

When Personalised Medicine, Gender and Dementia meet!

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Across the world, an estimated 44 million people now live with dementia, this number is set to double by 2030 and triple by 2050¹.

Dementia is one of the most debilitating conditions in modern society with huge health, social and financial implications². People's lives, families and communities can be disrupted from the onset of dementia, while dementia is also increasingly considered as one of the leading causes of death among older adults.

The direct financial cost of dementia to the European Union (EU) is estimated to be in excess of 130 billion a year³. Tackling the dementia challenge must become a G7 priority as finance ministers and central bank governors can only advance economies by taking up the key burden of dementia on health systems. The European Union is represented within the G7 and as such should present concrete EU actions if dementia is to be contained and not spiral out of control in the coming years.

The Commission, together with Member States, has made enormous progress in putting a human face on the digital agenda as innovation in technology supports health system reform, moving from the old medical model toward a more integrated way of thinking, integrated and continuity of care, with a specific focus on gender, will help communities address the dementia challenge as eHealth and mHealth start profiling in clinical and discharge pathways in nursing⁴. Nurses are in the unique and privileged position of having direct access to the daily care needs of people with dementia, and have a key role to play both in managing and preventing this condition. Nurses' unique insight of the patient conditions and familiarity with people's social and family contexts, enables them to form a comprehensive assessment to develop a more holistic picture of needs which form the input for 'personalised medicine' and 'personalised care'. Personalised medicine is not only about bringing innovation to medicines and diagnosis systems, it should be about providing the right health, targeted interventions to prevent diseases, appropriate care at the right time and building a community that allows individuals to make healthy choices about their health. There is substantial evidence indicating that the risk of developing dementia can be modified through a healthier lifestyle, including better control and detection of hypertension, diabetes and other cardiovascular

and skills to perform tasks such as ordering and interpreting tests and investigations and conducting physical assessments, next to the considerable knowledge of the healthcare system in which they work and its processes⁵, supports the upscaling of 'personalised medicine'. Consequently, nurses in advanced roles can enrich the care process of people with dementia by having oversight of the care plan, and help guide them through the system as necessary, review people's progress regularly, and ensure they have timely referral to combined health and social services when these are needed, and coordinate the discharge planning process from the hospital to the community in collaboration with other professionals, such as the pharmacist and physiotherapist, and provide post-discharge follow-up and care coordination with social services in the community.

Moreover, related to the pharma sector, with polypharmacy being an immediate risk, people with dementia require more intensive review of their regimes to ensure these are up-to-date and adequately respond to their needs. Nurses have unparalleled access to people's health and treatment profiles, and through regular reviews can ensure their medications are fit for purpose and respond to the complexities of individuals. Nurse prescribers have a key function in supporting people with dementia to cope with their overloaded at times medication regimes, ensuring the appropriateness and accuracy of prescriptions; providing education to people with dementia, as well as their families and carers about medication safety and proper administration, and reviewing medications regularly to ensure these fit the needs of the individual, and ensure timely referral when relevant investigations are needed to ensure safety of prescriptions⁶.

It is within this context that the G7 needs to look at DG Connect developments – not only purely the technological aspects such as interoperability and semantics, but more innovative is moving people and civil society jointly with technology towards 'innovative support'. Innovation becomes reality when healthcare professionals embrace and implement change. It is within this policy context that EFN developed evidence-based guidelines for nurses and social workers on the use of eHealth services, building on existing practices across the European regions on 5 main topics: prevention, clinical practice (COPP), integrated care (including advanced roles), continuity of care and ePrescribing. 120 deployed practices on ICT tools/systems used by health care professionals, mainly nurses, were collected throughout the EU and Europe. The project outcome, the designed EU guidelines enable system reform, bottom-up, in response to and in conjunction with people's needs; these guidelines now need to get implemented into the daily practice of professionals towards improving the quality of care and life for people living with dementia, as well as their families and carers⁷.

Therefore Horizon 2020 pays particular attention to gender. With the nursing profession, consisting of 91% women, it is necessary that science includes more evidence from women than is currently the case. Research outcomes and opportunities can be biased towards women, which can be countered by including the nursing profession's views when reforming the healthcare system. Whilst we continue to build systematic understanding of lifestyle and patient outcomes, we miss gender sensitive and responsive research in healthcare. As shown in EFN4Care, advancing gendered innovation ecosystems is key to further design sustainable health and social care systems and making sure dementia becomes part of the solution, not the problem. The body of evidence from across Europe on the benefits of nurse-led initiatives is growing. While nurses are ideally positioned to both lead and support such developments, there is limited nursing research in this area. Although there is evidence of European funding for a range of initiatives to support people with

a range of conditions, EFN is not aware of any systematic approach to promote research into services and initiatives that address the role of nurses and the contribution they can make to providing better quality and safe care⁸. Research funding in health care is often channelled through larger research centres, which are often medically dominated and so lack a broader representation from other disciplines such as nursing and social work. The nursing community acknowledges the support of the Commission to date but believes more European support is needed for nurse-led initiatives as well as nursing contribution to multi-disciplinary research within the area of Personalised Medicine, Gender and Dementia.

To conclude, for the past decade the European Institutions, and the European Commission in particular, have been championing a range of initiatives and making steady steps towards improving the quality, safety and efficiency of health service delivery in Europe. EFN has always advocated for a human face to innovation, otherwise innovation does not have a purpose. The nursing profession sees opportunities in Horizon 2020, especially when it comes to upscaling cost-effective practices which have shown their positive impact on patient and health outcomes. By making sure integrated and continuity of care works out in the field, nurses are ensuring quality and safety, maintaining the health workforce, managing chronic conditions, and containing healthcare costs. As the single largest occupational group in healthcare, nurses have a crucial and corrective role to play in the efforts to contain these challenges. EFN therefore urges politicians, policy-makers, health services researchers and clinicians to take concrete action to ensure the sustainability of EU health service delivery. As the nurses of Europe are concerned that too much focus is placed on the medicalisation of chronic illness and ageing, nurses advocate for a paradigm shift to move the political discussion from treatment to care, prevention and cost-effective patient outcomes. Investing in designing systems that can provide integrated care, moving care outside of hospitals and into primary/community care, encouraging interprofessional working and innovating with health solutions are necessary ways forward for sustainable and cost-effective healthcare provision in the EU and Europe.

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