The Health and Social Care Alliance Scotland (the ALLIANCE)

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Ageing and Frailty Standards consultation – ALLIANCE response

18 June 2024

Introduction

The Health and Social Care Alliance Scotland (the ALLIANCE) welcomes the opportunity to respond to Healthcare Improvement Scotland's consultation on the Ageing and Frailty Draft Standards for the Care of Older People.

The ALLIANCE broadly supports the proposed draft standards. However, we believe that there should be changes to the existing draft standards and additional standards included. If the standards, with our suggested changes, are implemented and delivered fully they will achieve change for older people living with frailty.

Our society is ageing, and policymakers should embrace this demographic shift. Currently in Scotland, over 1 million people are aged 65 or over. By 2030, 1 in 5 people in Scotland will be over 65[1]. With such an increase, there is a need to plan for, mitigate and prevent the negative effects of ageing.

An ageing population will require collaboration and joined up thinking to deliver the Ageing and Frailty Standards. Older people living with frailty should be empowered to coproduce the support and services they need and use at every point of planning, service design and delivery.

Question 3: How far do you agree that these standards will support early intervention and prevention for older adults who may be at risk of frailty as they age? Please tell us why you think this.

Slightly agree.

Question 4: How far do you agree that these standards will ensure that older adults who may be at risk of frailty as they age have choice, autonomy and ownership of their life and their care?

Slightly agree.

Question 5: How far do you agree that these standards will ensure older adults who may be at risk of frailty as they age experience a palliative care approach that helps them to live well with deteriorating health?

Slightly agree.

Question 6: Do you have any general comments on the standards?

The ALLIANCE agrees with the overall aim of the standards, in that they should contribute to ensuring national consistency, and improvements and promote positive, healthy and active ageing.

The Ageing and Frailty Standards should prioritise services on the outcomes of the people using and needing them. Good services will then be developed as a result.

We are pleased to see such a focus on proactive and preventative care for older people. Outcomes are better for older people when action is taken at an early stage rather than waiting for a crisis. Early intervention is not only better for the individual but also saves money for the NHS and systems as this delays or prevents more intensive treatment.

A person centred, holistic, human rights and outcomes based approach reduces poor outcomes and can reduce hospital admissions for people living with frailty[2]. Alongside this, early and preventative intervention is a way to improve outcomes by avoiding or lessening health risks and achieving cost efficiencies and demand. Such interventions support the person and services.

People living with frailty must have access to proactive, joined up care to maximise health and wellbeing and prevent problems arising in the first place. A collaborative approach should be taken at the local and national level, to move away from reactive responses towards promoting the conditions for good health and designing services around people's needs. Equally important is access to rapid, specialist services in the event of a health or social care crisis. Care and support plans should be tailored around the person's own goals and preferences and created with their unpaid carers and families in mind to meet their needs.

Frailty can be prevented and reversed through programmes like anticipatory care combined with comprehensive multidisciplinary assessment and preventative interventions such as[3]:

- Structured medication reviews for 'polypharmacy' to prevent medicine related harm and reduce health and care resources.
- Falls prevention and urgent response for fall related injuries which are common in older people, limit independence and quality of life and increase mortality and healthcare costs.

Wider prevention measures include shifting care from hospital to communities, supporting self management, building resilience, tackling health and wider inequalities, tackling social and commercial determinants of health, promoting better mental and physical health, family support provision and implementing public health measures to reduce drug and alcohol related harms.

In the United Nations (UN) Decade of Healthy Ageing, they stated that there are four action areas:

1. Change how we think, feel and act towards age and ageing.
2. Ensure communities that foster the abilities of older people.
3. Deliver person centred, integrated care and primary health services that are responsive to older people.
4. Provide access to long term care for older people who need it.

These actions are enabled by listening to diverse voices and enabling meaningful engagement of older people; nurturing leadership and building capacity to take appropriate action, integrated across sectors; connecting various stakeholders to share and learn from the experience of others; and strengthening data (of which we elaborate on in answer to question 30), research and innovation to accelerate implementation.

The ALLIANCE's *Five Ambitions for the Future of Health and Care* outlines five key themes for achieving transformational change. These are focused on ensuring everyone's rights and dignity are respected in line with human rights principles, like those found in the United Nations (UN) Principles for Older Persons. The Five Ambitions include: leading courageously, reimagining how we invest in social services, measuring success based on personal and rights based outcomes, and sharing power and addressing imbalances among individuals, sectors, and policy makers[4]. We would urge that the Ageing and Frailty Standards reflect these Five Ambitions to encourage everyone involved in health and social care to think ambitiously about the future of our public services, and what is needed to support everyone to thrive.

