

SPECIAL FEATURE:
COVID-19 & INFECTION CONTROL

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## Innovation in care

How can genomic sequencing enhance the treatment of rare diseases?



Dr Paul De Raeve, General Secretary of the European Federation of Nurses Associations, explores how the COVID-19 outbreak has highlighted the need for a European Health Union

ealth policy' is a concept covering all aspects of healthcare provision, including the delivery of healthcare to the population; the regulation of health professionals; the protection of public health; and health promotion. The concept of a unified EUwide health policy has not always been an obvious one: instead, it has been developing over time as EU health crises emerged on the political agenda.

However, the ongoing COVID-19 outbreak has greatly impacted the EU political debate as the virus heavily impacted EU citizens' life. The EU was not prepared at first, and a solidarity network among Member States on equipment – including PPE, masks, and ventilators – and human resources (nurses and doctors) came into operation when the crisis had already hit many Member States hard. Although the 2013 Ebola crisis had already alerted EU politicians that 'we are not prepared unless we are all prepared', we

now find ourselves in a situation of 'non-preparedness and each country doing its own thing'. All politicians and policymakers, together with key health stakeholders, now need to learn together from this crisis and reflect on how we can be better prepared for the next pandemic. All EU health stakeholders need to move towards the best co-ordination solution for EU citizens and be better prepared. A holistic and altruistic approach to EU Health Policy design is key for future preparedness within the EU.

## The state of play of healthcare policy in the EU

The biggest development in EU Health policy design occurred with the Treaty of Lisbon (2010), which granted additional powers to the EU in relation to public health. Article 168 of the Treaty of Lisbon<sup>1</sup> adds that the Union shall in particular encourage co-operation between the Member States to improve the complementarity of their

health services in cross-border areas. Most of the EU's public health advancements today are justified by the existence of this article. Thus, the EU can only adopt health legislation within the limitations of protecting public health (ibid., art. 168), approximation of laws (ibid., art. 114) or social policy (ibid., art. 153).

The principles of conferral (arts. 4 and 5, Treaty on European Union [TEU]) and subsidiarity (Article 5, TEU) make it impossible for the EU to develop a consistent, effective and efficient healthcare co-ordination policy and a healthcare ecosystem on an EU-wide level. However, Article 14 (eHealth) of Directive 2011/24/EU of the European Parliament and of the Council of 9 March 2011 on the application of patients' rights in crossborder healthcare does not deal with the essence of the problem, which is the EU's healthcare ecosystem fragmentation.

The EU's 'Decision No 1082/2013/EU' on serious cross-border threats to health does not solve the core issue, because the EU still must respect Member States' autonomy in operating their own health systems — even during global pandemics. Hence, now is the time for the Member States to reflect on what role the EU should play during healthcare crises and focus on the boundaries of the current European treaties. It is unacceptable for EU citizens that still, in the year 2020, the subsidiarity principle



is hindering their protection from and preparedness for COVID-19 due to the EU's inability to act as a union, tackling the crisis at the European level, instead of taking 'country-by-country' actions. As Europe begins to explore the political, legal and financial tools to construct a European Health Union, including an embedded European Health Research Programme, with the ambition of making the European healthcare ecosystems work together holistically, the Commission, the EU Member States and the European Parliament could convince EU citizens of the rationale for developing a better Health Union.

## Subsidiarity and EU co-ordination

The EU institutions can and must play a role to serve as a platform to co-ordinate emerging healthcare crisis at the European level. Co-operation between Member States towards protecting and promoting public health is a key driver for EU health policies.

The COVID-19 outbreak has proved the need of a holistic and integrated approach that goes beyond the above-mentioned Directives and the subsidiarity principle. EU countries must not be left acting alone in an unco-ordinated manner. In turn, this means that the way the EU institutions understand their work together with the Member States need to be turned around. For example, looking at that the European Semester Country

reports and recommendation, the European Commission should reflect on what it needs to cocreate to support Member States with a well-functioning co-ordination mechanism to save lives and provide economic stability to the European Union. This latter point will be looked in more depth in the following section.

## The European Semester Country Reports: the need for a co-creation approach

The COVID-19 outbreak has resulted in a situation in which national Governments are taking different decisions (on PPE, on masks protocols, on lockdowns, etc), depending on varying expert epidemiological advice. On the other side of the spectrum, EU citizens expected and demanded clarity and co-ordination on the rules and decisions taken.

