EFN Brussels Office
Clos du Parnasse 11a
B-1050 Brussels

Tel. +32 2 512 74 19
Fax +32 2 512 35 50

E-mail efn@efn.be
Web www.efnweb.org

Registration Number
NGO0476.356.013

European Commission
DG Health & Consumers
Directorate D: Health Products and Systems
Unit D3 – eHealth and Health Technology Assessment
Office: B232 B-1049 Brussels
SANCO-EXPERT-PANEL@ec.europa.eu

Brussels, 24 April 2014

Concern: PUBLIC CONSULTATION ON THE PRELIMINARY OPINION ON DEFINITION PRIMARY CARE WITH EMPHASIS ON FINANCING SYSTEMS AND REFERRAL SYSTEMS

The European Federation of Nurses Associations (EFN) welcomes the EC Public Consultation on the preliminary opinion on the 'Definition of a frame of reference in relation to primary care with a special emphasis on financing systems and referral systems'.

The EFN takes note of the positive messages included in this document regarding greater investment in the primary care workforce (education, training and working conditions) and attention to inter-professional team working. However, regardless the specific acknowledgement to needed inter-professionalisation in primary care, the wording of the entire document reflects otherwise, lacking mentions to the wide range of professionals that actually work in primary care.

Therefore, the EFN recommends that greater attention should be paid to recent developments in primary care, such as advanced nursing roles (e.g. family nurses, nurses as case managers, etc.) and social care. To that end, firstly, the EFN has formulated specific input following the structure of the document and, secondly, the EFN provides examples of different initiatives at national level that are strengthening the focus on primary care.

Best regards,
Paul De Raeve
EFN General Secretary

EFN Input to the EU Public Consultation on "Primary Care"

EFN's specific comments/changes on the document

Section ABSTRACT

LINE 118 = A strong primary care system can be the starting point for effective referral AND DISCHARGE systems.

Section BACKGROUND

LINE 210 = effective referral AND DISCHARGE systems

Section 3.1.2 Health system goals

LINE 352 = TO ADD: and sufficient, ADEQUATELY SUPPORTED, HIGH EDUCATED, COMPETENT and motivated health WORKFORCE.

Section 3.1.3 Challenges for health systems in a changing world

LINE 473 = TO ADD: Investing in people's health and encouraging and promoting a healthy population are values in themselves, as they promote a healthy workforce able to actively participate in the labour market. Ref to EFN Position on investing in health. http://www.efnweb.be/wp-content/uploads/2014/01/EFN-Position-Paper-on-Investing-in-Health.pdf

LINE 488 = TO ADD: Lack of equipment, reduced supplies and inadequate staffing are placing patients' lives in danger on a daily basis all over Europe. Ref to: EFN, Caring in Crisis. The impact of the financial crisis on nurses and nursing. Available at http://www.efnweb.be/wp-content/uploads/2012/05/EFN-Report-on-the-Impact-of-the-Financial-Crisis-on-Nurses-and-Nursing-January-20122.pdf

Section 3.2.3 Developments in Primary care

Primary Care continues to adapt

LINE 668 = TO ADD: The case managers describe having the time and the skills to assess a mix of clinical and social problems, and then accessing the correct networks to help elderly people with multiple illnesses navigate a complex system of providers. Rationale: There is evidence highlighting the role and effectiveness of case managers as coordinators of different providers in primary care, especially for the management of long-term conditions.

Ref to:

- Lupari M. Chronic illness case management service (CICM). Royal College of Nursing, 2011 (http://www.rcn.org.uk/__data/assets/pdf_file/0009/319644/2010_RCN_research_6.3.1.pdf).

- Elwyn G1, Williams M, Roberts C, Newcombe RG, Vincent J. Case management by nurses in primary care: analysis of 73 'success stories'. Qual Prim Care. 2008;16(2):75-82.
- Freund et al. Study protocol Effectiveness and efficiency of primary care based case management for chronic diseases: rationale and design of a systematic review and meta-analysis of randomized and non-randomized trials. BMC Health Services Research 2010, 10:112

LINE 705 = replace telemedicine by TELEHEALTH and TELECARE.

The role of patients is changing

LINE 713 = replace “physician (GP)” by HEALTH PROFESSIONALS

LINE 715 = the sentence should be rephrased. Primary care is not only based on the relationship between the patient and the physician. Traditionally, many other health professionals have been involved in the delivery of primary care.

Primary Care coordinates people’s care

LINE 721 = replace “medical care needs” by HEALTHCARE NEEDS.

LINE 728 = replace “integrated medical records” by INTEGRATED PATIENT records.

LINE 732 – 742 = It seems the only professional involved in Primary Care are the doctors! There is a multidisciplinary team.

Primary care seeks to balance continuity and access

LINE 748 = continuity may be about a HEALTH AND SOCIAL CARE professional or health centre.

