

## Input to Call for Evidence on European Care Strategy

[HIV Outcomes](#), a network comprising of over 35 individuals and organisations jointly advocating for improving the well-being of people living with HIV, **welcomes the European Care Strategy and its foreseen reforms in long-term care (LTC)**. HIV Outcomes is pleased that improving well-being for those in care is one of the Strategy's main objectives, as highlighted in the ['2021 LTC in EU' report](#) (hereinafter the report).

In line with our input to [Green Paper on Ageing](#), **this Strategy should seek to improve well-being for people in LTC and living with a long-term condition**. According to the European Health Interview Survey (EHIS),<sup>1</sup> **people living with long-term conditions self-report poorer well-being than the general population, and often face greater LTC dependency**.<sup>2</sup> As highlighted in the [Green Paper on Ageing](#) and the Commission's Report on ['The Impact of Demographic Change'](#), **the growing burden of long-term conditions and multimorbidity associated with the increase in life expectancy**, will become a major challenge for care systems in the coming future, so the well-being of people in care living with such conditions should be a key target of this Strategy.

It is known how complex it is to improve well-being for those in care living with a long-term condition. We, therefore, call for the **adoption of integrated models of LTC based on multidisciplinary and cross-sectoral cooperation between care and healthcare practitioners, as they are best positioned to meet the needs and improve well-being for this population**.<sup>3</sup> We fully concur with the report in that LTC and healthcare policy should be seen together because not only does healthcare policy have a direct impact on LTC, but also greater dependency of LTC and healthcare services is reported among those living with long-term conditions.<sup>4</sup> **The provision of integrated LTC is thus essential and should be encouraged in this Strategy**.

In moving towards integrated models of LTC, we want to raise awareness of the importance of **health-related quality of life (HRQoL) – an umbrella indicator to capture the multi-dimensional issues challenging well-being for those living with a long-term condition** with the help of self-assessment tools.<sup>5</sup> Traditionally, HRQoL is used in health technology assessment, but it is gaining prominence in post clinical trials, more precisely in oncology and HIV as a guiding paradigm towards more targeted and person-centred models of care. As such, **it can help assess the quality of LTC by offering a more precise and measurable indicator than quality of life (QoL)**.<sup>6</sup>

<sup>1</sup> European Commission, Directorate-General for Employment, Social Affairs and Inclusion, *Long-term care report : trends, challenges and opportunities in an ageing society. Volume II, Country profiles*, Publications Office, 2021, p. 25.

<sup>2</sup> European Commission, Directorate-General for Employment, Social Affairs and Inclusion, *Long-term care report : trends, challenges and opportunities in an ageing society. Volume II, Country profiles*, Publications Office, 2021, p. 25.

<sup>3</sup> Tu et al. (2013). Adoption of the chronic care model to improve HIV care In a marginalized, largely aboriginal population. *Canadian family physician Medecin de famille canadien*, 59, pp. 650-657.

<sup>4</sup> Entwistle, V. (2018). Why Health and Social Care Support for People with Long-Term Conditions Should be Oriented Towards Enabling Them to Live Well. *Health Care Anal.* 2018; 26(1), p. 48–65

<sup>5</sup> HIV Outcomes (2021). Advocacy toolbox: factsheet on the health-related quality of life of people living with HIV. Retrieved from <https://hivoutcomes.eu/advocacy-toolbox/>

<sup>6</sup> Zubritsky, C. (2013). Health-related Quality of Life: Expanding a Conceptual Framework to Include Older Adults Who Receive Long-term Services and Supports, *The Gerontologist*, 53(2), pp. 205-210; Igarashi, A. (2020). Quality Assurance in Long-Term Care and Development of Quality Indicators in Japan. *Gerontology and Geriatric Medicine*, 6, pp. 1-7.

