Nurses in Europe codesigning an EU value-based health and social care ecosystem

Dr Paul De Raeve, Secretary-General of the European Federation of Nurses Associations (EFN) provides an in-depth perspective on the extent to which nurses in Europe are codesigning an EU value-based health and social care ecosystem

In a European society where a growing number of people live with co-morbidities, non-communicable diseases and need complex care interventions, health and social care systems are expected to give greater importance to value-based outcomes. Value-based health and social care (VBHSC) is based on the patient's experience, with a focus on the quality of life, rather than the length of stay and moving away from medical diagnoses and complications systems (ICD-10 and DRG system) towards achieved outcomes from a patient perspective.

As different dimensions need to be considered in the health and social status, the promotion of healthy lifestyles is to be included in the value-based health and social care systems and as such, patients, providers and researchers should co-design the reforms needed to achieve an inclusive system for both prevention and promotion, so that they are stepping in before you get a disease. This approach refers to both self-management and co-responsibility.

In this context, the advanced role of nurses is necessary to respond to patients and citizens' unmet needs within a people-centred approach, based on the tailored continuity of care pathways which until today, has failed to turn integrated care into a reality, often financed through EU pilots.

However, to ensure a thorough implementation of an EU value-based health and social care ecosystem approach, it is key to shift from a fee-for-service payment system – which prioritises the volume of interventions over effective, efficient and even safe people-centred care – towards bundled payments, prioritising care pathways and continuity of care thus leaving the medical DRG approach behind.

The European debate[1]

The current discussion on value-based healthcare, not value-based health and social care, is often approached as a disruptive model of healthcare for Europe, hitting most of the EU policy debates, demonstrating that health is a top concern not only for EU citizens but also for politicians and health stakeholders.

However, a reflection process on disruptive innovation for health in Europe understood as 'creating new markets or add substantial value to the existing market' is too limited for investing in such a fundamental reform. We need to go beyond the market and growth discussion, focusing on improving outcomes for patients and citizens not just in the health sector, but combining health and social care, which are two interlinked sectors.

Add to the value-based equation key components as trust, user-centred innovation and data enabling technology to act, next to teamwork and health literacy, this will make the transformation of the existing models less disruptive for patients, citizens and healthcare professionals committed to their profession in the most complex and difficult working conditions they must operate in. The slogan "take care of those who care" needs to be taken more seriously when designing value-based health and social care ecosystems in the EU.

Following up on Prof. Rifat Atùn (Harvard School of Public Health and the Economist Intelligence Unit)[2],

suggestions on the three key ecosystem challenges that need to be solved in the context of VBHSC – higher burden of disease (multi-morbidity) and disability; growing demand and expectation and higher costs – it is clear that concerning these elements, care team composition and advanced nurse roles need to be urgently addressed to make VBHSC ecosystems operational, implementable and most importantly, trustworthy. By assessing the needed regulatory changes, together with new business models and value networks, the current political discussion has the potential to build a holistic picture of how health and social care structures can be adapted to keep pace with innovation.

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Despite some inspiring ideas that are circulating, most of the political debate still focuses on the medical component of healthcare, promoting the disease model and academic silo thinking which makes a real value-based discussion and regulatory co-designs based on value-based public procurement tools, difficult, unfortunately. It is time to move away from this silo value-based discussion towards an inclusive value-based approach that creates value for all EU citizens, combining the health and social care sector and empowering patients and the health and the social care professionals who are making it all happen on the frontline.

What value-based healthcare means for nurses

Value-based health and social care is a concept supported by the nursing profession if the conceptual framework goes beyond cost-control and markets[3]. From a nursing perspective, the creation of value for patients and citizens should be the main objective of all actors involved. Therefore, to provide a better quality and safe care outcome, such value should go beyond economics, relating more to the quality of care, life and wellbeing. As such, it is important to design a health and social care ecosystem that optimises value-for-money and outcomes, shares accountability and liability and inevitable risks and rewards. Additionally, it is central to have a stronger focus on outcomes and more robust outcome measurements, including the patient experience and continuity of care data.

