. In a few lines, she summarised all key-messages and main take-aways expressed by all the speakers.

She reminded all the stakeholders present on the key importance of nurses for the well-functioning of our healthcare systems and the wellbeing of citizens. Their role should be supported and empowered by all – hence making the Nursing Now Campaign aims and goals so timely for the profession. She also stressed the importance of commemorating the “WHO 2020 Year of the Nurse and the Midwife”, to celebrate nurses’ contribution to our societies.

She finally shared some insights on the digitalisation of healthcare, the topic being discussed at this event, and on how nurses are natural innovators ready to take on board new technologies that decrease their workload and improve patient care.





Evening Session – Dinner Debate

“Nursing Now! Digitalisation in the Healthcare sector: end-user co-design”



Yves Mengal – EFN Executive Committee Member

Yves Mengal, from the Fédération Nationale des Infirmières de Belgique (FNIB) and EFN Executive Committee Member, thanked Olivier Chastel (MEP) for facilitating access to the European Parliament meeting room and in making this event and dinner a success. He confessed how he is proud to be a nurse and engaged with the participants on singing “*proud to be a nurse*”.



Juozas Olekas – MEP

Juozas Olekas, part of the European Parliament Committee on Agriculture and Rural Development, reminded how nurses are at the frontline, together with patients, always enhancing patient’s trust. They play a central role in our healthcare systems and should be empowered.



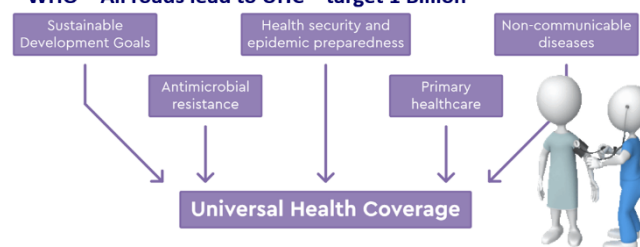
Elizabeth Adams – EFN President

Elizabeth Adams, EFN President, picked up on the ideas said during the afternoon session, relating to the Nursing Now Campaign and the 2020 “WHO Year of the Nurse and the Midwife” and explained that she believes it is quite significant that the WHO has, at last, declared a year dedicated to one profession: NURSING!

Being an admirer of the work and legacy of Florence Nightingale, she continued emphasising the policy drivers guiding digitalisation in healthcare: political, societal, and professional drivers.

She then took all the stakeholders present into a journey of the Nursing Now Campaign and all it is aiming to achieve, explaining that there will be a global shortfall of 18 million health workers by 2030 (nursing and midwifery account for 9 million), and that for Dr Tedros Adhanom Ghebreyesus, WHO Director-General, “*Governments must see jobs for nurses and midwives not as cost but as an investment in sustainable development*”. In conclusion, all roads of innovation must lead to achieving Universal Health Coverage³².

WHO – All roads lead to UHC – target 1 Billion



³² <https://www.who.int/health-topics/universal-health-coverage>

The Nursing Now Campaign is a 3-year global campaign a programme of the Burdett Trust, co-chaired by Lord Nigel Crips with a global Board and Patron Princess of Cambridge. Its vision is to improve health globally by raising the profile and status of nurses and midwives worldwide, as well as influencing policymakers and supporting nurses and midwives to lead, learn and build a global movement.

The campaign aims to:

1. Influence UHC, NCD and other policy;
2. promote and develop nurse and midwife leaders;
3. disseminate effective practice;
4. create, identify and share evidence of impact; and,
5. invest in all aspects of nursing and midwifery.

There are 24 million nurses and midwives globally – half the professional health workforce, with nursing being the largest professional group with direct contact with patients/citizens. Elisabeth Adams believes we need to enable nurses and midwives to work to their full potential and engage them as end-user co-designers. This will improve access to health and deliver health policies with the triple impact of improving health, promote gender equity, and strengthen global economies.



Healthcare is changing fast and so should the workforce. To tackle that, we all need to demonstrate that the profession of nursing and midwifery are exciting and rewarding careers. Furthermore, healthcare systems around the world are facing great change and there are great opportunities for innovation. Innovation is only achieved if it delivers value for the user. Decisions taken to collaborate with end users will influence the future successful implementation and the care delivered to patients and communities.

Therefore, it is imperative that nurses and midwives are constructively involved in **co-creation of innovative solutions** that will future shape of health care in the current environment. They are in pole position to give **voice** to the **quality principle** and **lead** the development of new models of care.

“It is not the strongest of the species that survive, nor the most intelligent, but the one most responsive to change”, Charles Darwin



Roland Strauss – K4I Director

Roland Strauss, Knowledge4Innovation Director, explained that he considers nursing to be the finest profession on Earth. For him, nursing is *“about helping people who suffer and those who are in need”*. He reminded the audience that the planet is in need, and that nurses can make a very valuable contribution to planetary health.

Nursing is about helping those who suffer and those who are in need”



Anne Marie Rafferty – ENRF Founding Director

Anne Marie Rafferty, ENRF Founding Director, started her intervention by thanking the EU institutions for funding EU projects of which nursing researchers and nursing professionals can benefit from.

