COMFORTage

Prediction, monitoring and personalized recommendations
for prevention and relief of dementia and frailty

Person-Centric Language Framework

Guidelines for Inclusive Language

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Purpose of this document:

The purpose of this document is to promote respectful, precise, empowering language for all persons; it focuses on age-inclusive language, person-centric language, recommended language on caregiving, and context-based language recommendations.

All COMFORTage partners are encouraged to use inclusive language in all project-related communications (e.g., short papers, deliverables, social media, scientific publications) and to widely promote the principles of inclusiveness outside the consortium.

Language change is necessary but insufficient. Without structural changes (employment, healthcare access, policies), new terms will eventually absorb the stigma of the old – so all partners are encouraged to avoid practicing discrimination behind a veil of polite terminology.

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Context:

This document outlines a number of key issues pertinent to understanding why it is important to use age-inclusive/person-centric language in large-scale projects like COMFORTage. It draws on international guidance developed over the past 20 years concerning the critical need for inclusive terminology, efforts that have accelerated significantly over the past five years and are likely to be scaled-up even faster as the Decade of Healthy Ageing comes to an end.

Language shapes perception, policy and practice. Non-inclusive language is often embedded in everyday terminology, and sometimes goes unnoticed, particularly by non-native English speakers. The language people use can often, intentionally or unintentionally, include stereotypes. Stereotypes may alter how we think, leading to prejudices (which alter how we feel) and possibly to discrimination (which alters how we act). Today, health and social frameworks worldwide, but also particularly in the European Union, increasingly emphasise the importance of inclusivity. Inclusive language strengthens credibility and is aligned with European standards, and was pointed out in a series of 2024 Joint Technical Reports (i.e., JRC138088, JRC138090, JRC138117).

Ageism is just one example of a stereotype. Ageism refers to systematic stereotyping, prejudice, and discrimination against individuals based on their age. Grounded in the false assumption that age alone defines a person's capabilities, this bias is both inaccurate and deeply harmful (Kajander, Wurm et al., 2024; Kajander, Meyer-Wyk et al., 2024). Moreover, ageism negatively impacts individual health, overall quality of life, and the broader economy (Wurm et al., 2024). It may manifest itself in all levels of society, from internalised self-bias to systemic policies that exclude older adults; moreover, specific terminology can inadvertently reinforce negative stereotypes (WHO, 2021).

The term "ageism" was first coined in 1969 (Levy & Macdonald, 2019), hence, combatting ageism is not a recent endeavour. It is, however, a primary requirement for healthy ageing (WHO, 2021), and requires a shift in how we communicate. As global lifespans increase, the definition of "old age" is also shifting. Today's older adults are generally healthier, living longer, and contributing significantly to their communities and societies through continued employment and voluntary activities. Recognising that older adults are a diverse, heterogeneous group is essential.

Internationally, professionals and organisations (e.g., American Medical Association, American Psychological Association, United Nations (UN), World Health Organization, National Centre to Reframe Aging led by the American Geriatric Society), are increasingly adopting guidelines (AMA, 2020; APA, 2020; WHO, 2021; OECD, 2025) to reduce bias and ensure older populations are represented with respect and accuracy. The UN officially designated 2021-2030 as the "Decade of Healthy Ageing".

In **Europe**, the European Commission (EC) published in early 2021 a green paper on Ageing, fostering solidarity and responsibility between generations, immediately endorsed by the AGE Platform Europe. The Commissioner for Older People for Northern Ireland (COPNI) differentiates between institutional, inter-personal and self-directed ageism as a multidimensional form of discrimination that is present across a wide range of public and private services, nearly half of their respondents having experienced either form (COPNI, 2024).

Age discrimination is still an issue across Europe (EC, 2025) and, as the EC renews its commitment to equality and intergenerational fairness, it must close a persistent gap: the lack of a dedicated, strategic focus on ageism and age discrimination. Ageism remains one of the least addressed forms of inequality in the EU framework (AGE Platform Europe, 2025) and where available, the implementations are often fragmented, with weak monitoring, limited data and insufficient involvement of civil society organisations (AGE Platform Europe, 2026).

Research shows **stigmatising language** contributes to fear, shame, and social isolation (Low & Purwaningrum, 2020). Negative terminology impacts the wellbeing of people living with dementia and their families, increasing stigma and discrimination (Dementia Australia, 2021).