LINE 752 = in this section there is a strong focus on the specialisation role in primary care that goes against the evidence that suggest that the number of GPs and general care nurses is not enough compared to high levels of unneeded specialisation in the health systems. As the paragraph currently stands, it gives a wrong message on the need of investing in major specialisation in the health workforce whilst the evidence asks otherwise.

Primary care is collaborative

LINE 762 = Replace “specialisation” by “INTERDISCIPLINARY”. The term specialisation in this sentence is not appropriate as it is referring to the different links between different professionals and how all them work together in primary care.

LINE 772 = Replace “medial information” by PATIENTS/CITIZENS’ HEALTH INFORMATION.

The primary care workforce is changing

LINE 865 = Replace “medical history” by “PATIENTS HEALTH HISTORY”. In an integrated team as primary care needs, the patient history must be completed by numerous professionals, therefore, keeping isolate records from different professionals won’t contribute to the coordination needed.

Section 3.3 The role of referral systems in strengthening health system performance

General comment = this section lacks information about discharge and the needed coordination to facilitate the transfer of patients to home care to be followed by primary care.

LINE 965 = replace “GPs and others” by HEALTH PROFESSIONALS.

LINE 1017 = replace “GP” by HEALTH PROFESSIONAL.

LINE 1579 = replace “GP” by HEALTH PROFESSIONALS.

Section 3.3.3 Conclusion

LINE 1015 = Another point is the repeated use of –“patient-centred approach” which should be replaced by PERSON-CENTRED APPROACH. Patients should never be called consumers.

LINES 1016 – 1017 = comment: Generally the paper talks about interprofessional team work which is fine, but it simplifies repeatedly that this is a concern only including the relationship between the patient and the GP. We would highlight this by an example from the text, page 31: “this includes a form of personal relationship between the GP and the patient through a patient list “(The reference is wrong based on the previous wording in the sentence above as in 1012 – 1014).

Section 3.4.4 Paying providers to promote efficiency and quality in primary care delivery, including financial incentives to improve care coordination

LINES 1318 – 1321 = Comment: Compensation should be linked to the care activity. One of the problems with health systems is that they are organized based on the roles and interactions between the professions and financial control systems. There is evidence that in the Swedish primary care the visit to a physician is more beneficial economically for the care centre, than compared to visiting another profession which in the end leads to increasing costs for the society. Instead, the compensation should be linked to the care activity carried out not to *who* performs it.

Section 3.4.6 Conclusions and Recommendations

LINES 1576- 1580 = Comment: We believe that is to be wrong to strongly point only to the physician's responsibility for the patient's continuity in the conclusions and recommendations. We know today that this continuity should be attributed to nursing and this is also cost efficient. This offers great development opportunities in advance nurse practioners and case management for nurses. For example, in Sweden, there are several nurses led centres within the primary care, such as in ASTHMA/KOL, children’s healthcare centres and diabetes.

LINE 1630 = To add as a bullet point: Research on interprofessional teams needed for primary care with special emphasis on nurses advanced roles.

LINE 1666 = To add as a bullet point: stimulate interprofessional equitable partnerships.

LINE 1689 & 1690 = should read as follows: stimulate the development of integrated partnerships between citizens, patients, providers INCLUDING NURSES (ADVANCED NURSE PRACTITIONERS, NURSING HOMES, HOME BASED CARE) , SOCIAL SERVICES AND OTHER HEALTH PROFESSIONALS and informal caregivers in order to better address health challenges.

EFN additional information to support the document

In addition to the specific comments provided above, the EFN would like to share examples from different National Nurses Associations on care models working on primary care that are contributing to the integration of the health and social care systems and are being cost-effective. These examples described below form part of an EFN report of good practices in primary care that is available here: http://www.efnweb.be/wp-content/uploads/2012/05/EFN-Report-on-Caring-for-the-Future-Cost-Effective-Integrated-Care-Models-May-2012.pdf

FINLAND

Name of the initiative:

Case Manager in Chronic Care Model in Finnish Primary Health Care Settings.

Level of involvement:

Partner: The Finnish Nurses Association funds the programme, and owns the rights to the model.

Target groups:

Hospital care, work of professional people, self-care.

Aim of the initiative:

The Chronic Care Model brings a new Case Manager Operation Model for the most challenging client group – clients with multiple illnesses and who need a lot of support and services. A Case Manager is a nurse, a public health nurse, or a midwife with a long work experience in this branch and with the necessary supplementary education. In addition to client work, the Case Manager must develop the activity. Based on the Case Manager Approach, she or he must support the other nursing staff working in the organisation without the same supplementary education.

Brief description of the initiative:

The Chronic Care Model actively searches for patients who have the greatest ability to benefit from the services. Only the most solvent persons use new treatments and medication (first). The ability of these two groups to benefit from further efforts is often marginal. In this group, the further efforts bring the greatest health benefit.