She then talked with passion and detail about Florence Nightingale. She presented her as a nurse researcher and a great innovator. In Florence’s words, *“nurses need to multiply themselves!”*. She was interested in many fields of life, and ultimately that led her to be a statistician too – she was even a designer of new data systems.

When it comes to nurses co-designing, she stated that it brings the added value of developing human-centred tools and values into quality improvement approaches in healthcare organisations.

For her “*nursing save lives and nurses will save health systems*”. However, she regrets that there is an estimated 18 to 19 million nurses’ shortage in the world.

EFN Executive Committee Members

The Members of the EFN’s Executive Committee introduced their areas of work within EFN and political priorities linked to Education, Workforce, Quality & Safety.



Nina Hahtela, EFN Vice-President and Chair of the Professional Committee explained the EFN’s work on the areas of education (Directive 2013/55/EU, Annexe V, and safeguarding principle of Mutual Recognition of Professional Qualifications) and nurses’ access to lifelong learning activities.

Aristides Chorattas, Chair of EFN’s Workforce Committee, explained how his committee is working on topics affecting the nursing practice (e.g. nursing competencies, skills, and wages), as well as some other areas that are expected to grow in importance in the present and nearer future (e.g., nursing shortages, the gender issue, the ageing workforce, nurses’ working conditions).



Jana Gelatiková, Chair of EFN’s Public Policy Committee, eased the audience into the big lines of her committee’s work: antimicrobial resistance, value-based healthcare, long-term care, the digitalisation of health, the European Semester’ Country

Reports, and the European Pillar of Social Rights.

Phil Ni Sheaghda, EFN Executive Committee Member concluded that the highest trusted profession is nursing and that “*We need sufficient and safe nursing staffing at all levels*”.



Elizabeth Kuiper – EFPIA

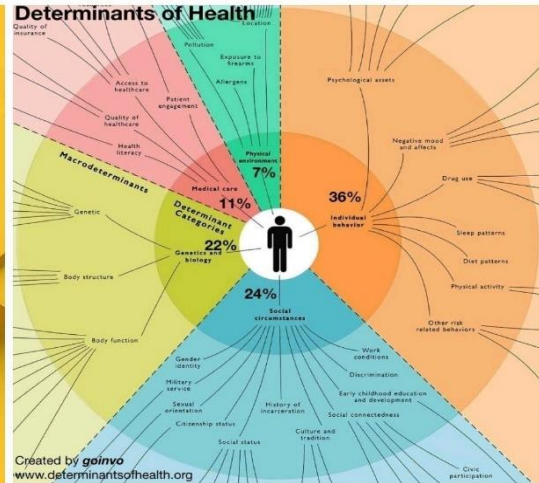
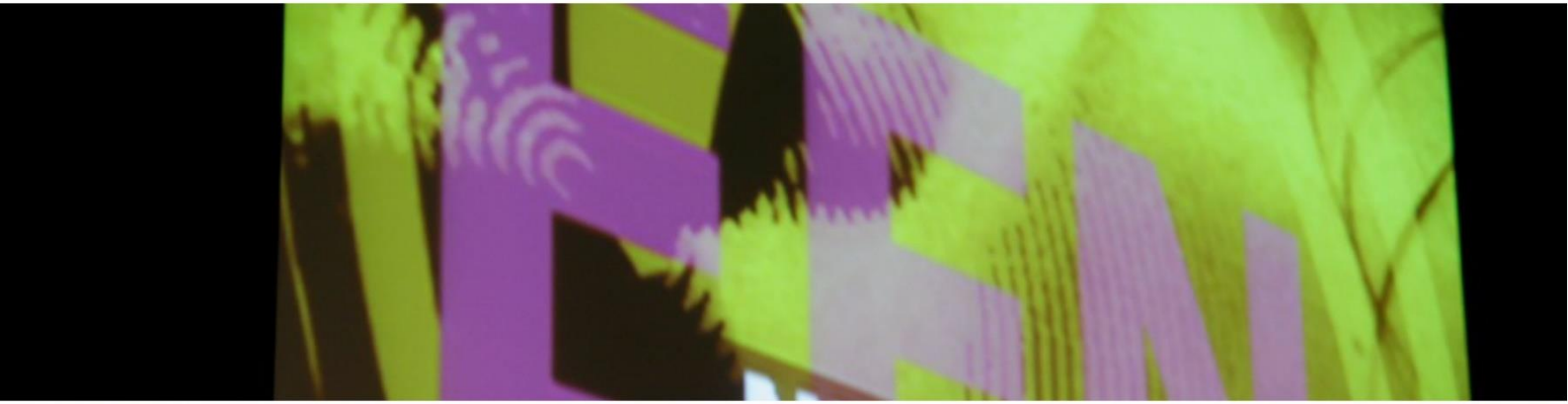
Elizabeth Kuiper, EFPIA Public Affairs Executive Director, feels that the role of nurses is often overlooked. Nurses are the closest to the patients, and this is very important. We should further engage in the nursing profession when we talk about the transformation of healthcare systems. We should also include nurses as co-designers in projects financed by the Innovative Medicines Initiative (IMI) – a very important research fund that must engage with the nursing profession. Finally, the nursing profession should be included in the Healthcare Coalition.