The United Nations Convention on the Rights of Persons with Disabilities (UN CRPD, 2006) and EU initiatives, including the Council Conclusions on Supporting People Living with Dementia (2015) and EU Disability Strategy (2021-2030), emphasize dignity, autonomy, and full participation. Organizations including Dementia Australia (2021), Alzheimer Europe and the European Working Group of People with Dementia (2023), and Alzheimer's Society of Canada (2017) have published inclusive language guidelines. Their core principles state that language should be: accurate, respectful, inclusive, empowering, and non-stigmatising.

With early biomarker diagnosis, stigma now affects even symptom-free individuals who have had positive test results for Alzheimer's (Stites et al., 2022), making respectful language more critical than ever.

In addition, inclusive language for carers means using respectful, precise, non-stigmatising wording when speaking to or about people receiving care, and when describing caregiving roles. It supports dignity, autonomy, and accurate understanding of the care relationship. The approach aligns with person centric communication from the COMFORTage Framework, emphasising neutral, empowering terms that avoid stereotypes or assumptions.

Caregiving terminology differs across countries and may carry unintended meanings; some terms ("informal", "helper", "demented") can be misleading or devaluing, while alternatives ("family carer", "care worker", "person living with dementia") are more respectful and clearer (ISO Technical Committee 314, n.d.). This may have distinct implications for the use of inclusive language in a variety of cultural and national contexts, and in multiple languages.

Methodological Approach:

The document is grounded in already-established frameworks including person-centred care, social model of disability, and anti-stigma communication principles, ensuring that recommendations are evidence-based rather than prescriptive or arbitrary.

The content was developed through a mixed methods, multi-stage process that included literature review, cross-referencing terminology recommendations across different international sources to identify consensus positions, identifying emerging trends in language use, input from consortium partners representing different countries and disciplines, review by individuals with lived experience of ageing and dementia care, development of practical, accessible recommendations, alignment with COMFORTage project values and communication framework, and review and revision based on consortium feedback.

Intended function:

This document serves six functions in the COMFORTage project:

- **Foundational Framework:** A common understanding and shared commitment to inclusive language across all consortium partners, work packages, and project outputs.
- **Educational Resource:** An evidence-based rationale for why language matters, drawing on existing research and policy frameworks to demonstrate that inclusive terminology is not merely a matter of political correctness but has tangible impacts on health outcomes, social inclusion, and project effectiveness.

- **Practical Guidance:** Concrete, actionable recommendations that consortium members can immediately apply in their activities, e.g. research protocols, communication and dissemination activities, etc.
- **Quality Assurance Tool:** A reference point for reviewing project deliverables, ensuring consistency in terminology across diverse national contexts and disciplinary perspectives.
- **Advocacy Instrument:** An expression of COMFORTage positions into responsible research, demonstrating to funders, policymakers, and the broader scientific community that the project complies with the highest ethical/social standards.
- **Risk Mitigation:** Prevention of potential harms to research participants and stakeholders by addressing inclusive language use pro-actively, thereby safeguarding the reputation and impact of the project.

As a European project with potential global impact, COMFORTage recognizes that English-language guidelines may not translate into or apply directly to all partner countries. This document was conceived as a foundational framework underpinning the development of practical, localized inclusive language guidelines by COMFORTage partners. It is meant to facilitate and encourage culturally-appropriate, language-specific adaptations (rather than direct, literal translations) while maintaining core principles and documenting how partners navigate particular, local contexts.

Last, but not the least important aspect, COMFORTage should consider how project outputs might be received in diverse international settings beyond Europe.

Moving Forward:

Adopting person-centric language requires intentional effort, organisational commitment, and ongoing reflection. It means examining not only individual words but also the **underlying assumptions and values** those words reflect.

Language change is necessary but insufficient (AGE Platform Europe, 2021). Without changing the structural reality and society, e.g. in terms of employment, healthcare access, policies (AGE Platform Europe, 2025), new terms will eventually absorb the stigma of the old (the so-called “euphemism treadmill”) while creating the illusion of avoiding the practice of discrimination behind a veil of polite terminology (Pinker, 2002).