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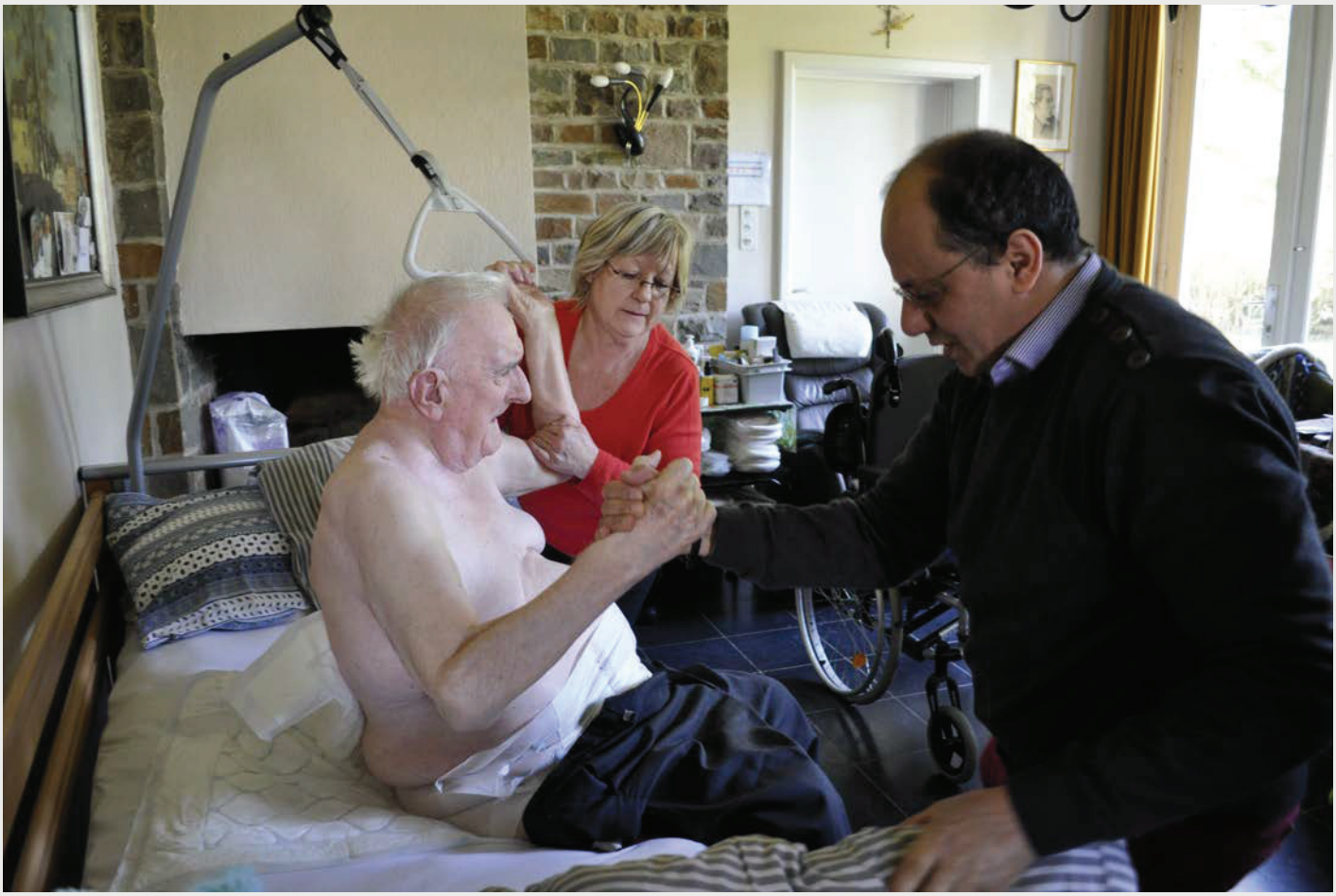
In particular, the measurement of "outcomes" needs to be designed with and for patients, bringing in the notion of the quality of life. Health and social outcomes measurements should go beyond just medical data and include continuity of care, accessibility and prevention indicators relevant for patients and citizens, crucial for improving their quality of life and their loved ones, often providing informal care, supported by nurses in advanced roles to achieve a level of integrated care. Anyhow, we need to be realistic as there is no single metric or set of indicators that will give the complete picture of health system efficiency in a country[4].

Nowadays, the separate health and social care systems collect huge amounts of data on activity, but little information is given on the impact and results of these activities, particularly from the perspective of the patient, citizen and people. Yet people-centred care will never become a reality if systems fail to routinely and systematically collect information about experiences and outcomes of care pathways and modify these pathways, based on the data collected. Knowing that over 80% of households in ten EU member states report difficulty in covering the costs of professional home care services[5], it is key to bring health and social care combined into the value-based ecosystem design.