Moreover, the COVID-19 outbreak occurred in a context in which most EU healthcare systems were already under heavy pressure due to already existing challenges: the rise in life expectancy, the ageing population, the growing number of people living with co-morbidities and chronic diseases, etc. Some already existing structural weaknesses — as outlined in the different Country Reports of the European Semester — have now deepened. The aftermath of the economic crisis of 2008, which negatively influenced health workforce-related policies and recruitment, has shown that Europe's healthcare systems need to be

strengthened to be better prepared to future possible scenarios such as the current pandemic. Therefore, it is helpful looking back at the 2016-2020 European Commission's Country Reports, identifying the underlying themes that could help co-designing the European Health Union.

#### Prevention and primary care

The logic behind prevention is simple: one does not have to treat or cure what can be prevented. Hence, prevention is the most cost-effective healthcare action one can advocate for. Throughout the Country Reports, the European Commission points towards prevention as the way forward together with fostering primary care. However, advocating for prevention requires a strong shift in the way healthcare is provided across many EU countries. It would require that healthcare budgets are shifted away from hospital care towards primary care models.

Those countries whose healthcare systems perform well are those with strong primary care systems. Primary care has many strengths as opposed to hospital/inpatient care. First and foremost, it can be provided at 'simpler' and less demanding healthcare facilities that can be closer to citizens. This is particularly useful for those countries in which the population may be spread across large rural areas, where significant regional differences between the largest populated cities and rural areas occur. As outlined

in the Country Reports, the optimal implementation goes by shifting away from the traditional medical-oriented model of organising care, supported by a strong primary care network of community care nurses, having an alleviation for the hospital sector.

## Hospital and inpatient care

Hospital and inpatient care are more expensive, requires more complex and expensive facilities, and can only be provided at high technology facilities, which normally are present in big urban areas, or close to them, where the concertation of the population is higher. Traditional models of healthcare have greatly focused on diagnosis, cure and treatment, not on preparedness, nor prevention and primary. The EU healthcare ecosystem should free up space in hospitals, fostering other means of care such as primary care, home care and/or long term care.

### Long term care

In the context of ageing populations, most EU Member States lack strong and well-functioning long-term care systems for the elderly and the people who need it. Long term care systems are necessary for taking care of people who are now too old to be able to be fully self-sufficient, and to do so with the maximum human dignity possible. As of now, most long term care is provided at home by family members (mainly women), providing care at their own expense, with no remuneration. However, as the population is ageing, EU Member States are starting to develop and implement long term care systems to alleviate the situation. Deficiencies in long term care systems have been exacerbated by the COVID-19 crisis.

### Workforce

Sufficient and safe workforce staffing levels are key for the right functioning of healthcare ecosystems. The Country Reports indicate that those countries with worse scoring health indicators are also those where shortages of healthcare professionals persist. When shortages occur, these tend to be more acute for the nursing profession. Workforce shortages lead to many problems which can only be solved with policies that empower the health workforce. As outlined in the Country Reports, there are a number of reasons accounting for workforce shortages. Namely insufficient, poor working conditions, wrong retention measures, as seen by the high number of nurses leaving the profession across many countries, or simply insufficient funding in the system, making frontline staff redundant. In the context of the ongoing COVID-19 crisis, workforce shortages have become more significant than ever before. Several EU countries have introduced emergency measures such as hiring back retired healthcare professionals or introducing student nurses as assistants. Of course, these measures are not taken without a risk.

#### EU health research budget

Although the previous European Commission, under the mandate of President Juncker, made clear that the health programme would be absorbed by other programmes into the enlarged European Social Fund, COVID-19 has changed that political perspective. A standalone health programme is needed to be able to act during health emergencies and to better protect frontline healthcare professionals and workers. This standalone health programme should be fit for purpose, improving the health conditions across all EU Member States through better prevention, access, and continuity of care. This shift would give the EU institutions greater capacity to act during future health emergencies.

Furthermore, a European health data space is needed to enable the pooling of health data from EU citizens in a defined and standardised manner, with the Electronic Health Record as key foundation for continuity of care. This would have a positive influence on being better prepared for the next upcoming health crisis.

When a health crisis occurs, the nursing profession is always at its frontline serving citizens and patients. This has been part of the European history since the time of Florence Nightingale. In times of war and pandemics, when the populations need healing and support, the nurses are always at the frontline day and night. For that reason, the European Nursing Research Agenda should be part of the European Health Research Programme, aiming at providing the evidence for EU and national leaders, as well as health stakeholders, to take concrete and immediate actions to support and protect the European Citizens.