The possible future **translation** of inclusive terminology may present significant challenges that COMFORTage partners should navigate carefully, and take into account the structural linguistic differences (for example: grammatical gender, word order and construction, compound words), semantic and cultural challenges (like concept equivalence, stigma and connotation, formal vs. spoken language).

Note: For convenience, the most frequent **recommendations** regarding the usage of inclusive language were summarized into two tables (Table 1. Age-inclusive terminology recommendations and Table 2. Person-centric terminology recommendations). Each table uses a type of traffic light system (red: to be avoided, and green: inclusive alternatives). Each lists the term or phrase to be avoided; the implications of the problematic term/phrase, either an alternative or a variety of alternatives and suggestions for usage.

Table 1. Age-inclusive terminology recommendations

Term/phrasing to avoid	Problematic implication	Inclusive alternatives
"seniors", "elderly", "the aged", "ageing dependents", "old-old", "young-old", similar "other-ing"	homogenising; stereotyping, may suggest members of group are not part of society but rather a group apart; implies frailty	"older persons," "older people," "older adults," "older patients," "older individuals," "persons 65 years and older," and "the older population" – these terms are considered neutral
"Anti-ageing"	implies ageing is negative (stoking/shaming)	"Healthy ageing" or "ageing well"
"Senior moment"	reinforces cognitive decline trope; stoking/shaming	Avoid idioms; describe behaviour
"Digital natives", "digital immigrant", "digital outcast"	implies older adults are incapable	"Different digital experiences", "age-related digital gap"
"Time bomb", "silver tsunami" (+/- similar catastrophic terms about growing population of older people)	homogenising, stereotyping, stoking/shaming	Talk affirmatively about longer and healthier lives and ageing as an opportunity
"Accumulated youth", "young at heart" (references to youth when describing older age, or positive aspects of a person's personality)	stereotyping, homogenising (by contrast)	Use direct affirmation of being old ("I'm old and that's ok") or alternative adjectives to describe positive aspects of one's personality
Pronouns ("they", "them") or framing that are "other-ing" older people as a group to set aside assuming they are different from "we"	stereotyping, homogenising, emphasis on division/gaps	Use "we" and "us" pronouns in reference to the universal experience of ageing and giving a voice to self-advocates
"Our older people" (possessive pronouns assuming older people are someone's property)	stereotyping, stoking/shaming, dividing (may imply burden)	Remove the possessive pronouns; avoid paternalistic approaches ("elderspeak")
"Vulnerable", "at-risk" population (adjectives around frailty to describe a whole age group)	homogenising, stereotyping, stoking/shaming	Specify the exact risk factors that are putting people in situations of vulnerability

Table 2. Person-centric terminology recommendations

Term/phrase to avoid	Problematic implication	Inclusive alternatives
Sufferer (people suffering cognitive impairment/deficit)	Implies the person is defined by suffering; passive victim with no quality of life; reinforces stigma	Person with dementia / Person living with dementia/cognitive impairment/ person diagnosed with dementia
Patient (outside medical context)	Medicalises the person's entire identity; inappropriate in social or community settings	Person with dementia / Individual / Person's name
Dementing illness, Demented, Affliction, Senile dementia, Senility	Grammatically awkward and focuses on ongoing deterioration	Dementia / Alzheimer's disease and other forms of dementia/ symptoms of dementia
Disease, illness	Negative connotation	Condition
Challenging behaviour(s)	Blames the person; frames behaviour as problematic rather than communicative	Changed behaviour / Expression of unmet need / Behaviour with changed meaning
Difficult behaviour	Judgemental; fails to consider underlying causes (pain, confusion, fear)	Behaviour that is difficult to understand / Behaviour signalling distress or unmet need
Behavioural problem	Pathologises natural responses to confusing or frightening situations	Changed behaviour / Communication through behaviour
Deteriorating / Deterioration	Focuses only on decline; ignores preserved abilities and personhood	Condition progressing / Experiencing changes / Living with advancing dementia
Burden, burden of care	Implies person is a burden; contributes to guilt and shame	Context based – see Table 3
Carer burden, burden of caring	Frames caregiving as negative; may not reflect carer's actual experience	Context based – see Table 3
Suffering caregiver	Assumes all caregiving is negative; ignores moments of connection and meaning	Caregiver experiencing stress / Caregiver needing support
Person living with dementia (when referring to family member)	Incorrect use; this term is reserved for the person who has been diagnosed with dementia	Family member of someone with dementia / Supporting someone living with dementia / Living alongside someone with dementia
Early-onset dementia	Ambiguous; can mean early stage or younger age; creates confusion	Younger-onset dementia
Pre-senile dementia	Outdated; links to discredited concept of "senile dementia"	Younger-onset dementia / Dementia diagnosed before age 65
Subject	Objectifies participants; outdated in ethical research	Participant / Person with dementia
Case	Dehumanising; treats person as medical specimen	Person / Individual / Participant
PWD (abbreviation)	Reduces person to acronym; depersonalising	Person with dementia (spell out the term in full rather than using an abbreviation)