Outcomes:

The objectives of the model: good availability of high-quality and necessary services, to improve client-centricity and freedom of choice, to secure skilful labour, to strengthen and develop management, to promote health, and to prevent illnesses.

Published information:

Mikko Nenonen, Senior Health Policy Advisor at Finnish Medical Association, Seija Muurinen, Special Researcher, National Institute for Health and Welfare, Finnish Nurses Association.

“How the Case Manager Model Is Managed?” [Miten johdetaan terveyshyötymallia] Premissi 2011; 1: 54–8.

GREECE

Name of the initiative:

Hellenic Red Cross is a volunteer organisation with a great contribution in the field of chronic diseases and elderly care.

Level of involvement:

Hellenic Nurses Association supports and promotes the works of Hellenic Red Cross.

Target groups

Elderly, chronic diseases, immigrants, homeless and poor, prisoners and other vulnerable groups of people.

Aim of the initiative:

The Red Cross is one of the largest non-governmental organisations in Greece with a complex project based on voluntary action and the immediate response of the citizens. Mobilises and always aims to alleviate human suffering in times of war and peace, supporting wounded, the sick, refugees, elderly, and people with financial difficulties and people from each vulnerable population group.

Brief description of the initiative:

Training
Service "Health Education"
Services for Primary Health Care
Service "Gerontology"
Service “Home Care"
Volunteer Nursing

Outcomes:
The results of the action of this organisation have a major impact on public health and the sustainability of health systems, especially to coordinate the care between primary and secondary care and between health, social and community care.

Published information:

Websites: http://www.redcross.gr/ and
http://www.samarites.gr/?section=983&language=en_US

More general examples of nurses involved at organisational level for the implementation of integrated care in chronic diseases are the following:

1. Hellenic Nurses Association is involved as associate partner in an EU Project for heart failure nurses. The aim of this project is to implement an e-platform for education, supporting and counselling heart failure nurses while they provide integrated care models in home settings and while they coordinate between primary and secondary care.

2. There is an initiative (called GALILEE) from the Greek Church, a hospice programme coordinated by a volunteer organisation led by an administrative board in which there aren't nurses, but nurses have a very important role at organisational level and for providing integrated care models for elderly people with chronic diseases in home settings. Hellenic Nurses Association supports and promotes this programme. However, it is not active nationwide (More info in website: http://www.galilee.gr/)

3. There is a non-profit organisation called "MERIMNA" which provides integrated care models in children with chronic diseases (cancer) in home settings. This organisation is not led by a nurse but by an administrative board in which there is a nurse. Nurses have a very important role at organisational level and for providing integrated care models in children with cancer and coordinating between primary and secondary care. Hellenic Nurses Association supports and promotes this programme. This is an organisation whose main purpose is caring for children and families facing a serious illness, a loss or death. The company was founded in 1995 by nine experienced scientists from the wider field of health and education, who work on interdisciplinary implementation of the objectives of Welfare. It is not currently active nationwide. (More info in website: http://www.merimna.org.gr)

4. The Ministry of Health announced recently that it is going to establish a national system called "Help at home" which will be staffed by health professionals (included nurses) in order to provide integrated care models for chronic diseases in home settings. Nurses will play a very important role in this initiative, coordinating between primary and secondary health care.

5. There are some patient organisations providing integrated care models for children with chronic diseases (cancer) in home settings. These organisations are not led by a nurse but by an administrative board without a nurse in it. Nurses have a very important role to play in providing integrated care models for children with cancer. The Hellenic Nurses Association supports and promotes these. They are not active nationwide. (More info in websites: http://floga.org.gr/, http://www.elpida.org, http://www.pisti.gr/).

PORTUGAL

Name of the initiative:

Community Health Care Unity (Portuguese acronym - UCC)

Level of involvement:

No direct involvement of the Ordem dos Enfermeiros (OE). Nevertheless, the OE is participating in the policy process of the ongoing Primary Health Care Reform, where the UCCs were one of the initial flagship initiatives. The OE has also provided support to all the colleagues that have presented applications and has created an observatory to monitor continuously the development and results of the process.

Target groups:

The people that are usually considered the most frail, vulnerable or at risk or with high levels of dependency in the community.

Aim of the initiative:

To provide, ensure and increase the access to health and social care to the population in their communities, especially those that are considered most frail or at risk.

Brief description of the initiative:

The Community Health Care Unity (Portuguese acronym - UCC) is a formal unit, created by governmental law, with a formal contract comprising a package of health services to be delivered and with indicators of quality to be achieved. The UCC is led by a specialist nurse and is constituted by a multidisciplinary group (dentists, nurses, physicians, physiotherapists, psychologists and support staff). The objectives are to ensure care to the most frail, vulnerable or at risk people or with high levels of dependency in the community. And also to promote health and provide health education, integrate family support networks and implement mobile health units, while coordinating with the other primary health care units, and local stakeholders.

