

Brussels, 17 July 2020

## Eurocarers priorities and contributions eHSG work programme

*Eurocarers is pleased to, for the first time, be a member of the eHSG 2020-2022; to actively contribute to its work and provide the perspective of informal carers. Our aim is to act as a voice for informal carers, irrespective of their age or the particular health need of the person they are caring for.*

### ***Priorities for the eHSG 2021-2023 from the point of view of informal carers***

Key priorities from the point of view of *informal carers* that could be addressed during the mandate the eHSG and in view of the Terms of Reference are:

- **Health Data, including the development of a European electronic health record exchange format (EEHRXF).**

From perspective of informal carers key issues is that not only the health record is exchanged with health professionals but the format is such the needs and potential access by informal carers are built into the EHR by default (consent by default).

**Trust/ risk** - When going digital and sharing health data with other (health/social) professionals, what are the risks that sharing of such personal health data could be used in a discriminatory way, e.g. by age or disability, to limit access to public services such as e.g. access to school, health insurance, acute care etc? This has direct and serious consequences both for the patient but also their carers (personal finances, social exclusion, mental health etc)

- **Digital health services**

Requires access to Internet, and also ***informal carers need the necessary digital skills*** to access and make use of available eHealth solutions. If this cannot be ensured, an “analogue” option is required to bridge the gap. Informal carers are a vulnerable group who are already excluded, may be less tech-savvy, and so they often appreciate access to complementary in-person services such as emotional support, counselling.

Being able to access (health/social) web-based services is appreciated, especially during the COVID19 crisis. However, many times information was not up to date, or services normally available online were not any more accessible or temporarily withdrawn due to COVID19. **eHealth literacy** may also be addressed by the eHSG – as in where can informal carers turn to, to find reliable and trustworthy (health/health service) information.

eHealth/digital services should allow for an **integrated and seamless access to both health and social care services** as needs of informal carers usually spans both these care domains given the long-term nature of their care provision.

- **Health data protection and privacy issues**

Access to eHealth services by the informal carer on behalf of the care-dependent person. Appropriate identification mechanisms of the informal carer as they should be considered are part of the “care team”. The **health data** needs to be in a format that is not only accessed and used by healthcare professionals but also adequately and appropriately **involves and is shared with the informal carer**. Potential issues of **consent, confidentiality, and privacy** with regard to the sharing of health data (possibly relates to cybersecurity).

- **Digital tools for citizen empowerment and person centred care**

Digital health technologies are one **important component in the toolbox of support measures for carers**, along with affordable access to additional community-based care services and other support measures e.g. respite care, emotional support, counselling, peer support, home care. eHealth solutions enable and facilitate the independence of the care-dependent person thus improving their quality of life, but can crucially also be valuable in improving the wellbeing and quality of life of the informal carer.

There is a need to **codesign of eHealth solutions that bridge the gap between informal carers and professional carers/care workers**

See Eurocarers updated fact sheet is available [here](#).

- **Other cross cutting aspects** Ethical/legal issues:

The shift of care from hospital to home, early discharge from hospital etc, often enabled through telehealth and other digital solutions, has further put the balance of care onto patients themselves and their informal carers. This also raises the question of who carries (healthcare professional) responsibility when more and more complex care is provided (by an informal carer) at home rather than in the hospital setting?

### **Type of contributions Eurocarers can provide to eHSG:**

Eurocarers can able to provide some limited time e.g. to support the work of a sub-group, by consulting with our members of the following active Working Groups:

- the ERWG **Eurocarers Research Working Group** (for research/evidence-related issues) and
- the EPWG **Eurocarers Policy Working Group** (for policy-related issues that impact upon informal care)