The ALLIANCE welcomes recognition in the policy context of relevant international human rights treaties. We would also recommend that explicit reference is made to equality and intersectionality, as well as human rights. Taking an intersectional approach to policy and practice means recognising that some people experience infringements of their rights because of inequality and discrimination related to their characteristics or how their characteristics intersect and taking action to mitigate and prevent this. In addition, achieving outcomes will not look the same in practice for everyone receiving treatment and accessing services.

Applying the AAAQ framework of the right to health is a practical way for human rights, equality and intersectionality to considered in both policy and practice [5].

To ensure the improvement of health outcomes and prevent or reduce health inequalities, goods, facilities, services and systems that help us to live long healthy lives should be:

- Accessible
- Available
- Appropriate
- High Quality

There is a need to build in time for everyone to be equally involved in development and implementation. This encourages dissolving the perceptions and assumptions of hierarchy through active participation and listening with the option of challenging and clarifying points whilst maintaining respect and mutual appreciation of experiences.

Question 7: Would you like to give more detailed feedback on any of the individual standards?

Yes.

Standard 1: Service Design

Question 8: Do you agree with Standard 1: Service design? Please tell us why you think this.

Slightly agree.

We elaborate on our response in answer to question 9.

9. Do you think that there are any necessary changes to Standard 1: Service design that the Development Group should consider?

All health and social care services need to ensure that services for older people living with frailty are designed and delivered using the following principles[6]:

- Frailty can be improved but treatment and intervention need to be individualised.
- Intervention is aimed at improving physical, mental and social functioning to avoid adverse events, for example, injury, hospitalisation, institutionalisation. This contrasts with the strictly disease orientated biomedical approach taken to many other long term conditions.
- Support will need to be sustained over a long time and will need to continue even through intervening crises and adverse events.
- As far as possible, the intervention plan must enable the participation of the older person with frailty.
- There must also be engagement with unpaid carers and families whose needs should also be considered.

At all points of service design and delivery, collaboration and coproduction with older people living with or at risk of frailty, their unpaid carers, families and the workforce are essential. Coproduction approaches should build on the good practice established by organisations working with underrepresented groups, such as the People Led Policy Panel[7]. Coproduction is critical in improving the Ageing and Frailty Standards, so they reflect people's priorities and fill in any implementation and service gaps.

Whilst we know that Healthcare Improvement Scotland has undertaken engagement with stakeholders and interest groups, we are concerned that the draft Ageing and Frailty Standards appear to have been initially developed by professionals in the field, not those with lived experience.

The ALLIANCE and University of the West of Scotland (UWS) collaborated on a research project called Frailty Matters[8]. Through the project, we developed and implemented an educational intervention for community and district nurses, which also contributed to the development of the Frailty Matters House[9]. The programme was coproduced, developed and delivered by people with lived experience. Involving people with lived

experience from the beginning ensured their concerns were addressed and resulted in a truly coproduced model that could prove invaluable to many integrated community teams.

Through the research project, people with lived experience told us that they do not recognise themselves as frail and the “label of frail” was not embraced. There is also evidence that older people do not want to be considered as frail. The language and management of frailty can act as barriers to engaging with older people who may not perceive themselves, or wish to be defined, by a term that is often associated with increased vulnerability and dependency[10]. Similarly, community nurses also told us that frail was not a term readily used when caring for people. This demonstrates a disconnect between clinicians or health and social care decisionmakers and the experiences of people.

We agree that the standards should aim for full, systematic integration. Among the most important determinants of good, person centred care are continuity of care and care integration.

Health and social care commissioning arrangements must also reflect a joint approach across all disciplines which takes account of the multi disciplinary nature of care for and working with older people. Integrated working provides the best model for decreasing admission, readmission, and minimising length of stay, morbidity and mortality. There must be an emphasis on evidence based early decision making and holistic management.

Continuity of care and integrated care involves[11]:

- Sharing of older people’s information between health and social care professionals
- Trusted and shared assessments
- Continuity of care which is personalised
- A single point of access for all services

Older people living with frailty and their unpaid carers should not have to retell their stories, or the stories of the person they look after, whenever they access a health and social care professional.