Usman Khan – EPF

Usman Khan (EPF) expressed his personal admiration for the EFN and its team, that despite of consisting only on a few people, is capable of achieving a big impact and gathering plenty of stakeholders from different backgrounds and nationalities in one room to discuss nurses’ contribution to healthcare systems. In the same vein, he said that the event organised by the EFN in the European Parliament was, for many of the attendees, their introduction into the so-called “*European bubble*”, that is, the world surrounding the EU institutions and their daily activities.

This is what nurses are good at: empowering others to engage in the political discussions, leading to policies that impact on the citizens we represent, nurses for EFN and patients for EPF. Usman continued saying that there is “*almost a magical relationship with the patients and the nurses*”. Patients’ trust in nurses is huge – and we should build on this trust!



Stakeholder engagement and end-user's co-creation are two concepts in the same equation of social impact! A distinction is drawn between participation and engagement. The relatively ineffective nature of participation in meetings, committees and focus groups as tool and policy design methodologies remain the prerogative of the policy actors who may, or may not, take account of the views advanced by stakeholders through the numerous participation mechanisms. Instead, stakeholder engagement as a concept goes beyond participation because co-decision, ensuring that consensus must be achieved during the development phase of the co-creation process.

Engagement in the co-creation space is to build public understanding of a value-driven policy/tool in which the design becomes influenced by the public interests at play and the trade-offs implicit in any governmental decision. And that is where nurses and nursing come in!

Nurses are natural healthcare innovators and are at the frontline of care, ready to upscale new digital health tools for the benefit of patients, and ready to teach them on how to use them.

Therefore, it is central SMEs, Industry, researchers, policymakers and politicians engage nurses in the co-creation of any supportive tools/policy as end-users. Nurses input must be considered by developers to better respond to the needs (unmet needs) of the citizens/patients/healthcare providers. Nurses work towards the continuity of communication and information at all levels to provide holistic and integrated care for European cancer patients based on their needs.

For the upcoming Horizon Europe Framework Programme for Research and Innovation to succeed, it is key that the researchers and the technical partners engage with the end-user, not just as advisors, but as co-designers of processes and outcomes. Fostering end-user engagement and co-creation are key criteria of impact, reflected in the Key Performance Indicators (KPI). We need to move from 'endless promises' to 'deployment and impact'. Nurses are in a position in the EU to support frontline European scaling-up for impact and change.

“Nurses are natural healthcare innovators and are at the frontline of care, ready to upscale new digital health tools for the benefit of patients”

WHO defines scaling-up as “(...) *deliberate efforts to increase the impact of health service innovations successfully tested in pilot or experimental projects so as to benefit more people and to foster policy and programme development on a lasting basis*”

Aimed at testing/scaling up the feasibility and usefulness of a specific activity/solutions, the testing/scaling up are used to try out different approaches/solutions, develop evidence-based strategies, identify good practices, and provide frontline guidance for the benefit of possible future innovations in the healthcare ecosystems.

As such, there are different dimensions to be taken into account when scaling-up and, although different, they are all interrelated. Having the experience of frontline testing/upscaling, deployment strategies and site visits, peer reviews, namely within the context of the EU legislation and projects, the EFN and ENRF believe that these are very important to evaluate the state of implementation of the solution from a user's/end-user's point of view, and provide a qualitative evaluation and feedback on their state of development and involvement of users/end-users.

The EFN and ENRF are EU umbrella organisation, providing substantial contribution to EU projects by bringing the nurses' views and expertise in: making the IT solution fit-for-purpose; identifying, assessing, and bringing in good practices examples; and making sure that the interests and needs of all end-users, patients, citizens, nurses, other healthcare and social professionals involved in care and ICT, are properly taken into account when designing the project.

Building requirements for evaluations into policies from the start, and defining their objectives clearly, will improve the usefulness of evaluation and facilitate planning. This can be done through mapping, impact assessment, and conduction of case studies. The nurses' views in the entire process will be the highest in identifying elements that can be effective for building the project outcomes/deliverables.

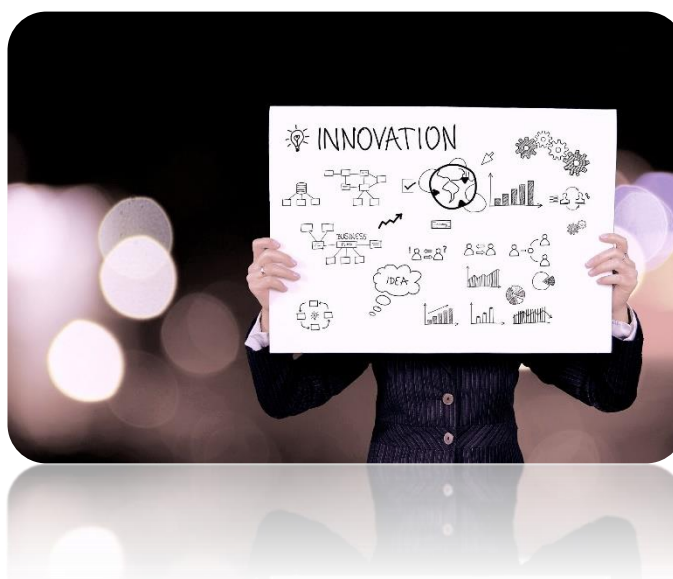
Finally, the EFN and ENRF believe that the expected impact relies on boosting deployment of digital solutions throughout EU and beyond, through uptake by the network members but also the memberships of the involved stakeholders. If the project establishes appropriate methodologies for development and uptake of the deliverable(s) and ensures a good dissemination and publication to inform end-users and public policy design, based on the results gathered and through the support of the aiming at securing continuity and sustainability, then the project will achieve a wide awareness of its results, and bring momentum to start discussing within EU countries and governments, and use the experiences and expertise gathered for the benefit of implementing actions in the EU Member States.