### INITIATIVE PARTNERS



### OBSERVER MEMBERS

- European AIDS Clinical Society (EACS)
- European Center for Disease Prevention and Control (ECDC)
- Fast Track Cities
- UNAIDS
- UNITE

People living with HIV are affected by these issues and **should be also targeted in the Strategy. HIV has turned into a long-term condition thanks to recent therapy breakthroughs, yet they report poorer well-being** than the general population.<sup>7</sup> People ageing with HIV demand **quality LTC to manage the needs associated with the condition and its often disabling co-morbidities**, such as mental disorders, osteoporosis, respiratory diseases, etc.<sup>8</sup> Worryingly, the impact of these co-morbidities on well-being may be exacerbated by psychosocial factors such as discrimination and stigma, and by the other comorbidities linked to ageing.<sup>9,10</sup>

In care settings, it has been reported **episodes of stigma and discrimination towards people living with HIV and/or other stigmatised conditions** (e.g. mental disorders, skin diseases, obesity, etc.)<sup>11</sup> Protecting vulnerable individuals from abuse or neglect is rightly reflected in the report as a prerequisite for quality LTC.<sup>12</sup> The Strategy should, therefore, **include actions aimed at tackling stigma and discrimination and at educating care workers**.<sup>13</sup> In addition, with the increase in life expectancy and the breakthroughs in retroviral therapy, the number of old people living with HIV is larger than ever and can be subject to issues of triple stigma related to ageism, HIV and anti-LGTBQ prejudice in care settings.<sup>14</sup>

In view of this evidence, we hence recommend that the European Care Strategy:

1. calls for the **adoption of integrated models of LTC** as best positioned to meet the needs of those in LTC and living with long-term conditions,
2. recognises **HRQoL as a valuable indicator to measure well-being and guide policy reforms** towards more targeted and person-centred models of LTC,
3. addresses **stigma and discrimination in care settings** (e.g. towards people living with HIV and other stigmatised conditions).

HIV Outcomes reiterates its support for this proposal and remains at your disposal for any questions.

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<sup>7</sup> HIV Outcomes (2021). Advocacy toolbox: factsheet on the health-related quality of life of people living with HIV. Retrieved from <https://hivoutcomes.eu/advocacy-toolbox/>

<sup>8</sup> Merritt et al., (2013). HIV and disability: a pilot study exploring the use of the Assessment of Motor and Process Skills to measure daily life performance. *Journal of the International AIDS Society*, 16(1); Benito et al. (2012). Pulmonary infections in HIV-infected patients: an update in the 21<sup>st</sup> century. *European Respiratory Journal*, 39, PP. 730-745; Hileman et al., (2015). Bone loss in HIV—a contemporary review. *Current opinion in endocrinology, diabetes and obesity*, 22(6), pp. 446-451; HIV Outcomes (2021). Advocacy toolbox: factsheet on the comorbidities of people living with HIV. Retrieved from <https://hivoutcomes.eu/advocacy-toolbox/>

<sup>9</sup> Bernard et al., (2016). Addressing the medical and support service needs of people living with HIV (PLWH) through Program Collaboration and Service Integration (PCSI). *Calif J Health Promot*, 14(1), pp. 1-14.

<sup>10</sup> Collins et al. (2020). What It Means to Age With HIV Infection Years Gained Are Not Comorbidity Free. *JAMA Netw Open*. 2020;3(6), pp. 1-3.

<sup>11</sup> Depla et al. (2005). The role of stigma in the quality of life of older adults with severe mental illness. *International Journal of Geriatric Psychiatry*, 20(2), pp. 146-153; Hinshaw, S. and Stier, A. (2008). Stigma as related to mental disorders. *Annual Review of Clinical Psychology*, 4(1), pp. 367-393; Lakuta, P., et al. (2017). How does stigma affect people with psoriasis? *Postepy Dermatol Alergol*, 34(1), pp. 36-41; Puhl, R. and Heuer, C. A. (2009). The stigma of obesity: a review and update. *Epidemiology* (17), pp. 941-964;

<sup>12</sup> European Commission, Directorate-General for Employment, Social Affairs and Inclusion, *Long-term care report : trends, challenges and opportunities in an ageing society. Volume II, Country profiles*, Publications Office, 2021, p. 22.

<sup>13</sup> HIV Outcomes (2021). Advocacy toolbox: factsheet on stigma and discrimination for people living with HIV. Retrieved from <https://hivoutcomes.eu/advocacy-toolbox/>; Beals et al. (2009). Stigma Management and Well-Being: The Role of Perceived Social Support, Emotional Processing, and Suppression. *Personality and Social Psychology Bulletin*, 35(7), pp. 867-879.

<sup>14</sup> Peate, I. (2015). The health-care needs of the older gay man living with HIV. *Care of the older person*, 18(10), pp. 492-495.