The ALLIANCE's Community Links Worker Programme illustrates the Scottish Government's vision "for multi disciplinary teams to work together to support people in the community and free up GPs to spend more time with patients in specific need of their expertise"[12]. Primary care is often the first point of contact people have with health services, particularly through GP practices. Link Workers enable GPs and practice staff to focus their time on people with medical issues and may reduce the need for people to attend Accident and Emergency for non urgent problems.

Although unpaid carers can be recorded in GP systems, recording and use of this information is inconsistent and varies by location and service. Due to this, not everyone's choices, needs, preferences, goals or communication requirements are adhered to because this information is not shared[13]. Likewise, an individual's medical history, reviews, conditions and outcomes are not easily accessible across health and social care. This can lead to adverse consequences for older people living with frailty as staff and policymakers cannot see what works and what does not.

During a consultation on the See Hear Strategy carried out for Scottish Government by the ALLIANCE's Scottish Sensory Hub, we heard from people with lived experience of deafness, sensory loss and dual sensory loss on what they want to experience in health care services and their interactions with healthcare professionals. One participant told us that their "experience of health care is that it treats people as 'the eye' and not the whole person"[14]. This reflects a wider problem of the concerns that people genuinely have and do not feel are being met.

As part of the consultation on the National Care Service, most unpaid carers (86%) surveyed by Carers Scotland were in favour of a new electronic health and social care record, believing it could help to share information and be identified as an unpaid carer[15]. This support was

reinforced in the State of Caring report with two thirds (63%) of respondents wanting information about them or the person they care for shared across services, so they do not have to repeat themselves[16].

Vitally, the third sector must be recognised for the work it does to provide support when there is low resource or capacity in the public health and social care sector. The ALLIANCE hosted a joint focus group with Healthcare Improvement Scotland where a representative from Highland Hospice noted that sharing information should be enabled across health and social care services including the third sector as it does so much without access or oversight to records or information[17].

We are encouraged to see that there is a reference to the ethical use of technology in line with the Digital Health Strategy and Scottish Artificial Intelligence (AI) Strategy[18].

There is also a generational dimension to digital exclusion, which can mean that some forms of support and services are not accessible for those older people who do not want to, or cannot, access the internet[19]. For older people with mental health issues, these barriers seemed insurmountable[20].

As services adapted to provide online services during the COVID-19 pandemic, many older people struggled to receive support and there was a general feeling that everything would only now be available online[21]. Some participants felt there was a lack of awareness around how to help people get online and how to provide support for those who were new to this technology. For many older people, another major barrier was the cost. With Voices Of eXperience (VOX) and Scottish Care, the ALLIANCE has developed the Human Rights Principles for Digital Health and Social Care so barriers such as these can be brought down[22].

Standard 2: Identification and Assessment

10. Do you agree with Standard 2: Identification and assessment?

Slightly agree

We elaborate on our answer in response to question 11.

11. Do you think that there are any necessary changes to Standard 2: Identification and assessment that the Development Group should consider?

As stated in the Comprehensive Geriatric Assessment (CGA), identification and assessment processes should evaluate the whole person: the medical, social, psychological, and functional. This enables the development of detailed care plans for treatment, support and review[23].

Frailty should be identified to improve outcomes and avoid unnecessary harm[24]. Whatever the level of input that is needed for an individual, the resulting process of assessment, individual care and support planning and regular review is vital to provide an evidence based management plan for frailty.

Older people aged over 65 are the main users of adult social care services[25]. However, they can find that they are pigeonholed often without a detailed assessment of their needs as either eligible to receive treatment or not eligible[26]. Studies demonstrate that there is a lack of clarity over what frailty is and how it should be measured across the health and care sector. As a result, frailty is rarely consistently identified[27].

Identification and assessments of frailty should also be carried out for older people who are prefrail or showing signs of frailty. Extensive research has shown that in conducting CGAs individuals are more likely to go home, have an increase in independence and a reduction in mortality[28]. Those who took part in a CGA on a hospital ward had a 30% higher chance of being alive and being in their own home after 6 months[29].

To improve identification, health and social care staff need to receive regular training in ageing and frailty, dementia, sensory and inclusive communication, mental health and disability awareness and human rights so that they can become familiar with recognising frailty and the associated conditions and barriers that often come with it.

Likewise, older people living with frailty should be provided with accessible and inclusive information on their individual conditions. Having the knowledge and understanding of frailty can help them to self advocate and inform health and social care professionals to take action to prevent a poor outcome (or even to avoid intervention) and to start a pathway of care to address the issues contributing to frailty[30].