The long-term trustful relationships patients have with frontline nurses can facilitate the smooth collection of outcome data. Through a regular sustained direct contact with the patient, appropriate support and coaching, nurses can make a significant contribution to measuring outcomes in a systematic way, supported by technology and being part of a culture in value-based ecosystems that empower patients, citizens and people.

However, when it comes to measuring outcomes, the main concerns relate to "who will collect the data" and what impact this will have on nurses' direct patient time, knowing that they are already overstretched in terms of their workload. Nurses need technologies, including blockchain, at their disposal to support patients in collecting relevant outcome data, with new tools to measure patients' outcomes over time and across their entire healthcare journey spanning hospital, ambulatory and community care, as well as mental health long-term and social care outcomes. It is important to have standardised measures to compare these outcome data, which should be easy to interpret by all end-users. So, personalised electronic health records (PEHR) need to be available frontline through blockchain.

Likewise, privacy and standardisation of outcomes are fundamental to protect data against unjustified use. Having said that, nurses and nurse researchers need to be clear on how complex data, including qualitative data, can be deciphered and applied to support health and social system reform towards people-centred care. The industry will also need to be much clearer about how technology will bring nurses closer to patient care while collecting frontline outcome data, often on the request of patients the family themselves. How to measure the impact of care on people's pain, function and quality of life, as well as their experience of care as key indicators of performance and how these measures can help move health and social care ecosystems for-

ward towards better value, need to be further explored with end-users in a co-creation mindset, instead of only consultations and academic expert-meetings, often in privileged meetings although the OECD PaRis project showed already huge progress. But please remember, not all EU member states are a member of the OECD!

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To give deployment a real chance, as our medicine for pilot-itis, key end-users in the VBHSC ecosystem need to support frontline nurses empowering patients. In the long run: 'What is good for patients is good for nurses'. In this sense, the advanced nurse practitioner (ANP) is central to improve access and outcomes in a people-centred approach, ensuring the continuity of care across primary and secondary health and social care sectors. ANP is maintaining the continuity of care, as case managers, hold enormous potential for citizens to become active contributors and partners in the decision-making process, with ANP facilitating access, engagement and trust.

As an advanced role, nurse prescribing, supported through ICT solutions, shows already that in many member states that there are clear benefits for patients and citizens, in terms of increasing accessibility towards increased health and social literacy, facilitating a better understanding of the complexity of service delivery and reimbursement. Examples include prescribing in nurse-led warfarin clinics, community and hospital settings and national databases to enable transparent reporting of prescribing practice. End-users reported significant benefits through more accurate and effective prescribing, enabled through holistic nurse assessment, which also fosters a continuity of care. As a result, patients, citizens and people appear to be empowered with greater access to quality prescriptions and knowledge about their medications, as well as their potential side effects.

And as such, prevention comes into the equation, led by advanced nurse practitioners, creating a more refined and comprehensive view of the full value of investment in health and social care. This will sharpen the focus on disease prevention and avoidance of disease progression, incorporating the value of having citizens in good health and the benefits that this brings for the health and social ecosystem, for society and the economy.

Creating value for patients

To create a real value for patients, a shift is needed from a fragmented system in which patients struggle with access and in finding their way in the system – especially for patients suffering from multi-morbidities that need to interact multiple times with the system – towards a patient, citizen and people-centred model that empowers the individual[6]. Scaling up through end-user co-creation remains the key challenge! The evidence-based solutions often proposed by experts and EU advisors still miss the patient, citizen and people approach, resulting in recommendations being out of touch with reality. The outcome measurements currently used are not sufficiently developed by and for patients and citizens, that do not see their priorities reflected. The value of the patient and citizens perspective means something that brings concrete benefits and improvement in health and social terms, or in the quality of life. The patients' priorities need to be reflected in terms of the outcome measurement with data that will inform the definition of EU standard sets of outcome measures that really matter to patients, with measures that should shift from individual episodes to an integrated approach.

This approach implies to include patients' participation at all levels of the health and social care ecosystem design and to follow patients' feedback by actions. A good example going towards this direction is the PaRIS initiative[7], based on patient-reported measures to enable better decision at clinical and policy level. PREMS and PROMS are the way forward, but more elements should be included such as life improvement. PROMS and PREMS need to be used to monitor and shape decision-making, leading to better outcomes and more value, by tailoring the continuity of care to people's preferences. As such, personalised medicine

gets finally a higher level political dimension, moving from a medical discussion towards a health and social outcome discussion.

