



EUROPEAN SOCIETY OF MEDICINE

GLOBAL HEALTH CENTER · HEALTH EQUITY COMMITTEE

19 October 2026

<https://doi.org/10.18103/ghc.01>

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Response to the public consultation on the draft Global Standards for Long-Term Care

Health Equity Committee, Global Health Center, European Society of Medicine

The Health Equity Committee of the European Society of Medicine welcomes the opportunity to comment on the consultation draft of the Global Standards for Long-Term Care.¹ As the first global framework of its kind, the draft gives every country, whatever the maturity of its long-term care system, a shared reference for what good care should provide and protect.

We particularly support three features of the draft:

- its treatment of equity as part of rights-based care: “a rights-based approach demands that appropriate care be accessible to all, with priority attention to those currently underserved” (Chapter 1, section 3.1);
- the standards on equity and financial protection (Standards 22 and 23), which address cost, one of the main barriers to care;
- its phased approach to implementation, which makes the standards usable in countries that have no formal long-term care system.

Our comments concern the health-care dimension of long-term care. They share a single aim: to carry commitments that the draft already makes into its standards, quality statements and indicative measures, so that countries can act on them and monitor progress. Each recommendation includes a version suited to settings with limited resources. Throughout, we read equity as the draft does: care that is accessible to all, with additional support in proportion to people’s needs and the barriers they face, rather than identical provision regardless of circumstance.

SUMMARY OF RECOMMENDATIONS

1. **Pain.** Turn the principle that “no one should suffer unnecessary pain at any stage” into a quality statement on regular pain assessment and relief, with an indicative measure.
 2. **Prevention.** Name the preventive care with the strongest evidence (strength and balance activity, vaccination and oral care) in assessment and care planning, at home as well as in facilities, and act on the social needs that assessment identifies.
 3. **Specialist advice at a distance.** Recognize teleconsultation and tele-mentoring as ways of bringing specialist advice to people cared for at home and in rural areas, as a complement to in-person care where it is available, and as a lifeline where it is not.
 4. **Decisions that follow the person’s goals.** State that decisions on investigation, treatment and hospital transfer rest on the person’s clinical needs, the course of their condition, and their documented goals and preferences, not on age, a diagnosis of dementia or the care setting, and that they are reached through shared decision-making.
 5. **Emergency preparedness.** Add a quality statement requiring tested emergency plans, in facilities and for home-based care, covering extreme heat, disease outbreaks, natural disasters, power or water supply failures and armed conflict.
 6. **Hearing from those least often heard.** Include in the measurement of care recipients’ experience people who face barriers related to language, literacy, education, income, ethnicity, religion, sex or culture.
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1. Make the commitment on pain measurable

The draft states that “no one should suffer unnecessary pain at any stage” (Chapter 1, section 2.3). We strongly agree. At present, however, this commitment does not appear in any standard, quality statement or indicative measure, and unrelieved pain is not among the harms listed under the quality principle (section 3.5), alongside falls, pressure injuries and medication errors.

Pain is common among people who receive long-term care, and it is most likely to be missed in those least able to report it: people living with dementia, people with communication difficulties, and people who do not share a language with those who care for them.² Unrecognized pain often shows itself as agitation or distress. In a cluster-randomized trial in nursing homes, systematic treatment of pain reduced agitation among residents with dementia,³ which links pain directly to the draft’s concern about chemical restraint (Quality Statement 5.2).

Unrelieved pain is also a question of rights. The UN Special Rapporteur on torture has observed that where a failure to provide pain treatment “condemns patients to unnecessary suffering from pain”, States “not only fall foul of the right to health but may also violate an affirmative obligation under the prohibition of torture and ill-treatment”.⁴

Some countries have already written pain relief into national policy: Brazil’s National Palliative Care Policy, adopted in 2024, defines palliative care in its public health system as health actions and services for the relief of pain, suffering and other symptoms.⁵

We recommend:

- a quality statement in Standard 3 (community-based health services) and Standard 6 (service provision in long-term care facilities), for example:

“People receiving long-term care are assessed for pain at regular intervals, using validated observational tools where self-report is not possible, and those with pain have a documented plan for its relief that is reviewed for effect.”

- including pain in comprehensive needs assessment (Quality Statement 1.2) and in care plans (Quality Statements 1.3 and 6.1), with training for care workers and family carers in recognizing the signs of pain in people who cannot report it, such as facial expressions of distress, restlessness and changes in sleep, using tools such as the PAINAD scale;⁶
- access to essential pain medicines, including controlled medicines where clinically indicated, in line with resolution WHA67.19,⁷ alongside non-pharmacological measures such as repositioning, heat or cold, massage and relaxation;
- naming unrelieved pain among the harms in section 3.5 and among the quality indicators of Standard 30.

Indicative measures:

- Process: proportion of care recipients assessed for pain in the past three months, with a validated observational tool where self-report is not possible.
- Outcome: proportion of care recipients with identified pain whose pain was reduced at review.

WHERE RESOURCES ARE LIMITED: Community health workers and family carers are trained to ask about pain and to recognize its signs, with a clear route to a health worker who can treat it.