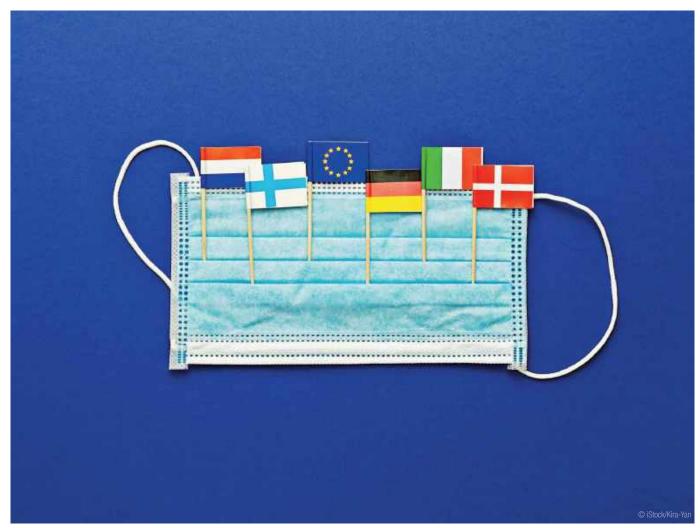
To fulfil the urgent needs of the frontline nurses and healthcare professionals, as well as the citizens, the EU should empower the nursing profession and nursing research to co-create the European Health Union, making sure future EU health policies are fit-for-purpose.

The COVID-19 outbreak and the EU Ebola crisis show significant similarities in the measures needed to protect EU citizens. To be better prepared for the next outbreak, we need to be all prepared (EFN, 2015):

 Support the EU health workforce, in particular nurses, to respond to the challenges of Infectious Diseases of High Consequences (IDHC) without compromising its safety and wellbeing, through co-ordinating and building capacity in the nursing workforce, providing further access to vital education and training that includes opportunities for regular drills on donning and doffing PPE, and assuring the provision of adequate resources and support for a safe working environment;

- Explore the causes, mechanisms and consequences of stigmatisation related to the care and treatment of IDHC within the European Health Research Programme and based on outcomes, take appropriate actions to tackle stigmatisation;
- The new coronavirus outbreak has brought stigmatisation with it. Frontline healthcare professionals, including nurses, has been unfairly stigmatised by some citizens as dangerous and disease carriers. Other citizens consider them to be modern heroes; however, popular support needs to be translated into professional and political support;
- Continue to encourage investment in preparedness, learning from the lessons and knowledge gained so far, and enhancing monitoring and follow up initiatives. Protecting the health workforce, as well as the public, from future health threats should continue to remain a priority for all Member States individually and the European Commission collectively, ensuring that relevant protective equipment, appropriate education and training, and protocols are made available to frontline staff;
- Ensure the public and health professionals are well aware about an existing network of IDHC centres or the national civil protection authorities ensuring that information and support is provided across all healthcare settings, including community care and elderly care homes;
- Co-creating and co-designing with frontline nurses fit-for-purpose political decisionmaking processes and policies for IDHC preparedness is a must. This is a challenge for the European Commission as their only counterparts are the Member States and sometimes academics who they ask for advice, but not frontline healthcare professionals. Healthcare professionals and NGOs are often kept out of the decisionmaking equation, making political actions often unfit-for-purpose. This accounts for the lack of pragmatism in the decision taken by the European Commission handling the COVID-19 crisis. Past exercising of best practices and fulfilling academic frameworks

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do not draw an EU strategy for supporting the nursing frontline. The new coronavirus outbreak proves that more EU support to the frontline is needed when emergencies emerge. EU citizens need EU policies that protect frontline staff from working overtime and of being continuously understaffed;

- Analyse the impact that the economic crisis and the cuts in healthcare (decreased resources, decreased staff, overtime, etc.) have on the capacity of healthcare ecosystems and health professionals in responding to Ebola, COVID-19 and other IDHC outbreaks; and
- It is essential to explore how different healthcare systems are responding to this crisis and to monitor and measure the impact of the COVID-19 on the nursing workforce. Then, the nursing workforce will need to be better equipped to be able to handle the next pandemic. The Union Civil Protection Mechanism (UCPM) could be the key to strengthen capacity and future EU co-ordination.

#### **Conclusions**

The COVID-19 outbreak is having an unforeseen impact across all EU countries, and it is affecting all layers of society. COVID-19 is reshaping the

EU political priorities and strategies to get the European Union acting as one. The European Commission continues being a stakeholder with whom the nursing profession engages in constant dialogue, but a new area of co-operation has arisen co-ordinating actions to tackle the health crisis with the EU Member States.