Outcomes:

Not available yet. Although the initiative was quite successful in terms of adherence as a high number of applications were submitted (255) and presently 158 are operating with perceived success. However, the OE is apprehensive regarding the effects of the introduction of user fees to the delivery of nursing care. This measure that can also be seen as the recognition of the worth of nursing and nurses is, probably, going to have a detrimental effect on the care provided, as in a time of great economic crisis people can refrain due to the incapacity to pay for the care they need.

SWEDEN

Name of the initiative:

The Swedish Association of Health Professionals (Vårdförbundet) has presented 4 examples of integrated care: 1) National elderly care coordinator, 2) Healthcare coach, 3) "The Hip Line", 4) Systematic Improvement work.

Level of involvement:

1) National level, commissioned by the Government, 2) + 3) County/regional level, 4) Directly on activity level in the health care.

Target groups:

1) The most sick elderly in the population, 2) The most sick individuals, 3) Especially the elderly and the disabled, 4) The direct patient care in health care activities.

Aim of the initiative:

1) Improving and ordination the health care for the most sick elderly

2) Improve the health care chain and enhance efficiency in health care for chronically ill patients, often the elderly

3) For better treatment of hip fractures in the care chain with direct admission from the patient's home to a hospital ward and the streamlining of costs associated with treatment of hip fractures

4) Improve the direct patient care in a structured manner.

Brief description of the initiative:

1) The Government invested 4.3 billion Swedish kronor during the electoral period, in order to improve health care and care for the sickest elderly. A senior coordinator has been appointed to submit proposals on how to better coordinate care. The goal is to get the care of the elderly to interoperate better, in home health care, primary care, elderly care, the clinic, and in the hospital services.

2) A small group of patients with many diagnoses account for a quarter of all acute admissions to acute hospitals. Within a research-based development project, Stockholm County Council offers a Care coach to support and follow the most ill patients. The purpose of the healthcare coach system is to improve the quality of life and security of the most seriously ill and most care heavy patients. The care coaches are specially-trained nurses. They can support the patient to better understand their symptoms, their disease and its treatment. The goal is to prevent deterioration of the disease and help patients with the right care at the right time. Only the most seriously ill patients are offered to participate in the project. Patients are selected after rigorous analysis in order to identify patients at risk of abandonment and deterioration that can be prevented if proper actions are placed in the right time. Today 10% of the patients in Sweden account for almost 80 percent of the cost of care. Out of these, one percent accounts for a quarter of all acute admissions. An initial assessment shows that patients who have a "vårdcoach" experience a higher quality of life and a better social and physical life.

3) The "Hip line" started in order to reduce unnecessary emergency waiting times. The patient is placed directly into a care unit after x-ray and determined diagnosis. This has proven

to save costs. The method is developed by a care team, under the supervision of a nurse (Ami Hommel) whose Ph.D was about the method, see website below. Ami Hommel was awarded with “Salu-Ansvars award” (20000 euro) for the good results.

4) Systematic improvement work is made in a structured way in many places in the Swedish health care system today. It ranges from pharmaceutical inspection to time flows at a reception as well as nursing measures for various medical treatments. In Sweden, we have a national platform for the dissemination improvement knowledge (FBK), (http://www.lj.se/infopage.jsf?nodeId=39588). The platform is a forum and a meeting place that aims to establish improvement knowledge relevant to educations, to disseminate and develop knowledge on a national, regional and local level. Its member organisations all contribute to the building of networks. The national platform also acts as a driving force to develop improvement knowledge, not only on different levels but also between organisations, professions, academia, and healthcare activities. Examples of activities are: arrangement of workshops and meetings on different themes between practitioner educators, leaders and researchers, investigating the current status of the subject "improvement knowledge" in undergraduate education, further explorating the scientific and ideological underpinning of improvement knowledge in a Swedish context. The Platform has gained interest and engagement among patients, students, educators, clinicians, researchers and organisations with special interest in the area and can be described as a network of networks.

Outcomes:

1) The work of the national elderly care coordinator is too early in the process to measure any results yet. 2) The care coach has proved to be beneficial for both the economy and for the patient’s wellbeing. 3) The “Hip line” has also proved to be beneficial financially as well as for the patient’s wellbeing. 4) Improvement work has a positive impact on the patients, on the economy as well as on the working environment.

Published information:

1) National elderly care coordination, http://www.sweden.gov.se/sb/d/14471/a/185123
3) Summary of Ami Hommels doctoral thesis in English
http://www.lu.se/o.o.i.s?id=12588&postid=548642
4) Information about improvement knowledge on Qulturums webside
http://www.lj.se/infopage.jsf?nodeId=31736