2. Name the preventive care that keeps people well

The draft describes long-term care as “the long tail of prevention” and states that “prevention, therapy and reablement should be integrated into long-term care, not replaced by it” (section 2.2). The standards do not yet say which preventive measures should be integrated. Physical activity is not addressed in any standard. Quality Statement 7.1 rightly expects residents and staff of facilities to be “fully vaccinated against appropriate conditions”, but there is no equivalent for people who receive care at home. Oral health is not addressed.

People who receive care at home are often unable to leave it, and are therefore the least able to reach the clinics where preventive services are delivered. Vaccination efforts should therefore be judged not only by doses administered or overall coverage, but by whether they reach the older people who are most vulnerable and least well served.

We recommend:

- **Physical activity:** individualized activity emphasizing balance and strength, included in assessment and care planning (Quality Statements 1.2, 1.3 and 6.1) and in the fall-prevention protocols of Quality Statement 2.3. WHO’s guidelines recommend such activity on three or more days a week for older adults, including those living with chronic conditions or disability,⁸ and the ICOPE guidelines recommend multimodal exercise for older people with declining physical capacity.⁹
- **Vaccination:** extending the expectation in Quality Statement 7.1 to home and community-based care (Quality Statement 3.1), so that people receiving care at home are offered the vaccines recommended for older adults under national schedules, such as influenza, pneumococcal, COVID-19, respiratory syncytial

virus and herpes zoster vaccines, at home if they cannot travel, with accessible information on their benefits and possible side effects so that people can make informed decisions, consistent with the life-course approach of Immunization Agenda 2030.¹⁰

- **Oral health:** including oral health in needs assessment and daily personal care, with mouth care, help with dentures and referral for treatment, consistent with the WHO Global strategy and action plan on oral health 2023–2030.¹¹
- **Social needs:** section 2.5 of the draft asks that assessment explicitly consider the social determinants of health. We suggest carrying this into Quality Statement 1.2, so that assessment records needs such as inadequate food, heating, housing or income and social isolation, and leads to support or referral through the person's care coordinator (Quality Statement 1.4).

Indicative measures:

- Vaccination coverage among care recipients, at home and in facilities, compared with the older population as a whole, and disaggregated where feasible by disability, income, location and care setting.
- Proportion of eligible care recipients unable to leave home who are offered and receive recommended vaccines at home, and the documented reasons for missed or delayed vaccinations.
- Proportion of home-based and facility-based long-term care services with protocols for vaccination assessment, referral, administration, documentation and follow-up, coordinated with primary care.
- Proportion of care recipients with a physical activity plan, and with an oral health check in the past year.
- Proportion of care recipients with social needs identified at assessment who receive support or referral within an agreed time.

WHERE RESOURCES ARE LIMITED: Community health workers include simple strength and balance exercises, a check of vaccination status, a look at oral health and a question about food, heating and money in routine home visits.

3. Bring specialist advice to where people live

Quality Statement 3.1 aims for people to receive health services at home “without requiring admission to hospital or other health facilities”, and Quality Statement 17.1 calls for supervision adapted “to the realities of community-based and home-care contexts”. The draft does not, however, address telehealth or remote support for care workers.

In rural and low-income areas, the scarcest resource is often specialist expertise in the care of older people, palliative care, wound care and mental health, rather than buildings, and people who receive long-term care are the least able to travel to it. Tele-mentoring links local health and care workers with specialist teams through regular, case-based sessions. In the Project ECHO model, primary care clinicians in rural New Mexico supported in this way achieved hepatitis C cure rates equivalent to those of a university specialist clinic,¹² and during the COVID-19 pandemic the model's nursing home network reached 9058 nursing homes in the United States.¹³

We recommend implementation guidance in Quality Statements 3.2, 14.3 and 17.1 so that:

- providers, care workers and community health workers have access to specialist advice by teleconsultation, and to case-based tele-mentoring, within agreed response times;
- remote support complements in-person assessment and care where it is available, and does not replace it; for people who are isolated or cannot reach in-person care, it may be the only timely route to specialist

advice, including for triage decisions;

- services work over the telephone and low-bandwidth connections; where people are expected to take part digitally, they have access to suitable devices, affordable connectivity, accessible software and support with digital skills, as the draft already recognizes for carer training (Quality Statement 11.2); and people who cannot or prefer not to use technology keep an effective non-digital route to advice and care;
- consent, confidentiality and data protection are ensured, consistent with WHO's Global strategy on digital health.¹⁴

Indicative measure:

- Proportion of long-term care providers, by rural and urban location, with access to specialist advice within an agreed time.

WHERE RESOURCES ARE LIMITED: A named specialist contact, reachable by telephone, for community health workers and care workers, together with periodic group case discussions.

4. Base care decisions on the person's goals, not on age, diagnosis or setting

The draft affirms “the right to make decisions about one's own care and daily life” and holds that “shared decision-making is the norm for all” (section 3.1); states that acute intercurrent problems are addressed with curative intent where appropriate, “with decisions based on a person-centred approach” (section 2.3); asks facilities to “include more advanced care planning to enable compliance with residents' wishes” (Quality Statement 6.1); and presumes legal capacity, with supported decision-making (Quality Statement 28.4).