However, the main takeaway of the COVID-19 outbreak is that the European Commission needs to look for formulae to solve the subsidiarity nightmare, at least in the context of health crisis, to ensure that the EU can act in a co-ordinated and even manner across all EU countries. This is a need and a demand of nurses at the frontline, as well as of citizens. If the EU politicians fail in creating a European Health Union, the whole of the EU institutions risk to be perceived merely as a bureaucratic complex of institutions that are not reliable in the context of health emergencies.

Therefore, the European Union should not only facilitate collaboration among Member States but should aim to increase its number of competences in the health area.

The European Commission needs to start looking at the European Semester Country Reports on a different way, particularly after the COVID-19

crisis. The Country Reports identify a series of health trends in which there is room for improvement across all Member States. The next step would be to liaise with the nursing profession to formulate EU policies that benefit Member States in improving their healthcare ecosystems as needed. The EU institutions should actively coengage with all EU health stakeholders, especially the nurses, to be better prepared frontline. That way, all EU countries will be much better prepared for the next pandemic / health emergency.

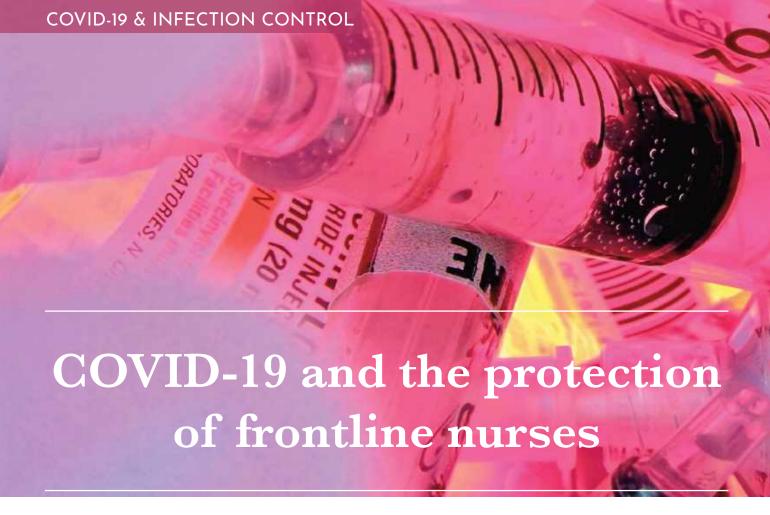
Finally, the EFN continues being engaged with all interested EU and health stakeholders to do what is best for the frontline nursing profession across the EU and Europe, and in doing so, maximising the health outcomes of patients affected by the COVID-19 disease.

#### References

 Treaty of Lisbon: http://eur-lex.europa.eu/JOHtml.do?uri= OJ:C:2007:306:SOM:EN:HTML

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What can the implementation of the 2010 EU Directive on Sharp Injuries teach us about preventing COVID-19 infection in clinical settings?

lorence Nightingale's influence on the fields of society and politics; philosophy; science; education; and literature is well documented, demonstrating that on political matters she was an astute behind-the-scenes political activist. She campaigned based on the data she collected to show politicians the evidence for her arguments to improve the working conditions for nurses.

At times of the EU COVID-19 crisis and emergency situation, it is key to reflect on existing EU legislation to strengthen healthcare systems in the EU and importantly, support and protect frontline nurses while doing their job.

Therefore, the European Directive on Sharp Injuries provides an opportunity to look at its professional and societal impact though the legacy of Florence Nightingale. It is key to look into how EFN lobbied

the EU to improve the working environments of three million EU nurses, making sure the European Parliament, the European Commission and the European Council not only develop EU legislation, but equally important transpose Directives into daily reality. That transposition in the COVID-19 crisis is key to save the lives of both citizens and healthcare professionals.

# Why did we need a European Directive 2010/32/EU; and why this Directive is important to tackle COVID-19?

Sharps injuries, and particularly needlestick injuries, bring the risk of potentially life-threatening infections into the daily working life of millions of health care providers. More than 30 dangerous bloodborne pathogens are transmitted by contaminated needles, including hepatitis B,

hepatitis C and HIV. The bore of the needle acts as a reservoir for blood and other body fluids and small amounts of blood can result in potentially life-threatening infection. Additionally, the emotional impact of a sharps injury can be severe and long lasting, even when a serious infection is not transmitted.

Sadly, every year in Europe approximately 1.2 million needlestick injuries are incurred by healthcare staff (European Commission, 2009). A study from one European country reported that needlestick injuries were the most reported type of significant exposure, with 63% of those injuries caused by hollow bore needles. 45% of these occurred amongst nursing professionals and 37% amongst healthcare professionals. A much lower incidence was identified amongst allied ancillary staff, with most being sustained from inappropriately discarded needles in rubbish bags. Another European country study reveals that the highest risk area for the likelihood of needlestick injury is venous blood drawing (>38%), and that only 20% to 50 % of all needlestick injuries are reported.

