

Measuring the outcomes and comparing the quality of long-term care services

AIM decided to write this reflection paper in order to feed into the discussions currently taking place at European Level on the establishment of EU indicators for long-term care (LTC).

The topic of outcome measurement and quality assurance of long-term care services has become more relevant than ever in view of the Covid19 pandemic. The outbreak is indeed deeply affecting older people (in need of LTC or not), their carers, families and friends. As AGE-Platform Europe rightly highlights¹, the current coronavirus pandemic poses distinct threats to the equal enjoyment of human rights by older people. They can suffer from mistreatment, solitude, isolation. They see their access to healthcare and medicines limited, sometimes on basis of age discrimination. And their dignity is under stress, while ageist comments spread in the media, conveying a pejorative image of our older generations. Their carers, who work front-line, often lack the necessary material and protective equipment to look after their patients, putting their own health but also their patients' and families' in danger. Some contract the disease, which puts further pressure on an already preexisting shortage of staff.

Such a catastrophic situation speaks for the establishment of guidelines or standards of quality, as well as for a wider strategy on pandemic preparedness specifically targeted at vulnerable groups (a topic which goes beyond the focus of this paper). A first step in setting those standards is measuring outcomes and agreeing on what to measure and how. This paper gives some hints on both questions.

AIM is convinced of the added value and of the potential role that the EU can play in achieving better quality in long-term care services. Beyond the exchange of best practices - note that our [LTC position paper](#) calls for the establishment of a Steering Group by the European Commission- , a common definition and understanding of LTC, standardized assessment instruments and guidelines, as well as outcome and quality indicators are concrete achievements which would greatly contribute to the improvement of services across the EU.

¹ AGE-Platform Europe, 2020

What is quality in long-term care? ²

The following principles should be applied for services to be qualitative:

- **Non-discrimination:** Quality services should be provided without discrimination and in the respect of human rights and dignity.
- **Person-centeredness:** Services should be person-centred and timely address the changing needs of individuals. Their main objective should be to improve users' quality of life while respecting their wishes and putting them at the centre of service planning and care management. Services should take into account physical, intellectual, cultural and social perspectives of older people, but also of their families or other relatives. They should be driven by the needs of both patients and carers.
- **Prevention:** Services should aim at preventing the deterioration of health and well-being; and promote the capacity to live independently, for example, by empowering patients from an early stage. In the same vein, older people should be empowered to regain the ability or to learn to cope with their limitations.
- **Availability & accessibility:** Services should be available and accessible. Their geographic proximity is important, but also the provision of impartial, comprehensive and adapted information on available services.
- **Transparency:** Services should be transparent and information to users clear and comprehensible. LTC often relies on a variety of services which can be difficult to navigate.
- **Integration & continuity:** Care should be integrated. Services should be comprehensive and take into account the different needs and preferences of beneficiaries, as well as their capabilities. Integration of social and health care as well as the continuity in the delivery of those services should also be ensured, following a life-cycle approach. A strong collaboration between care providers allows to facilitate the transitions between different services.
- **Outcome-orientation:** Services should also be outcome-oriented and evidence-based. Improving the health and well-being of users but also of their carers and families should remain the main concern.
- **Resilience:** As the current Covid-19 outbreak teaches us, services have to be resilient. Not only is that resilience to be measured in financial terms but also in view of all the above-mentioned aspects which are to be ensured also in times of crisis.

What should be measured?

When discussing LTC quality, literature usually refers to Donabedian's distinction between structures or input (equipments, drugs, facilities), processes or the use of resources (waiting lists, intervention rates, referral rates, workforce training) and outcomes (mortality, disability, quality of life, functional ability, satisfaction).

It is worth noting that the aspects to be measured and therefore the indicators will be dependent on the type of organisation of LTC: formal institutional care, formal home-based care, formal home nursing

² AIM agrees with the principles put forward by the WeDo project for the establishment of a quality framework for long-term care services (Wedo Partnership, 2012)

care and informal home care.³ Some indicators might also vary according to the patients' healthcare status or dependency levels (e.g. dementia-specific quality of life indicator). However, some guiding cross-cutting principles can be highlighted, as the reader will see below.