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Term/phrase to avoid	Problematic implication	Inclusive alternatives
Hopeless, Unbearable, Tragic, Empty shell, Disappearing, Stealing them away, Fading away	Avoid language that dehumanises or portrays the person as "gone."	Disabling, challenging, life-changing, stressful
Mental illness (in casual speech), Nuts, Insane	"Mental health condition" reduces stigma and promotes a holistic view.	Mental health condition / mental distress
Carer related: "helper"	Minimises skills, unclear role: the use of this word is discouraged as it may diminish the value of support or assistance provided	Carer, family member, friend…
Informal caregiver	Suggesting low value, does not represent the complexity and the essential nature of care provided. Unpaid care should be recognised for its value.	Carer, family member, friend

Controversies and points to consider especially on caregiving:

Several uses of language in the fields of work on ageing, dementia, frailty, and the provision of care remain controversial. Here we first examine the focus on the term, "caregiving burden". We then name several other terms which may prove to be difficult in their practical use dependent on the context surrounding their usage.

Some authors argue that recognising caregiving as a burden does not in any way negate the dignity or personhood of the individuals being cared for. Rather, it opens up possibilities for improved care and contexts of care for both caregivers and patients, by acknowledging the social, psychological, and relational practices that may lead to negative or undesirable outcomes for the people involved in the delivery of care. Examples from three sets of such authors follows.

Liu, Heffernan & Tan (2020), for example, qualify three key attributes of caregiver burden identified from the literature on nursing ethics: self-perception, multifaceted strain, and duration over time. None of these categories pertains directly to qualities or negative attributes of the patient, nor do they imply that the person being cared for is what constitutes the burden.

Haan et al. (2025) argue that for family/informal caregivers in particular, the need to provide care might not be an actively chosen task. The situation may give rise to financial, relational, and familial issues that may cause frustration and feelings of the person being "burdened". Again, these factors do not necessarily imply that the person receiving care is the burden, but rather they point to the socio-relational and socio-economic context in which care is provided.

Similarly, Kropf & Schmidhuber (2024) trace the idea of caregiver burden back to the psychological conditions underpinning the provision of healthcare, by also acknowledging the physical repercussions it may have on caregivers (e.g., heart disease, muscular-skeletal impairments, or disturbed eating and sleeping behaviour).

In contrast, we argue that there are three imperatives pleading **against the usage** of terms related to "burden".

(1) In practice, the term "burden" leads to **implicit bias**: even if the academic definition of "caregiver burden" is objective, the pragmatic (mis)use of the word in social and clinical discourse often places "blame" on the existence of the patient (DEEP, 2015; COPNI, 2024).

(2) The continuous use of "burden" terminology may contribute to "**self-fulfilling stigma**" ("affiliated stigma"), where family members internalize shame, further reducing their wellbeing and engagement with care (Lu et al., 2024).

(3) The usage of the term "burden" may lead to **patient-centred invisibility**: focusing on caregiver burden can inadvertently lead to a person receiving care being viewed as a series of symptoms to be managed rather than a human being attempting to communicate unmet needs (Molony et al., 2018; Warren, 2022).

Our interpretation is that the term's potential to inflict symbolic harm on the person being cared for is significant, even if the original sense of "caregiver burden" remains a valid clinical and ethical construct for identifying physiological and psychological risks.