“Unless we are making progress in our nursing every year, every month, every week, take my word for it we are going back”, Florence Nightingale

The EFN and ENRF have Digitalisation high on its professional and research agenda, and acknowledge that frontline nurses and nurse researchers must remain a part of this initiative as emerging healthcare challenges such as the ageing population, chronic diseases, staff shortages, increasing healthcare expectations and rising healthcare costs are driving the demands for a more efficient, accessible, high-quality and affordable healthcare.

In relation to the healthcare digitalisation, the main role of the EFN and ENRF within the consortium is to promote an EU added value by combining data, infrastructure and expertise. Nurses and nurse researchers can contribute to address three key elements of the current transformation of health ecosystems: building trust, promoting user-centre innovation and ensuring an appropriate use of data to enable technology.

The uptake of digital solutions in healthcare is strongly connected to the implementation of the EU General Data Protection Regulation (GDPR) setting out the requirements in the use of data in terms of portability and access, important both for patients and for the healthcare professionals that have to use the data for service delivery, for continuity of care. The GDPR needs to increase patients' trust, and the EFN and ENRF can be a facilitator towards this interpretation as nurses play a crucial role in building that trust.







Digital Health

Nanobots
 3-D Printing
 Robotics
 Handheld Ultrasound
 Ultrasound-Chip Array
 Ingestible Sensors
 Implantable Sensors
 Telemedicine
 Mobile Clinics
 Virtual Reality
 Activity Tracking
 Wearable Devices
 Short Messaging Service
 Smartphone-Device
 Smartphone Microscopy
 Smart Tattoo
 Organ-on-a-Chip
 Lab-on-a-Chip
 Microfluidics

Electronic Medical Records

Data Visualization
 Ridge Regression
 Natural Language Processing
 Artificial Intelligence
 Machine Learning
 Brain-Computer Interface
 Bioinformatics
 Learning Health System
 Open Online Medicine
 Patient Generated Data
 Blockchain
 DNA Storage
 Phenotypic Clustering
 Social Media
 Knowledge Banks
 Crowdsourcing