Keeping the above-mentioned requisites in mind, which aspects should be taken into account when measuring the outcomes and the quality of LTC services?

As a first step, it should be taken into account that there is a need to achieve a **common understanding of long-term care**. Dandi (2012) highlights that Member States use a variety of definitions of LTC that do not always concur. AIM therefore calls for a common definition of LTC at European level.

As a second step, reliable and **standardized assessment instruments and guidelines** are necessary. Quality depends on how well a service covers needs. The assessment of these needs is therefore key. If a sufficient level of cross countries comparability is to be ensured, standards for the assessment of needs should be developed and agreed at EU level. (e.g. Residents Assessment Protocols⁴) AIM calls for the establishment of instruments and guidelines for standardized assessment of LTC needs at European Level.

a. Structural Indicators

Indicators of structural quality refer to the characteristics of the providers, their tools and resources, and the physical and organisational setting. Those indicators should pay specific attention to (note that the following list is not exhaustive):

- **Affordability:** Access to the essential services should not be dependent on their financial resources. If services are not free of charge a wide range of financial or in-kind support should be available so as to help to cover costs. This aspect is key in the evaluation. As good as a service can be, it will not be of much use if it is not affordable.
- **Needs assessment:** As already mentioned, standardised assessment instruments and guidelines are necessary to evaluate the needs of the elderly and adopt service provision accordingly. It is, according to us, a sine-qua-non condition to the development of high quality person-centred services.
- **Care facilities and employees:** The number of care facilities, their equipment, the size of staff and the efficient organisation of care is of course a crucial element if the accessibility and quality of care is to be ensured. These aspects are usually evaluated by Member States. When it comes to formal care, it is probably the easiest indicator to develop. When it comes to informal care, structural indicators are more difficult to evaluate. The points listed below should be part of both formal and informal care assessment.
- **Qualification** of the (social and healthcare) staff and training levels: The qualifications of the personnel are of course also relevant for the quality of care provision. Formal carers and other staff should be qualified and follow continuous training. Curricula of doctors should also be adapted and include specific training in view of ageing populations. Minimum qualifications or standard curriculum for formal carers should also be established, especially for the personnel that carries out actions which require high qualification. As far as informal carers are concerned, support and training should be provided regularly.

³ Dandi, 2012

⁴ OECD, 2003

- **Adaptation:** Facilities and equipments should be adapted and made accessible for all patients, including disabled elderly. This point concerns institutional care but also care at home, which requires the adaptation of people's house according to their needs, capacities and wishes.

b. Process indicators

Process indicators capture the activities within and between care workers and service users such as punctuality, methods for lifting, feeding or bathing etc.