Although the EFN and its members actively keep on campaigning to eliminate the risk of needlestick injury for nurses, focusing upon developing European standards to reduce the use of needles,

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ensuring the protection for exposed sharps through the use of medical devices, and ensuring safe work practices including through better education and training, it is important to focus down our actions and set priorities during the pandemic. The EFN's 2015 report 'We are not prepared unless we are all prepared' recommended greater support for the EU health workforce, in particular nurses, to respond to the challenges of Infectious Diseases of High Consequences (IDHC) without compromising its safety and wellbeing; through measures including:

- Co-ordinating and building capacity in the nursing workforce;
- Providing further access to vital education and training, including opportunities for regular drills on donning and doffing PPE; and
- Assuring the provision of adequate resources and support for a safe working environment.

# 10 years on from the Directive, what has changed for nurses and healthcare providers?

The EFN 2013 report on the implementation of Directive 2010/32/EU in the hospital and healthcare sector concludes that the transposition and implementation into practice at the workplace shows a positive impact of the implementation of

Directive 2010/32/EU into the clinical practice, in most EU Member States. A majority of respondents from the 28 countries represented in the analysis have measures in place to prevent sharps injuries. The data show that implementation of EU legislation on sharp injuries is well on track — however, more needs to be done to reach 'zero tolerance' in the field of sharp injuries.

Is this initial implementation progress still measurable in 2020? Do we know what is going on when it comes to sharp injury prevention in all EU Member States? Do we know how many nurses incurred injuries with a 'sharp instrument/needle' this year? The same holds for COVID 19 infections.

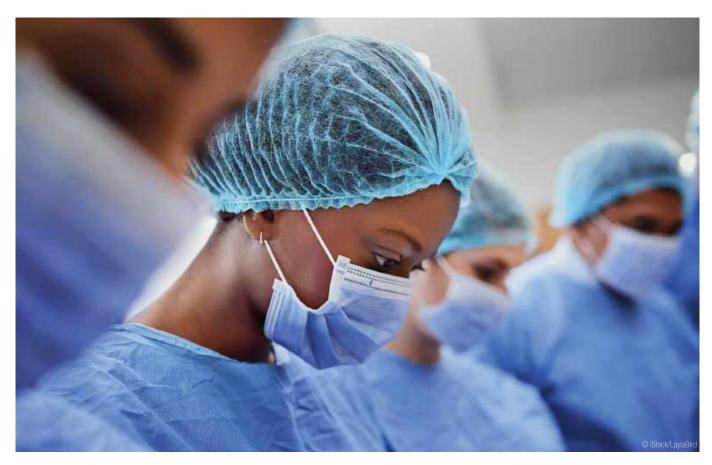
The 2019 report from HOSPEM and EPSU, titled 'Follow-up on the Directive 2010/32/EU', focusing mainly on the role and impact of the national social partners during relevant stages of the transposition and implementation of the Directive, reports on 30 replies from European Hospital and Healthcare Employers' Association (HOSPEEM) members and European Federation of Public Service Unions (EPSU) affiliates from 20 countries. The recommendations to the national and EUlevel social partners, to European institutions (in particular to the European Commission and EUOSHA) and the EU Member States are clear, but not surprisingly, these recommendations refer to

'continue to share', 'exchange of experiences', 'awareness-raising, while respecting national settings', 'continue to elaborate and promote': all quite soft approaches in the current emergency situation occasioned by COVID-19. It is clear, without collecting data, that nurses and doctors, are at high risk on a daily basis. Therefore, it is key to move now from 'recommendations' to 'rules'. Therefore, it is key that the EFN, representing three million EU nurses, takes a tougher stand; as politicians need to be reminded about their responsibility to protect frontline staff.

## Prevention and protection for safer work environments

The Directive 2010/32/EU certainly helped reduce needlestick injuries in some EU Member States. The standardisation of registration, reporting and follow-up systems of injuries with sharps injuries is an important step forward – but there is no EU-wide approach to measure accidents; and this is the key problem, both for sharps injuries and COVID-19 infections. Even with the technologies currently available, we have no concrete solution to monitor the unmet needs of frontline healthcare professionals (HCP), who are in survival mode daily and risking their own lives. It is time to move from 'patchwork' to 'EU co-ordination' and stop hiding behind 'subsidiarity'. We need to go beyond

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sharing best practices, if we want focused support to frontline nurses.