Big Data

Precision Health

Exposome
 Microbiome
 Epigenome
 Proteome
 Metabolome
 Circadian Rhythm

Optogenetics
 Pharmacogenetics
 Epigenetics

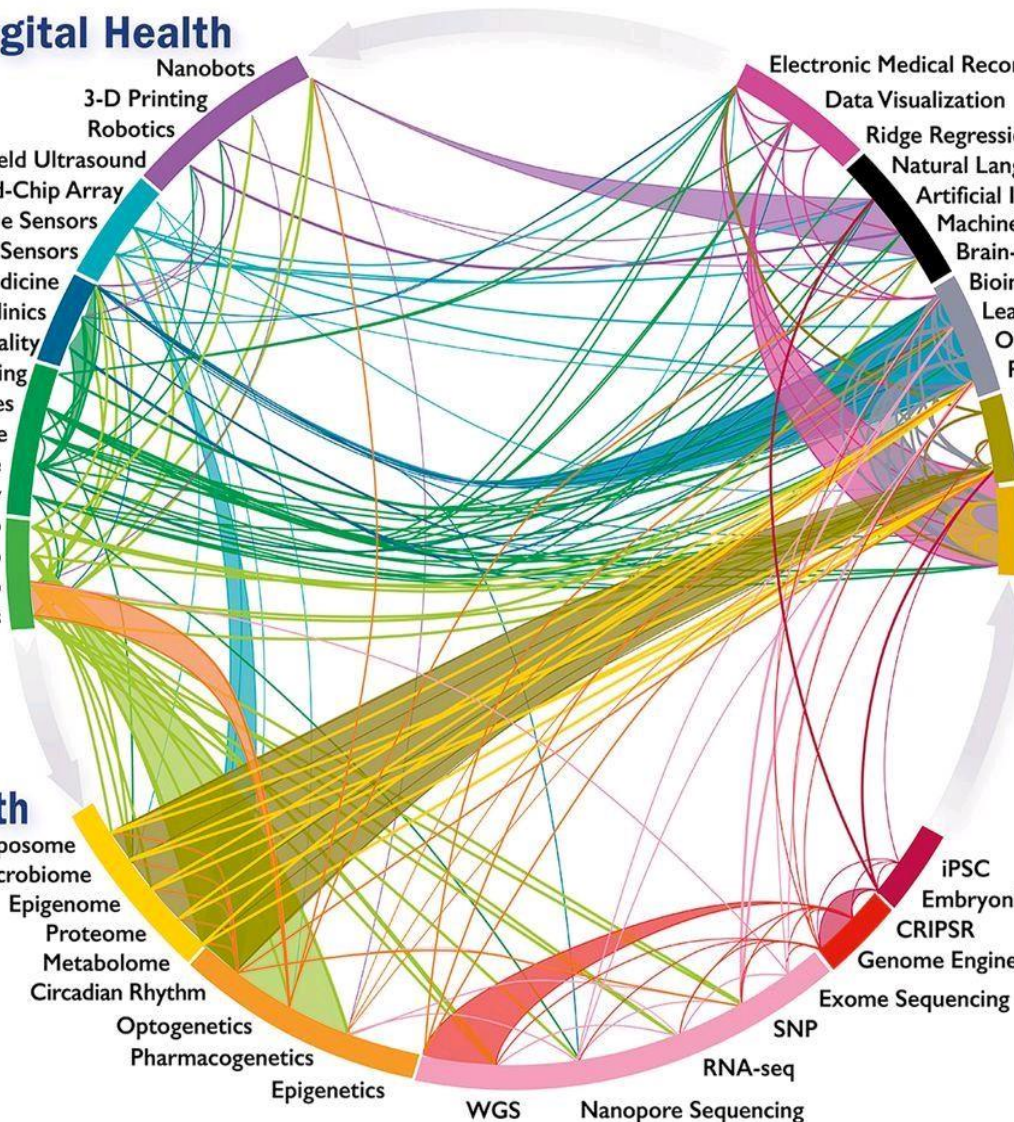
WGS

Nanopore Sequencing

RNA-seq

Exome Sequencing

iPSC
 Embryonic-Structural Variants
 CRISPR
 Genome Engineering



ANNEXE I – SPEAKERS DETAILS



Paul De Raeve (Moderator)

- ❖ European Federation of Nurses Associations
- ❖ Secretary General

BIOGRAPHY

Paul De Raeve was graduated as registered nurse in 1984, he obtained a Master's Degree in Nursing Science at the Free University of Brussels in 1989, and a Master degree in Statistics from the Catholic University of Brussels in 1996. In 2014, Paul got his Doctoral Degree at the Kings College University of London. In 2002, Paul De Raeve was appointed as General Secretary of the European Federation of Nurses Associations (EFN). The EFN Secretary General was appointed by the EFN members as Secretary General of the European Nursing Research Foundation (ENRF), making sure EU policy design and research evidence go hand in hand.



Maria da Graça Cavalho

- ❖ European Parliament
- ❖ MEP (Portuguese)

BIOGRAPHY

MEP Maria da Graça Carvalho is Portuguese, she has served in the European Parliament since 2019. Her political ideas lead her to the Socialist-Democratic Party at national level. She is now a member of the European People's Party (Christian Democrats) in the European Parliament. She is currently taking part of the Committee on Industry, Research and Energy.



Elizabeth Adams

- ❖ EFN President and Nursing Now Board Member
- ❖ European Federation of Nurses Associations

BIOGRAPHY

Elizabeth Adams is President of the European Federation of Nurse Associations representing 3 million nurses across Europe. She is a Board Member of the Global Campaign Nursing Now. She is Adjunct Associate Professor with Curtin University of Technology, Western Australia, Honorary Fellow Faculty of Nursing and Midwifery Royal College of Surgeons Ireland, Adjunct Faculty, Dublin City University and a Fellow of the American Academy of Nursing. In her previous post she was Director of Professional Development with the Irish Nurses and Midwives Organisation. Prior to this, as the Consultant, Nursing and Health Policy with the International Council of Nurses, Geneva, Switzerland she developed programme areas related to socio-economic welfare, occupational health and safety, positive practice environments, violence, human resources development, international migration, leadership, older person care, environmental issues and disaster nursing. She was the Director of the International Centre of Human Resources for Nursing and Director of the International Positive Practice Environments Campaign. She also served as national Director of Nursing and Midwifery, HSE in Ireland. This role included leading and implementing nurse and midwife prescribing nationally. Over her nursing career she has worked for both the Department of Health in Ireland and Western Australia. In her time at the Department in Western Australia she helped to manage significant health reform and was instrumental in establishing the nurse practitioner role in the State.



Maria Manuel Leitão Marques

- ❖ European Parliament
- ❖ MEP (Portuguese)

BIOGRAPHY

MEP Maria Manuel Leitão Marques is a Portuguese politician of the Socialist Party who has been serving as Member of the European Parliament since 2019. She previously served as Minister of the Presidency and of Administrative Modernisation since 26 November 2015. From 2015 until 2019, she represented the Viseu constituency in the Assembly of the Republic. Marques was the Secretary of State for the Administrative Modernization under the XVIII and XVII Constitutional Government of Portugal. In the 2019 European elections, Leitão Marques ran on the list of Prime Minister António Costa's Socialist Party. She has since been serving as vice chair of the Committee on the Internal Market and Consumer Protection.



Saila Rinne

- ❖ European Commission
- ❖ Head of Sector (DG Connect)

BIOGRAPHY

Saila Rinne currently works at the Directorate-General for Communications Networks, Content and Technology (DG CONNECT) of the European Commission. She is the Head of Sector for policy in the unit “eHealth, Well-Being and Ageing”. This unit’s main mission is to support innovative digital health solutions and services that foster the delivery of high quality and efficient health and care services and products and enable the empowerment of citizens in managing their own health. Saila has previously worked on the research and innovation activities of the Data Policy and Innovation unit in DG CONNECT and as a translator and terminologist in DG Translation of the Commission.