Among those indicators, it is vital to include measurements on

- **Patients' and carers' involvement:** The wishes of patients and their needs as well as their carers' and families' should be taken into account in service planning and care management. The will and choices of elderly people should be respected, just as their religious, ethical and social background through all phases of their lives. Non-discrimination should be a guiding principle.
- The respect of individuals' **fundamental rights:** all processes should respect individuals' dignity and fundamental rights. If a person can no longer be actively included in its care planning, the third party or advocate should take decisions that respect its wishes, needs, and rights.
- Support of **autonomy:** services should indeed support autonomy as much as possible, including through home adaptation, use of assistive devices or rehabilitation nursing. Early health promotion and prevention of age related diseases is key. The focus should on the person's health and abilities, rather than on his or her illness or incapacities
- **Monitoring and evaluation:** Internal evaluations should be carried out regularly and improvement proposals made and implemented on that basis. All actors should be involved. A dynamic and continuous quality improvement should allow examining the actions to be taken in the light of the results of the internal evaluation.
- Patients' and carers' **safety:** According to Dandi (2012), safety is the most neglected dimension when it comes to assessment. It is vital to take into account safety and risk factors in different areas in order to properly protect both users and their carers (application of health and safety standards; prevention of crisis situations; implementation of a conflict resolution service; support techniques offering individual and collective security relating to professional practices and guaranteeing basic human rights etc.)
- **Continuity and integration** of care: Consistency and continuity of actions and operations between social and health workers/providers, (informal) carers, elderly people and their families should be assessed. Inter-institutional and inter-professional cooperation and collaboration around and with the user but also the inclusion of caregivers and relatives in the coordination of care are indeed important elements. The coordination between health and social services should be ensured. Social assistance should be provided also in institutional settings, an aspect which is often forgotten.
- **Support to and training of caregivers:** Both formal and informal caregivers should be properly supported in their practices in different ways, such as: training, meetings for the exchange of techniques, private meetings etc. Personalised monitoring systems of services to both discuss care plans but also the means and working conditions of carers, should be put in place, in relation with the beneficiary and caregiver and in agreement with the beneficiary. Training and support should also be available to informal carers and relatives, who are the backbone of LTC systems. This issue is all the more important given the problem of staff shortages and the challenge of retaining nurses faced by Member States.

- **Comprehensive information:** Information to users and their relatives should be comprehensive, easy to understand and transparent. Information about social services supplier's aims, goals, functions and structure but also on invoicing should be easily accessible.
- **Medication :** Polypharmacy should be avoided and medication limited whenever possible. Medication should be subject to prescription. Hazardous drug combinations should be prevented and medication reviews regularly organised.

c. *Outcome indicators*

Outcome indicators relate to the final results of the activity, such as the functional status of individuals, their satisfaction with care and their quality of life. As David Edvardsson et al. (2019) highlights, research and data concerning LTC and its outcomes often focus on functional decline, neuropsychiatric symptoms, mortality (after interventions), reoperations, unplanned hospitalisations, health status or lack of safety (falls, unintended weight loss, etc.).

Yet, if these aspects are of course to be evaluated, health is more than merely the absence of disease and a reduction in those negative conditions does not necessarily ensure patients' well-being. A shift is needed to a **more positive view** of ageing. Indicators should take it into account and better balance negative and positive outcomes.⁵ While structural and process indicators are quite simple to identify and collect, outcome indicators are scarce in most countries.

Outcome indicators have indeed been judged to be the most difficult to collect and to interpret. Their measurement should cover areas such as symptom management, especially pain management; functional level; harm-free care, (that is, the absence of avoidable, adverse outcomes such as falls) but also well-being, quality of life and personhood (described as "letting people be people").⁶ Those last dimensions are key in the achievement of **patient-centred care**, which should, in our view, remain the main objective. Therefore, we highlight the need to include the following aspects in the establishment of outcome indicators – once more, the list is not exhaustive and subject to discussions with all relevant stakeholders. Other important aspects such as incidence of falls and fractures, prevalence of weight loss, hydration status, prevalence of delirious states, prevalence of pressure ulcers (to cite but a few) should of course not be neglected:

- **Satisfaction:** the best way to measure outcomes is to evaluate patients' satisfaction with the services they are offered. Their carers, families and other LTC staff should also be consulted. Employee satisfaction is indeed key, especially taking into account the already mentioned challenge of staff retention.
- **Well-being and quality of life:** The expectations of users, families and carers should be taken into account. As already underlined, quality LTC is more than treating health issues or covering basic needs. The personal development of individuals should remain an important goal, just as the establishment of perspectives for the future. People's feeling of attachment, of joy of life and of control over their lives should be assessed. Evaluating well-being is also key in preventing social isolation.