What the draft does not yet address explicitly is a quieter risk: that people who receive long-term care are offered less diagnosis and treatment than others because of their age, a diagnosis of dementia or where they live, rather than because of their needs or wishes. WHO's Global report on ageism documents age-based restrictions on access to health care.¹⁵ Such assumptions fall hardest on those least able to advocate for themselves.

We recommend:

- in Quality Statements 3.2 and 6.2, a sentence such as:

“Decisions about investigation, treatment, referral and hospital transfer are based on the person's clinical needs, the course of their condition, and their documented goals and preferences, and are not limited by age, a diagnosis of dementia or the care setting alone.”

- shared decision-making in care planning and treatment decisions, at home and in facilities (Quality Statements 1.3 and 6.1): the person receives accessible information about the options and their likely benefits and burdens, and decides together with care providers in the light of what matters to them, involving family members and carers as the person wishes;
- extending advance care planning to home and community-based care (Quality Statement 1.3): conversations about goals and preferences that are documented, reviewed regularly and whenever the person's health changes, and conducted in clear language adapted to the person's culture, cognition and level of education, using supported decision-making where needed and involving family members as the person wishes.

This protects people both from under-treatment and from treatment they do not want, and it is consistent with the draft's aim of avoiding unnecessary hospital admissions.

Indicative measures:

- Process: proportion of care recipients whose goals and preferences are documented and have been reviewed in the past year.
- Outcome: proportion of hospital transfers and major treatment decisions consistent with the person's documented preferences.

WHERE RESOURCES ARE LIMITED: Nurses or community health workers hold simple conversations about goals of care and record the outcome in a record held by the person.

5. Make emergency preparedness a standard

The draft identifies emergency and crisis response as a core function of long-term care systems and observes that “the COVID-19 pandemic exposed emergency response as a major failure point in long-term care systems globally” (section 2.4). The standards address infection prevention (Quality Statement 7.1), emergency respite (Quality Statement 10.3) and the protection of workers in outbreaks (Quality Statement 16.2), but no quality statement requires providers or authorities to prepare for emergencies more broadly.

People who depend on others for daily care are among the least able to evacuate, to keep cool, or to manage when power, water, medicines or care workers are interrupted, and older people are at particular risk during heatwaves.¹⁶ People cared for at home can be invisible to emergency services.

We recommend a quality statement under Standard 7, with parallel provisions for home and community-based care (Standard 2) and for coordination (Standard 29), for example:

“Long-term care providers and responsible authorities have written emergency plans, tested at least annually, that protect care recipients during extreme heat, disease outbreaks, natural disasters, power or water supply failures and armed conflict, and that ensure continuity of care, medicines and records.”

Implementation guidance could cover the evacuation of people with limited mobility; cooling and backup power for essential equipment; continuity of medicines, oxygen, vaccines and records; a register, held with the consent of the person or, where appropriate, their family or legal representative, of people who depend on home-based or facility-based long-term care, so that emergency services can reach them; protection of care workers; communication with families; and the participation of care recipients and their families in planning.

For disease outbreaks in particular, we suggest that preparedness also include long-term care facilities and home-based care in outbreak surveillance and early-warning systems; include older people, including those living with frailty or multiple conditions, in the clinical evaluation of new vaccines and treatments; and ensure that, where vaccines or other medical countermeasures are scarce, allocation is based on clinical vulnerability and exposure risk, without discrimination on grounds of age, disability, income or place of residence.

Indicative measures:

- Proportion of providers with an emergency plan tested in the past 12 months.
- Proportion of providers with contingency plans to maintain access to medicines, oxygen, vaccination, diagnostics and staff during public health emergencies.
- Inclusion of people who depend on home-based or facility-based long-term care in local emergency plans.

- Inclusion of long-term care facilities and home-based care services in outbreak surveillance and early-warning systems.

WHERE RESOURCES ARE LIMITED: A named local contact, and a list kept by community health workers or volunteers of people who would need help in an emergency.

6. Further comment: hearing from those least often heard

Quality Statement 30.2 rightly makes care recipients' experience a core measure, with adaptations for cognitive impairment. We suggest that it also name people who face barriers related to language, literacy, education, income, ethnicity, religion, sex or culture, and that it recognize participatory methods suited to settings where formal surveys are not yet feasible. In citizen-science approaches such as the Our Voice method, older residents document what helps or hinders their health in their own surroundings and work with local decision-makers on practical improvements.¹⁷ Such methods could also strengthen community participation (Standard 4) and stakeholder participation in governance (Quality Statement 29.3).

We hope these comments are useful. None of them asks WHO to adopt a new principle: each seeks to carry a commitment already present in the draft into its standards, quality statements and indicative measures. Members of the Committee would be glad to review the revised draft or to contribute to the implementation guidance that WHO plans to develop.

Yours sincerely,



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