Although the suggestion to retain the term is based on valid clinical and ethical scholarship, particularly regarding the non-voluntary nature of care and its real physical and economic costs, the advancement of person-centred care requires that we frame these real costs as "strains" or "challenges" arising from the context of care delivery, rather than as a "burden" originating from the person requiring care.

By shifting from a "burden-centric" approach to one focused on "strengths and resilience," healthcare systems can better facilitate the wellbeing of both the caregiver and the care recipient (see Table 3. Context-sensitive language: controversial terms).

Table 3. Context-sensitive language: controversial terms

Context	Recommended	Rationale
Clinical Assessment	Caregiver Strain Role Strain	Maintains focus on psychological and physiological weight of the role avoiding stigmatising "burden".
Societal/Policy Reports	Impact of Caring Socio-Relational Demands	Highlights "load" as a result of structural factors (lack of support, financial strain) rather than implications related directly to the person being care for.
Patient-Facing Communication	Caregiving Experience Support Needs	Focuses on the relationship and resources required to sustain it, preserving the dignity of everyone involved.
Research involving the Zarit Burden Interview (ZBI) – see APA, 2011	Self-Perceived Stress of Caregiver	Accurately describes what the Zarit Burden Interview (ZBI) is measuring.

While this document focuses on ageing, dementia and caregiving, COMFORTage may explore additional socio-ethical language challenges in future activities during the remaining project period.

Practical implications:

The implementation of inclusive language has numerous practical implications. Overall, COMFORTage should aim to:

- **Develop core principles:** This work is intended to establish underlying values, such as respect, dignity, autonomy, and accuracy that transcend specific word choices ("more than just words"). This position enables national partners to identify culturally-appropriate terminology that embodies these core principles.

- **Engage native speakers:** This engagement can take place by consortium partners involving people belonging to different language communities in translations, consulting with local advocacy organizations and people with lived experience, and by testing terminology with target audiences.
- **Embrace differences**: We recognize that identical terminology across all languages may not be achievable or desirable. As such, we focus on conceptual alignment rather than linguistic uniformity and intend to document differences transparently.
- **Address audience-specific needs:** Academic publications may require the use of different terminology than do patient-facing materials. As examples, policy documents may need to be aligned with official government terminology; community resources try to use language actually spoken by their intended audiences.
- **Improve research impact:** Some organisations recommend the rejection of submitted research papers based on usage of non-inclusive (e.g. ageist) phrasing (e.g. APA, AMA, AGS, GSA). Instead, inclusive language improves research quality by reducing bias, improving participants' engagement/retention (people-centric design), and securing community support leading to increased adoption/translation of research into practice.
- **Ensure ethical and regulatory compliance:** The adoption of inclusive language is in alignment with fundamental principles of ethical research (respect for participants, beneficence, justice), EU and overall human right frameworks, the clinical/medical Hippocratic oath ("do no harm"). It should be considered a moral responsibility of all communities involved with research.
- **Leverage a strategic advantage:** Inclusive language may be pragmatically appropriate for a variety of reasons. It demonstrates project/research quality and attention to detail (to the entities involved in funding or oversight) and a high-standard reputation and credibility (to stakeholders involved). It also increases the likelihood of positive media coverage and public engagement, and subtly enforces project and community leadership.
- **Promote personal development:** The adoption of inclusive language can have positive implications for the personnel involved in COMFORTAGE. It builds highly-sought competencies in a competitive contemporary research environment, enhances career prospects in an increasingly diversity-conscious society, fosters professional growth via reflexive practice, and develops transferable skills beyond the lifetime of the project.

Ongoing Challenges:

There are several challenges to the use of inclusive languages which are still underway: continuous language change and continuous societal change; generational differences; and overall balance.

Naturally, languages evolve over time; we need to continuously monitor societal perceptions, making sure that terminology remains up-to-date and preventing the "euphemism treadmill" (Pinker, 2022).

Societies also change. Different geopolitical and socioeconomical backgrounds are expected to influence the acceptability of proposed inclusive language alternatives; stakeholders need to "check the societal pulse" and adjust their strategies to drive change which goes beyond language use (e.g., the aim for "polite language") and achieves actual structural change (the reframing of ageing).

Generational differences were noted in same-language communities about preferred terms. Stakeholders need to educate others (i.e., dispel myths related to ageing) and promote intergenerational contact based on structured personal interaction (Burnes et al.,2019).