Furthermore, Continuous Professional Development (CPD) is an equally important step forward, but also here we see a lot of patchwork, with nurses lacking working time to follow face-to-face courses. During the time of COVID-19, there is hardly time to become a 'link COVID nurse', which is not a specialist nurse, but a general care nurse with a specific attention on each unit.

Before we start teaching, it is essential that nurses have the materials they need. The elimination of unsafe procedures as well as the transition to safe sharps protection mechanism and devices is key for frontline nurses — and this holds equally true for COVID-19!

On 24 March 2020 12 European organisations of healthcare professionals published a statement to the European Commission, calling urgently for equipment, resources and support:

'European organisations representing all healthcare professionals addressed common concerns and discussed what is right now needed to support the HCP.... Many HCP are now getting infected, and several doctors and nurses are dying. All HCP share the same concerns regarding the lack of safety in the workplaces. HCP are on the first line of response in the fight against the

COVID-19. HCP are faced with a distressing lack of personal protective equipment (PPE) in practically every Member State, as few governments and employers are prepared for pandemics after years of austerity. There is an imminent need for more resources to be able to manage the pandemic, including staffing levels, PPE and financial resources. It is therefore essential to work together to monitor and support the Commission's efforts to make sure that the protective equipment needed to combat COVID-19 is able to guickly reach the member states and HCP facing shortages. The European Union must make it a priority to ensure that all member states pull together resources and harmonise prevention protocols to ensure the protection of lives.'

We need to look at these issues from an EU perspective and propose co-ordinated solutions, with EU funds put together to address this emergency situation, in which DG ECHO should play a crucial role, due to their experiences outside of Europe. Specific attention should go to the lack of economic resources to provide safe protection equipment needed in Southern, Central and Eastern Europe, where health systems are already very vulnerable without the additional crisis of a global pandemic.

This automatically brings us to the empowerment of nurses in advanced role in public

procurements: nurses need to formulate the procurement criteria to buy those materials that support reduction of their workload and projects them from infections and injuries. Within this context it is important industry continues developing safety-engineered solutions, needlefree systems and safer hardware disposal solutions; but most important is that these solutions are developed in partnership with the frontline professionals. A good example is that of PPE, which is mostly designed by men to fit male bodies, while the nursing workforce mainly consists of women. Masks and PPE need to be developed by nurses and for nurses – but for this to happen, the industry needs to be more proactive and not reactive. Co-creation and codesign are essential, so nurses on the frontline, in hospitals and community care, can use materials that are fit for purpose.

# Opportunities and challenges for the next years to create a safer and healthier work environment

The main question is whether we have become complacent in the matter of sharps injuries. Do we have accurate frontline data on the different aspects of the Directive, including 'Risk assessment' (Clause 5), 'Elimination, prevention and protection' (Clause 6), 'Information and awareness-raising' (Clause 7), 'Education and



training' (Clause 8), 'Reporting' (Clause 9), 'Response and follow-up' (Clause 10) and especially 'Implementation' (Clause 11)? Do we have the data to show the frontline reality for nurses and nursing? How could the digitalisation of the healthcare sector facilitate these developments?

All these clauses in Directive 2010/32/EU are relevant to the COVID-19 crisis in the EU; however, Clause 6 is now a top priority to save lives: elimination, prevention and protection are key. Meanwhile Clause 8, education and training, is key to making sure nurses can focus their activities in the optimal way to protect themselves.

#### **Concluding remarks**

Being prepared needs to come back onto the political agenda. EFN states that 'what is good for citizens and patients, is good for nurses'. The safety of patients and citizens was dropped from the EU political agenda, unfortunately; and the European Agency for Safety and Health and the World Health Organization have other political priorities. Also, within the European Social Pillar, little room for manoeuvring will be possible within the 20 principles to address the impact of Directive 2010/32/EU on being prepared, on frontline nurses. Being prepared at all times, in a co-ordinated way, becomes a real challenge at the EU level.

This EU co-ordination can be done by focusing on the collection at the EU level of robust data from the professions concerned — in our case three million nurses — to assess the impact of not being prepared; not to blame and shame; to learn and to be better prepared for the next crisis. The HOSPEEM-EPSU Report says clearly that 'most of the problems reported are linked to deficits regarding the elimination, prevention and protection of risks from injuries and/or infections from medical sharps'. The EFN 2015 report on Preparedness adds:

'Continue to encourage investment in preparedness, learning from the lessons and knowledge gained so far, and enhancing monitoring and follow up initiatives. Protecting the health workforce, as well as the public, from future health threats should continue to remain a priority for all Member States individually and the European Commission collectively, ensuring that relevant protective equipment, appropriate education and training, and protocols are made available to frontline staff.'