Consequently, there will be better management and resourcing decisions following the change in mindset. Therefore, the right methodology and structure need to be put in place to have a meaningful patient, citizen and people engagement, with financing, incentives to change and adapt the current model. To this end, patients and nurses need to be empowered through digital literacy and patient-driven technology. Nurses coaching' skills in advanced roles are crucial to engage patients in this empowerment process and improve health and social literacy, as they have the capacity to explain in an easy to understand language what it is all about and how to best use these tools. This all comes back to one important component: building trust! And we all know that women play a central role in building trust!

In parallel, whereas it is widely shared that the reconfiguration of services around people, their needs, preferences and expectations is the way forward, we need to be realistic when it comes to the workforce needed to achieve person-centred and value-based ecosystems. The discussion is often very medical dominated, in terms of physicians running the systems, but we are already in 2018! So, let's change the rhetoric! People could potentially benefit the most from different care models that are more responsive to their needs and preferences and to help cut low-value and cost. However, helping them maintain health and wellbeing – and organising care around them – can be very complex if the 'continuity of care' is not fully developed and supported by technology[8].

From DRG towards value-based reimbursements

How to anchor performance assessments and reimbursement models on patient-reported measures is not clear yet. Those member states which moved towards value-based ecosystems have used the outcome data to close hospitals (e.g. The Netherlands), units (e.g. cardiology) and often made nurses redundant. This is not the way forward to build trust!

The conditions for the organisation of the value-based health and social care in Europe are challenging, from organising services into integrated practice units, measuring outcomes and costs for every patient in the system, moving towards bundled payments for care cycles, with integrated care delivery across separate facilities and sectors, as well as to expand excellent services geographically, including remote areas. Fee for services and disease-related groups have made the system bankrupt, knowing that solidarity is questioned in the EU. So, payment needs to follow the outcomes and value achieved. This implies transparency of results and costs. However, we need to be very careful that competitive accreditation systems, mainly imported from the US, are not becoming a market trend, which needs to be paid by someone. We are wondering who that will be.

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The traditional and still widely embraced the fee-for-service system, known for producing bad incentives and being generally accepted as an obstacle to improving the quality of care, cannot be deployed in value-based health and social ecosystems, integrating preventive care services. As fee-for-service prioritises volume of care over effective and efficient people-centred care, it is key for nurses to acknowledge outcomes-oriented designs, refocussing, even giving up, the traditional data collection indicators[9, 10, 11].

Higher societal economic value

Adding the dimension of societal economic value to the current value-based healthcare discussions, they should be tackled within the Principle 16 "access to health care" of Chapter III of the European Pillar of Social Rights, social protection and inclusion. The right of citizens to timely access, affordable, preventive and

curative health care of good quality, becomes a key societal and economic challenge in the EU, to be addressed with an urgent re-focus on 'moving care back to the community'[12] by designing, in co-creation with advanced nurse practitioners, a more holistic and economic approach to value-based health and social care[13].

To promote this approach, value-based health and social care need to focus on the continuity of care with health and social care teams being educated and trained together, with a strengthened teamwork to achieve better outcomes. So, there is no need for gate-keepers, dispatchers, rather a need for leadership in coordinating the care continuum in an advanced role, not being a 9 to 5 job. Therefore, political leaders need to realise and agree to bring the various end-users in health and social care – citizens, patient groups, professional bodies, service providers, insurers, industry, women representatives – together and formulate clear budgeted actions. There is often a roadmap without concrete actions, deadlines and impact measurements. Consequently, the EU should invest in policies promoting integrated and continuity of care, with end-users co-designing 'fit for purpose' health and social care ecosystems.

All EU and international institutions agree that the most important issue of the health systems is their sustainability and the need to transform volume approaches towards outcomes measurements, combining costs and outcomes to evaluate the value of the ecosystem, preferably health and social care combined. Creating positive economic value in societies by having a more holistic view on health and social care ecosystems – instead of silo views in education and work environments – will make it possible to achieve as the socio-economic value of nurses and nursing has been already researched[14, 15], but unfortunately not recognised enough in policy designs. ■

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