For example, studies show that there is a “know-do gap” with certain assessments in which guidelines are not implemented. Such factors include appropriateness or adaptation to settings, clear definition of roles within the process, good team setup and functioning, knowledge, awareness, patient involvement in service development, adequate resources, organizations supporting complexity, and social and political factors[31].

Systematic identification and recording of data on older people living with frailty would enable a better understanding of need, service planning, management, outcomes and impact of interventions.

Standard 3: Person-led care coordination and future care planning

12. Do you agree with Standard 3: Person-led care coordination and future care planning? Please tell us why you think this.

Slightly agree.

We elaborate on our response in answer to question 13.

13. Do you think that there are any necessary changes to Standard 3: Person-led care coordination and future care planning that the Development Group should consider?

Person centred care is about ensuring the people who use services are at the centre of their care. It ensures that care is personalised, coordinated and enabling so that people can make choices, manage their own health, and live independent lives, where possible[32].

Person centred care is also a key part of self management. Through the ALLIANCE's work on the Self Management Strategy for Scotland: Gaun Yersel, we found that when the health and social care system works with people as active participants in their health and wellbeing, all parties improve their knowledge, skills and confidence[33]. It also enables health and social care staff to see the whole person beyond merely the condition they present with.

In response to the most recent Health and Care Experience Survey, only 22% of participants reported being offered a choice and getting their preference of help and care support and services. 30% were not offered any choices in how their care was arranged[34]. These statistics show that people receiving care are not active participants in their care and have a distinct lack of choice and decision making.

The ALLIANCE recognises that due to the high demand and pressures facing the health and social care sector, continuity of care can be difficult. However, it is a crucial part of person centred care. We believe that the standards should reflect that due to the potential complexity of ageing and frailty, every effort should be made to ensure that people are seen by the same professionals with every visit or review. This will also contribute to services being accessible and easily navigable by older people living with frailty or their unpaid carers.

Older people should coproduce their current and future care. This way of working should be prioritised and enabled by staff and organisations.

According to the House of Care Model, there are four key elements to delivering effective care planning[35]:

1. Patients feeling engaged in decisions about their treatment and care and able to act on these decisions
2. Professionals, including staff and organisations, being committed to working in partnership with patients
3. Systems being in place to organise resources effectively
4. Having a whole system, ethical approach to commissioning health and care services

Shared or supported decision making (SDM) can be used to facilitate early intervention and prevention practices. ALLIANCE members and partners have noted that by the time people reach states of distress or crisis, it can often be too late to ensure respect for their rights, will and preferences[36]. This has been raised specifically in relation to older people and those with dementia.

Although SDM is promoted through policy and research, its implementation in routine practice remains slow[37]. Person centred care and the inclusion of patients in decisions can increase patient engagement and satisfaction, decrease unwanted health, and care service variation, and improve outcomes for disadvantaged patients[38]. Shared decision making is an ethical and human rights imperative.

A significant tool that enables older people to choose their care is self-directed support (SDS). If staff are working in health or social care, they should have the knowledge to provide older people with the options that are available for them to access care. This should not just be a siloed responsibility of local authorities but everyone within the health and social care sector. The standards should reflect the importance of SDS in providing choice and independence for older people living with frailty and disabled older people.

Our member Scottish Care found that there has been a failure in implementation of SDS for older people specifically accessing nursing and residential care home provision[39]. Most accessing care and support in care homes in Scotland have not been given their full rights under the self-directed support legislation.

Through the ALLIANCE's research, we found that over a quarter of participants had their SDS option chosen for them or were not offered all four options[40]. Although a larger proportion were able to access their preferred option, it reflects a substantial concern of wider SDS applicants that they do not have the choice and control that they were promised by the Act. Additional research noted an almost overwhelming sense that none of the SDS options are really a choice at all, with the simple reality of what is available on the ground dictating which option people receive their care and support under[41].

Such variation in interpretation and implementation has and can lead to people not receiving adequate support, their physical and mental health deteriorating, and family and friends being pushed into assuming unpaid carer roles. It also seemingly decreases the importance of the human rights principles underpinning the Self-directed Support Act[42]. This goes against commitments by the Scottish Government within the National Performance Framework, the Health and Social Care Standards, the SDS Strategy and Plans[43].

For older people to first have choice, autonomy and ownership, they must understand and have knowledge of what they are entitled to and the services and support they are being offered.