⁵ Edvardsson et al., 2019

⁶ Edvardsson et al., 2019

It is often argued that those elements are more difficult to measure in an objective way. However, there are already many measurement tools which have been developed and have demonstrated their effectiveness.⁷

- **Empowerment:** This aspect is also key in the previous mentioned dimension of well-being and quality of life. It encompasses different key aspects such as social participation, empowerment to live and cope with ones' own limitations but also the respect of elderly people's will. As AGE Europe explains⁸, the older person should have opportunities to continue old hobbies and to participate in new ones including social, cultural, civic or religious activities if she/he wants to, outside or inside his/her home. They also have the right to take some risks and be respected in their decisions. They should remain in control of their own life and care as long as possible.

How are those aspects to be measured?

A lot of literature has been published on the tools to be used to measure the above listed dimensions. For our last chapter, however, we do not wish to evaluate available tools but rather to highlight some key aspects to take into account when measuring quality.

Apart from the importance of developing reliable and valid **standardized assessment instruments and guidelines** (see above), **monitoring** systems are needed to support the evaluation of quality, promote informed policies and provide feedback to the various actors in the field. Service delivery should be evaluated regularly. Monitoring frequency should be standardised across countries to enable comparisons of the impact of quality assurance policies at the national level on the specific dimensions of quality of care. Standards should be monitored and information gathered in a systematic way.

The development of assessment guidelines at EU level, the monitoring and evaluation of LTC services should be under the responsibility of National **independent authorities**. Standards are often defined in several regulations established by a number of public institutions. (Zigante, 45) Ensuring quality should not be the responsibility of several institutions and duplication of quality checks should be avoided. Responsibility should lie within national governmental institutions, which should allow adequate multidisciplinary input from health care professionals, social insurance representatives, patients, and patients' representatives.

Finally, we would like to underline the potential of **information and communication technologies** in facilitating those evaluations, improving quality, but also enabling international comparisons. ICT use should be supported in order to achieve the integration of all the actors involved in LTC, including patients. The use of ICT also has the potential to reduce risks and increase quality by standardising care processes, enabling the remote monitoring of patients and empowering the patient in self-treatment. Furthermore, AI combined to eHealth and mHealth will probably revolutionize LTC and assessing the

⁷ Edvardsson et al. (2019) proposes a list of nine measures of well-being, quality of life and personhood: The ICEpop CAPability Measure for Older People (ICECAP-O); ; The Short Form 36 Health Survey (SF-36); Patient-reported Outcomes Measurement Information System ([PROMIS](#)); World Health Organisation Quality of Life ([WHOQOL-BREF/WHOQOL-OLD](#)); [EuroQoL-EQ-5D](#); Adult Social Care Outcomes Toolkit (ASCOT – also promoted by Zigante); Health-related quality of life for People with dementia (DEMQOL); Quality of life in dementia (QUALIDEM); Dementia Quality of life questionnaire (DQOL); The Thriving of Older People Assessment Scale (TOPAS); The Experience of Home Scale (EOH); and Personhood in Dementia Questionnaire ([PDQ](#)). AIM agrees that these measures could improve the potential to evaluate the quality of care in LTC, “based on positive or meaningful experiences of care, in contrast to historic approaches that have focused on reducing harms and risks for poor outcomes”.

⁸ AGE Europe, 23

quality of LTC services will include assessing the quality of those technologies and their use and developing standards to ensure the safety of their users. This aspect should not be neglected.

Sources:

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AIM Healthcare and social benefits for all

The International Association of Mutual Benefit Societies (AIM) is an international umbrella organisation of federations of health mutuals and other not-for-profit healthcare payers. It has 57 members from 30 countries in Europe, Latin America and Africa and the Middle East. 33 of its members, from 20 countries, are based in the European

Union. AIM members provide compulsory and/or supplementary health coverage to around 240 million people around the world, including close to 200 million people in Europe, on a not-for-profit basis. Some AIM members also manage health and social services. Collectively, they have a turnover of almost €300 billion.

AIM members are either mutual or health insurance fund.

They are: private or public legal entities; solidarity based; not-for-profit oriented organisations: surpluses are used to benefit the members; democratically-elected members play a role in the governance of the organisation.

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