Thibaut Kleiner

- ❖ European Commission
- ❖ Head of Unit (DG Connect)

BIOGRAPHY

Thibaut Kleiner is heading Unit E1 – Network Technologies – in the Directorate-General Communications Networks, Content and Technology (DG Connect) at the European Commission. This unit is in charge of Research & Innovation in the area of wireless optical networks, network architectures, Internet of Things, Satcom and manages the 5G-PPP. Kleiner has worked for the European Commission since 2001, occupying a number of positions, notably in the field of competition policy, where he was head of unit in charge of coordination, and member of Cabinet of Neelie Kroes in her previous mandate, where he notably supervised state aid (including during the banking crisis). He holds a Master from HEC Paris and a PhD from the London School of Economics.



Eva-Stina Slotte

- ❖ The association of Finnish Local and Regional Affairs
- ❖ EU Affairs Adviser

BIOGRAPHY

EU Affairs Adviser with a focus on Digitalization questions and a special interest for regional and local affairs. Working for the Association of Finnish Local and Regional Affairs since 2010. In Brussels since 2018.



Ricardo Luis Rosa Jardim Gonçalves

- ❖ UNINOVA – Instituto de Desenvolvimento Novas Tecnologias
- ❖ Full Professor

BIOGRAPHY

Ricardo Jardim-Goncalves holds a PhD degree and received his habilitation (Agregação) in Industrial Information Systems by the NOVA University of Lisbon (UNL). He is Full Professor at the New University of Lisbon, School of Sciences and Technology, and a Principal Investigator at UNINOVA – Instituto de Desenvolvimento de Novas Tecnologias. He has graduated in Computer Science, with MSc in Operational Research and Systems Engineering. His research activities have been focused on Interoperability of Complex Systems. He has been researching in European Commission funded projects during the last 30 years, with more than 250 papers published in conferences, journals and books. He coordinates the GRIS (GRupo para a investigação em Interoperabilidade de Sistemas; Group for Research in Interoperability of Systems) at UNINOVA (Instituto para o Desenvolvimento de Novas Tecnologias), CTS (Centro para as Tecnologias e Sistemas). He has a relevant standardization activity acting as member of the Planning and Policy Committee and project leader in ISO TC184/SC4.



Marc Lange

- ❖ European Health Telematics Association (EHTEL)
- ❖ Secretary General

BIOGRAPHY

Marc Lange has a 15+ years' experience in Digital Health as Secretary General of EHTEL, the one multi-stakeholder organisation within Europe that brings together organisations and individuals engaged in all aspects of eHealth. With EHTEL, Marc's mission is to enable the exchange of ideas and information leading to innovation in the delivery of eHealth solutions and the transformation of health and social care. EHTEL facilitates indeed interactions and sharing of knowledge among stakeholder groups. The association acts as a neutral forum, not as a lobbying group. Marc has 25+ experience in Project/Programme Management of international/European projects in social security, eID and eHealth. His experience covers domains such as (1) facilitating sharing good practices in a multi-disciplinary environment, (2) observing, analysing and synthesizing the progresses of this knowledge sharing process (3) contributing to policy definition for deploying innovative ICT services for the health care sector in particular and (4) supporting EU Member States and the European Commission in coordinating the deployment of their national projects.



Marc Taverner

- ❖ INATBA
- ❖ Executive Director

BIOGRAPHY

Marc Taverner brings 18 years of experience working with market leading, global technology companies in Bitfury. He is also the founder of a successful modem distribution company. Marc has held sales leadership roles with many leading technology companies, including the world's largest provider of unified communications services and market leaders in educational technology solutions. Marc received his BA Hons in European Business Studies from Brunel University, UK and Ecole supérieure de Commerce de Clermont-Ferrand, France.



Jacqueline Bowman-Busato

- ❖ European Association for the Study of Obesity
- ❖ EU Policy Lead

BIOGRAPHY

Jacqueline Bowman is a seasoned and entrepreneurial professional who cares passionately about making health ecosystems people-driven. Most recently, she is founder of Third-i, an innovative group of policy stakeholder engagement specialists based in the EU quarter of Brussels and London. Jacqueline brings over 20 years' healthcare & life sciences policy-driven advocacy, stakeholder engagement and strategic alliance-building experience to the table. Jacqueline Holds an LLB Hons (English Law & French Law), a Post graduate diploma in Strategic Communications and an MBA from the Vlerick Business School. She is Guyanese (South America)-born, British English mother tongue and also speaks French fluently with a passive knowledge of Flemish.



Dame Donna Kinnair

- ❖ Royal College of Nurses & EFN Executive Committee Member
- ❖ Secretary General RCN

BIOGRAPHY

Dame Professor Donna Kinnair is a British nurse and has been Chief Executive and General Secretary of the Royal College of Nursing since August 2018. She has specialised in child protection, providing leadership in major hospital trusts in London, teaching, and advising on legal and governmental committees. Prior to joining the RCN, Donna held various roles, including Clinical Director of Emergency Medicine at Barking, Havering and Redbridge University Hospitals Trust; Executive Director of Nursing, Southeast London Cluster Board; Director of Commissioning, London Borough of Southwark & Southwark PCT. She was the Strategic Commissioner for Lambeth, Southwark and Lewisham Health Authority's Children's Services.