We must turn this COVID-19 crisis into more frontline EU actions, not just an awareness campaign; not another CPD course or a National congress to talk about the challenge instead of solving it. A frontline approach, supported by the EU institutions, Parliament, Commission and

Council, is urgently needed to protect EU citizens and its health workforce in times of emergency and crisis. Nurses still get injured and infected because we lack the appropriate material in hospital and community care to protect nurses from Infectious Diseases of High Consequences.

We have conducted 10 years of awareness raising and training; it is now time to push for an EU approach to visualise Infectious Diseases of High Consequences and sharps injuries; and develop appropriate actions with the co-ordinated support of the EU institutions. Standardisation of registration, reporting and follow-up systems of IDHCs and injuries with sharps implies the need for a structured centralised system, which is interoperable at a European level. Respecting the responsibilities of the Member States in relation to the 'organisation and delivery of health services' is one thing, but protecting the lives of frontline nurses in carrying out their frontline job needs to become an EU legislative priority.

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## We need to explore blockchain as a new way to organise healthcare services

he potential of blockchain and distributed ledger technology (DLT) in the healthcare domain has been recognised by several stakeholders around the world. Blockchain applications in the healthcare industry span from health data exchange and identity management to drug supply chain, from insurance to personalised medicine<sup>1</sup>.

The European healthcare ecosystems face difficult challenges, such as the aging population, multimorbidity, healthcare workforce shortages, and the rising burden of preventable noncommunicable diseases<sup>2</sup>. Therefore, it is key to explore blockchain as a new way to organise healthcare services and as such develop more resilient, accessible and effective quality care to European citizens.

In this context, healthcare services can use blockchain-based tools to improve health outcomes, and are broadly recognised as an essential, not disruptive element to achieve sustainable healthcare systems that optimises nurses' time in support of patient care needs<sup>3</sup>.

Health data often lies within technologies that are not interoperable today, thus hindering its wider use<sup>4</sup>. More significantly, the use of people-centred health data is still under-developed across the EU<sup>5</sup>. The data is often untraceable and fragmented across different locations and systems, with potential adverse impacts on diagnosis, treatment and follow-up in primary care and community care settings. Therefore, a continuity of care approach becomes crucial for healthcare ecosystems as updated citizens health records are lifesaving for citizens, based on informed decisions made by the healthcare professionals.

## Benefits for person-centred care

Rather than having one central administrator that acts as a gatekeeper to data, a network of clinicians needs to have access to synchronised citizens' health records, visible to anyone with credentialled access, giving unprecedented benefits for person-centred care models in the EU.

Given the specific features of blockchain in establishing trust, accountability, traceability, and

integrity of data<sup>6</sup>, one of the key applications envisioned is electronic health record management and exchange. Blockchain provides interesting solutions in health record management, as it introduces a decentralised mechanism for controlling and accessing data, while also introducing a timestamp to the data, as well as a robust audit trails mechanism<sup>7</sup>.

Compared to traditional databases in biomedical and healthcare applications, blockchain provides clear benefits, including more robust data provenance models (improving both ownership control and traceability of the origin of a specific data asset); increased robustness and availability (thanks to the high level of redundancy provided by the technology); and improved privacy and security (thanks to cryptographic algorithms)<sup>8</sup>.

Blockchain can support the development of person-centred care models with specific focus on continuity of care, allowing nurses to process lifetime personal health data. Blockchain's ability to secure citizens' health data can give EU crossborder care a new dimension of deployment. These developments may reduce the workload of nurses' frontline, thereby making primary and community care more accessible<sup>9</sup>.

The European Commission has published a recommendation<sup>10</sup> on a European Electronic Health Record (EHR) exchange format that will facilitate citizens' access to their health

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information electronically and securely across all EU Member States.

The creation of the International Association for Trusted Blockchain Applications (INATBA) provides an opportunity for stakeholders to focus on the health agenda and find practical blockchain solutions that are fit for purpose, supporting the frontline professionals and delivering better health outcomes for citizens throughout Europe. Blockchain represents an opportunity to make healthcare ecosystems more efficient, improving the quality and safety of planned and delivered care, and empowering citizens and patients to better manage their own health.

## Added value for continuity of care

Blockchain has many unique characteristics, three of which make it particularly useful for continuity of care<sup>11</sup>. These are:

- Full traceability of any information on the blockchain;
- The ability to ensure data has not been tampered with; and
- Increased security.