All stakeholders willing to implement this person-centric language framework needs to find the right balance between standardization (clear, actionable general guidelines, needed for clarity) and localization (appropriateness of terms, adjusted based on local geopolitical, socioeconomical, cultural variables).

Actionable items:

- **Stop using non-inclusive language:** Non-inclusive language denotes outdated thinking. It should be modified for several reasons. On the research side,it may trigger automated rejection of publication submissions. On the personal side, it may subtly and unconsciously alter your cognitive processes (stereotypes), emotional balance (prejudice), and behaviour (discrimination). In a practical context, “elderspeak” in clinical settings may increase patient anxiety and reduce older adults’ compliance. On the part of the person with a condition, it damages the biochemistry of the people targeted by the non-inclusive language (Levy et al., 2016). Hence, the adoption of inclusive language translates into a positive medical intervention.
- **Educate:** On the individual level, improve your personal understanding on how and why non-inclusive language can do harm instead of dismissing its contrary, the use of inclusive language, as “wokeism”. Help dispel myths about ageing, dementia, and frailty. Shift your perspective from one of sympathy (having a perception of “vulnerable people in need of help”) to one of justice (“citizens have rights which are denied by non-inclusive language”). This mindset shift will help to defeat systemic non-inclusive barriers and promote positive policy change.
- **Promote inter-generational programmes:** Getting to know other people who are not familiar to you or are not members of your own family and are not the same or similar age to you is a form of structured contract which can have many benefits. For example, it can dismantle structural barriers, promote life-long learning, and enable the discovery of skills. Working on programmes that bring people of different ages together can challenge stereotypes, promote solidarity, and raise awareness.

Core principles:

This document suggests the following core inclusivity principles:

- **Put the Person First**: A diagnosis, an age, or a physical ability is just one part of a person's life, so avoid reducing anyone to a medical label / acronym / symptom. Person-centric language upholds an individual's inherent dignity and reminds us that they are a human being first.
- **Respect Self-Identification**: Always prefer the terms that people use to describe themselves. Language preferences can vary widely across communities, cultures, and generations. If unsure of how someone wants to be addressed, just ask respectfully.
- **Be Specific and Drop the Labels**: Avoid lumping diverse populations into monolithic categories. Instead, use descriptive, factual, and neutral terms that reflect an appropriate level of specificity. Only mention characteristics when genuinely relevant.
- **Focus on Strengths and Resilience**: Highlight what people can do rather than their limitations. Steer clear of framing older age or caregiving purely as “burden” or “tragedy,” and instead frame these experiences around resilience, relationships, and structural support needs. Avoid compassionate ageism, as it may patronize people by assuming they are frail or need saving.
- **Contextualize Behaviors and Needs**: When describing individuals living with cognitive changes or dementia, understand that their actions are often a form of communication. Use objective terms rather than judging their actions.
- **Embrace Intersectionality**: A person's experiences (e.g., digital, societal, healthcare-related) are shaped by overlapping identities (e.g., age, socioeconomic status, geography). Make sure your language acknowledges this complexity and doesn't assume a “one-size-fits-all” experience.
- **Watch Out for "Othering" and Alarmism**: Ditch language that divides or treats demographic changes like a crisis. Catastrophic metaphors stoke fear, division, and stigma. Inclusive pronouns (e.g. “we”, “us”) should only reflect that aging is a universal, shared experience.

- **Ensure Clarity and Avoid Assumed Defaults**: Keep language clear, accessible, and culturally sensitive. Don't assume everyone shares the same cultural norms, seasons, or idioms, which can inadvertently exclude global or diverse audiences. When translating concepts across regions, focus on cultural appropriateness and conceptual alignment rather than rigid literal translations.
- **Stay Curious and Open to Learning**: Language is fluid, and society's understanding of inclusivity is always evolving. Don't worry about being perfect; instead, stay open-minded, accept feedback gracefully, and recognize that the impact of your words matters much more than your intent.
- **Recognize the Power of Your Words**: Understand that the language we use shapes policies, perceptions, and even tangible physical and mental health outcomes. Inclusive language isn't just about being polite; it’s an active, ongoing intervention to reduce stigma, dismantle structural barriers, and promote justice and equality.

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