Yves Mengal

- ❖ Fédération Nationale des Infirmières de Belgique (FNIB) & EFN Executive Committee Member
- ❖ Vice-President FNIB & Former President AUVB

BIOGRAPHY

Clinical nurse, teacher and professor in nursing, nursing education, and health care institutions management, both at Bachelor in Nursing, Head Nurse levels (Higher Nursing School of Charleroi and Brussels) and Master level in Public Health - Nursing orientation at University of Brussels - School of Public Health and Adjunct General Director and Administrative Director of the University Public Hospital of Charleroi (Belgium), Yves Mengal was President of the Belgian National Federation of Nurses (FNIB) for 14 years, and President of the General Union of Belgian Nurses (UGIB-AUVB) for two years. He is now the Treasurer of EFN.



Juozas Olekas

- ❖ European Parliament
- ❖ MEP (Lithuanian)

BIOGRAPHY

MEP Juozas Olekas is a Lithuanian politician of the Socialist and Democrat Party who has been serving as Member of the European Parliament since 2019. He is now a member of the Group of the

Progressive Alliance of Socialists and Democrats in the European Parliament in the European Parliament. He is currently part of the Agriculture and Rural Development Committee.



Roland Strauss

- ❖ Knowledge4Innovation
- ❖ Co-founder and Managing Director

BIOGRAPHY

Thought Leader on the future of innovation in Europe. Main areas of expertise are at the intersection of science, technology, research, Innovation, data economy and EU policies and funding programmes.

Co-founder and Managing Director Knowledge4Innovation: the platform brings together innovation leaders from the private, public and academic sectors. Since 2009 the K4I Forum is hosting the annual European Innovation Summit in the European Parliament. Startup entrepreneur – IncubatorEurope: The main objective of IncubatorEurope is to bring Europe's knowledge and ideas to work. Turning knowledge into economic power to the benefit of society, creating solutions that solve urgent problems in areas such as health, food, environment, energy etc. is at the centre of our activities.



Anne Marie Rafferty

- ❖ European Nursing Research Foundation (ENRF)
- ❖ Founding Director

BIOGRAPHY

Anne Marie Rafferty is Professor of Nursing Policy, former Dean of the Florence Nightingale Faculty of Nursing and Midwifery, King's College London and currently the President of the Royal College of Nursing. She is a historian, health workforce and policy researcher, graduating from Edinburgh University in social science (Nursing Studies); as a clinical academic, Nottingham University MPhil (Surgery). She was the first nurse to gain a doctorate (DPhil Modern History) from Oxford University.

She is one of first nurses to be elected to the Fellowship of the Academy of Medical Sciences (FmedSci) & holds fellowships from the Royal College of Nursing, (FRCN) & American Academy of Nursing (FAAN). She was made Commander of the British Empire (CBE) by Her Majesty the Queen for services to healthcare in 2008. She served on the Prime Minister's Commission on the Future of Nursing and Midwifery, 2009-10 and been recipient of various awards; Nursing Times Leadership Award (2014); Health Services Journal Top 100 Clinical Leaders Award in 2015; 2017 nominated as one of 70 most influential nurses in the 70 years of the National Health Service. She was inducted onto the Sigma Theta Tau International Hall of Fame for Research in 2016 and elected Founding Director, European Nursing Research Foundation in 2020



Nina Hahtela

- ❖ Finnish Nurses Association
- ❖ EFN Executive Committee Member

BIOGRAPHY

Finnish Nurses Association President, Nina Hahtela is a Doctor of Health Sciences. Her doctoral thesis dealt with the workplace culture of health care and its relationship to nursing outcomes. Nina has works at the FNA since 2007, most recently as the organisation's health policy and development director. Prior to this she worked as a nurse and head nurse at the HUS Children's Hospital.



Aristides Chorattas

- ❖ Cyprus Nurses Midwives Association
- ❖ EFN Executive Committee Member

BIOGRAPHY

Aristides Chorattas RGN, Dip.N.A., BSc Cancer Nursing, MA Management Health Care Units, PhD(c) Home Care Nursing and Oncology Nursing. Aris is a Registered Nurse since 1992. He has worked in various fields and currently is in charge of an Oncology Unit in Cyprus. He has also served as a teacher in Nursing in a Private University in Cyprus and a clinical instructor and teacher in Nursing and Midwifery school in Cyprus. He is the Secretary of the National Nursing Association of Cyprus (Cyprus Nurses and Midwives-CYNMA) since 2012 and a member of the Executive Committee of the European Federation of Nurses Associations (EFN). He is the official delegate of his association to the International Council of Nurses and the President of the Accreditation Committee of CYNMA. He participated in the legislation formation at Ministerial Level for developing Community Nursing legislation (mainly Home Care Nursing) in Cyprus. He is currently participating in the negotiation processes between CYNMA and Cyprus' H.I.O. for establishing activities that the H.I.O. will include for Home Care Nursing coverage for the general population of the country.