But the advantages of blockchain should go way beyond traceability and security. Blockchain should build trust and support frontline staff in planning nursing care across clinical pathways, making sure outcomes are recorded without being an administrative burden, so that the nurses' workload can be reduced significantly, especially taking away the burdensome administrative tasks allocated and delegated to nurses. For continuity of care it is key that blockchain supports the holistic view of nursing care and serves as a single source of truth — meaning that all healthcare stakeholders can see the same information to which they have been granted access by the citizens and patients.

There are blockchain solutions which are now ready to be adopted in routine, real world scenarios; and most importantly, which are able to show a real return on investment, both in financial terms and in actual improvement in the existing workflow. Within this context, it is important that INATBA Healthcare Working Group explores the real needs in different health service provision scenarios, and of the environments and workflows in which healthcare professionals operates daily.

The true challenge is that the industry needs to meet with all relevant stakeholders to better understand the existing workflows and relevant shortcomings, to eventually co-create and codesign blockchain solutions in collaboration with the end users, to impact the way in which nursing care is provided in different real world scenarios.

The Research Data Alliance working group on blockchain in health data management<sup>12</sup> recently provided a basic framework for designing distributed ledger technology solutions<sup>13</sup>, that

might help innovation and deployment when digitalising the healthcare sector.

## Bringing innovation into practice

As a first step it is important to start developing the use case by identifying the problem or opportunity the end users are seeking to address through the solution and formulate clearly the expected outcomes, focusing – when possible – on tangible outcomes to be reached in the short or medium term.

Furthermore, it is important to establish benchmarks for future reference, by defining some key metrics to assess the results of the new blockchain-based system in comparison with existing systems and workflows. For this reason, it is of paramount importance to analyse in detail what is the current workflow for that specific operation and identify the relevant key performance indicator (KPI). This will serve as the ground truth for assessing the performance of the blockchain-based system, providing evidence of its efficacy or further guidance for improvement or redesign.

## Use case : blockchain improves planning of primary and community care

Optimising clinical pathways through blockchain and artificial intelligence (AI) are great opportunities for the nursing profession to process and to store nurses' activities and actions, as well



as monitoring the data that continuously feed into the nursing care process, and as such better plan daily activities.

A European society where a growing number of people live with comorbidities and non-communicable diseases in need of more complex nursing care interventions in community care settings, as the duration of hospital visits is forced to become shorter and shorter, and in need of more tailored care to address the unmet needs, can benefit from blockchain tools for community care.

The use case scenario supports the design of tailored continuity of care pathways, enabling a bidirectional flow of data between patients and authorised care actors, making data accessible across community care based healthcare networks, and allowing credentialed users to securely add, with the citizens' consent, to the nodes of information needed to make the continuity of care operational and effective.

In the case of chronic patients' management, some interesting initiatives have been launched, combining DLT with novel medical IoT devices (IoMT) to facilitate patient remote management, self-management, and continuous monitoring. Surely the adoption of IoMT can help improve the quality of care and reduce the occurrence of severe events which might otherwise lead to hospitalisation, while at the same time reducing unnecessary visits to emergency rooms.

Furthermore, the data coming from these devices need to respond to basic quality and safety criteria, which DLTs can help achieve by providing elements for proving data provenance and integrity, as well as — and not less importantly — the authenticity and identity of the loMT device itself.

The current systems of data entry by frontline nurses, who are now spending more valuable time in increased administration and data collection rather than caring for patients, is a real barrier to address the unmet needs. This adds

further responsibilities that distract frontline nurses away from the patient's bedside.

## **Concluding remarks**

Blockchain technology has great potential to boost continuity of care without being disruptive. Healthcare, especially now we are going through the COVID-19 pandemic, is already disrupted enough!

Blockchain can be a valuable support for the already overwhelmed healthcare sector frontline staff, and particularly for the nurses who coordinate continuity of care 24 hours a day, seven days a week, 365 days a year. It is therefore key that blockchain solutions enhance the interaction between the citizen or patient and the healthcare provider, ensuring access to more accurate, complete and trustworthy health data, thus positively impacting the delivery of more peoplecentred and personalised healthcare.

Blockchain solutions should have a positive and measurable impact on the nurses' workloads with a quantifiable rebalancing of tasks from



administrative support towards care delivery. In consideration of the pertinent role that nurses play in primary and community care, it is crucial to ensure that frontline nurses can independently deliver high quality and safe care by developing (throughout the EU) advanced capabilities in managing the chain of care.

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