Jana Gelatiková

- ❖ Slovak Chamber of Nurses and Midwives
- ❖ EFN Executive Committee Member

BIOGRAPHY

Jana Gelatiková is leading the heads of Regional Centres of Continuing Education in individual self-governing regions:

- Establishing collaboration with companies interested in organizing continuous education activities for nurses and midwives, ensuring and coordinating cooperation
- Creation of statements and opinions on the performance of the healthcare profession nurse and midwife, on the continuous education of nurses and midwives
- Professional counselling for the performance of the healthcare profession nurse and midwife,
- Commenting on legislative documents
- Lecturing to nursing students and midwifery
- Member of the working group on the preparation of projects for continuing education nurses and midwives in Slovak Chamber of Nurses and Midwives
- Active participation in conferences in the Slovak Republic and abroad – Lectures, Publishing activity
- Communication with foreign nurses associations (European Nurses Federation, ICN, ..) and partner organizations
- Work load head of Regional Center of Continuing Education in Žilinský self-governing region: Entering and processing of activities of continuous education in electronic system, Allocation of credits to activities of continuous education, Organization of activities of continuous education, Assessment of level of activities of continuous education – supervision, Communication with organizers of activities of continuous education, Work with valid legislative documents of the SR



Phil Ni Sheaghda

- ❖ Irish Nurses and Midwives Organisation
- ❖ EFN Executive Committee Member

BIOGRAPHY

Qualified as a General Nurse in 1988, she completed specialist qualification in Intensive Care Nursing and worked in nursing in Ireland, the UK, Australia and the USA. She was then appointed as Industrial Relations Officer with the Irish Nurses and Midwives Organisation in January 1998 and was promoted to Director of Industrial Relations in 2007. Phil is currently the General Secretary of the Irish Nurses and Midwives Organisation. She has spent the past twenty years representing the rights and entitlements of

nurses and midwives to: a fair wage, safe working conditions, correct staffing levels, a positive work/life balance, independence in practice and access to education.



Elizabeth Kuiper

- ❖ EFPIA
- ❖ Executive Director Public Affairs

BIOGRAPHY

Elizabeth Kuiper is currently Director for European Affairs at EFPIA, the European Federation of Pharmaceutical Industries and Associations. In this role, she leads the advocacy and public affairs of EFPIA and maintains a strong network of contacts with policymakers and other stakeholders. She reports directly to EFPIA's Director-General and works together closely with the other EFPIA directors active on the Brussels scene. Elizabeth previously worked as attaché at the Permanent Representation of the Netherlands to the EU, where she represented the Netherlands in EU negotiations in the field of health, pharmaceuticals and medical devices. Prior to this, Elizabeth worked as political adviser to the Minister of Health, Welfare and Sports in the Dutch cabinet Balkenende-IV, delivering special advice and support on healthcare policy related subjects. This was subsequent to her job at the Dutch Society of Surgeons. Elizabeth studied at the University of Utrecht and holds an MA in Dutch language and literature.



Usman Khan

- ❖ European Patient's Forum
- ❖ Executive Director

BIOGRAPHY

Usman Khan is the Executive Director of the European Patient's Forum. The European Patients Forum represents the interests of 150 million patients across Europe. As Executive Director, he works with President and Board to represent EPF across Europe. He leads a Secretariat Team of policy analysts, communications experts, researchers and project managers and build connections and alliances across our Membership and network. Besides that, he also holds an academic position at New York University (London). He completed his PhD in Public Policy at Sheffield University in 1990.



ANNEXE II - INTERVIEWS

To view the interviews from the following people, done during the EFN High level event in the European Parliament, on 5 February 2020, please follow this link: <https://bit.ly/33uVa48>



Paul De Raeve, Secretary General, European Federation of Nurses Associations



Virgilio Cruz-Machado, Dean, UNINOVA - Universidade NOVA de Lisboa



Anne Marie Rafferty, Founding Director, European Nursing Research Foundation (ENRF)



Nina Hahtela, EFN Vice-President



Ricardo Luis Rosa Jardim Goncalves, Full Professor, UNINOVA – Instituto de Desenvolvimento Novas Tecnologias



Mario Barile, Business Developer, Engenharia Informatica



Yves Mengal, EFN Executive Committee Member



Elizabeth Adams, EFN President and Nursing Now Board Member



Izabella Uchmanowicz, Director, European Nursing Research Foundation (ENRF)



Marcel Smeets, Director, OIZ



Guy Doumeingts, General Manager, INTEROP-VLab



Marc Taverner, Executive Director, INATBA



The European Federation of Nurses Associations (EFN) was established in 1971 to represent the nursing profession and its interests to the European Institutions, based on the nursing education and free movement Directives being drafted by the European Commission then. Representing 3 million nurses over 36 National Nurses Associations at European level, the EFN is the independent voice of the nursing profession.

The EFN provides a broad platform for developing health and social EU policy by supporting the European Union decision making process on all areas which affect the nursing profession. The EFN is strong on working towards a unified voice for nursing in the EU, promoting the value of nursing and strengthening the relationships between National Nursing Associations, specialist nurses and other health care professionals.

The EFN aims to bring to the attention of the EU the current and potential collaboration of nurses and nursing to meeting the health needs of the population throughout the Union.



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