In our Investigating Knowledge and Understanding of the Right to Health report, the ALLIANCE found that there is a lack of understanding in relation to the right to health[44]. This is particularly acute for underrepresented and marginalised groups as health information is often inaccessible and there is a shortfall in understanding by staff and services of people's entitlement to the right to health. More widely, there is a need for policy action to address

those social and economic determinants of health that have negative effects.

Vitally, as we elaborate on in answer to question 30, for older people living with frailty to fully access person centred and coordinated care, measuring the extent of the implementation of support and services is a necessity.

Standard 4: Support for staff and care partners

14. Do you agree with Standard 4: Support for staff and care partners?

Slightly Agree.

We elaborate on response in answer to question 15.

15. Do you think that there are any necessary changes to Standard 4: Support for staff and care partners that the Development Group should consider?

Due to the different experiences of staff and unpaid carers and contexts in which they provide support, we believe that Standard 4 should be split into two separate standards applying to each group.

In line with the National Health and Wellbeing Outcome, these standards should ensure that "people who provide unpaid care are supported to look after their own health and wellbeing, including to reduce any negative impact on their caring role in their own health and wellbeing." Improving support and training for unpaid carers and staff was a key recommendation of the Independent Review of Adult Social Care[45].

Whilst the standards do include criterion for unpaid carers to be informed about independent advocacy and have access to education, training and support, more is needed. Such support and relevant information must be accessible and proactively offered at the first point of contact with health and social care services.

For example, at the first point of contact with health and social care services and in subsequent assessments and reviews, unpaid carers should receive assessments and plans for their caring roles. It was found that 89% of respondents had not received an assessment or written plan for their caring role[46].

Other forms of support available for unpaid carers should be specified either within the standards or accompanying guidance. Support should include free support for their mental health, support with their caring responsibilities and access to independent advocacy and advice and respite breaks when needed. Unpaid carers should be provided with training and the use of equipment and technology to aid their caring role and prevent deterioration of their own physical and mental health.

As noted in the State of Caring report, providing care for someone is a highly challenging responsibility, frequently affecting the physical and mental health of those who are providing care[47]. Throughout Scotland, unpaid carers provide high levels of care, seldom having the chance to take a break from caring. They grapple with constant anxiety, stress, and the consistent prioritisation of the person they are caring for, often resulting in numerous sleepless nights and feelings of isolation. These factors collectively contribute to physical fatigue and emotional exhaustion.

Of those who accessed social care services, 57% were satisfied with the quality of care that was provided[48]. Nearly half (48%) said they would be listened to if they raised concerns about the quality of care provided. However, only just over a third (36%) said that they felt they could rely on social care services and a similar proportion (37%) said that care support did not meet their needs or those of the person they care for. Around a third (30%) said that social care was not consistent. For example, care was not provided by the same staff at regular times.

In relation to language, the term ‘care partner’ is used within the consultation document. An unpaid carer is a family member, partner, friend

or neighbour who helps a person with daily activities that they would not be able to manage if they did not have help. This could be a partner, family member or friend who has a long term or terminal illness, someone who is disabled, has a mental health condition, is affected by addiction or who needs extra help as they grow older[49]. There are approximately 800,000 people in Scotland providing such unpaid care. It would cost an estimated £13.1 billion every year to replace the care they provide[50].

We believe that the term 'unpaid carers' should be used within the standards to avoid confusion and recognise the work they do, their experiences, and rights and outcomes that should also be addressed and met by the standards. This is in line with the National Health and Wellbeing Outcomes, the Independent Review of Adult Social Care and the Carers (Scotland) Act[51].

Standard 5: Keeping Active

16. Do you agree with Standard 5: Keeping active?

Slightly agree.

We elaborate on our response in answer to question 17.

17. Do you think that there are any necessary changes to Standard 5: Keeping active that the Development Group should consider?

Within the Scottish Government's A Fairer Scotland for Older People framework, it was recognised that remaining active and engaged in communities is a clear priority for older people[52].

Older people living with frailty and dementia have said that a key factor to living was having day to day activities[53]. For many, this was a higher priority than 'functional capacity' such as memory or cognitive function. Vitally, it does not matter the activity but the value that each person finds in it and the addition that it makes to their quality of life.

To encourage participation and understanding of keeping active, people should be made aware of the risks and benefits of any activities they are signposted to, with a clear and accessible description of it. Organisations should ensure that any activity which an older person living with frailty is referred to is fully trained in ageing and frailty and the impact it is on living well. In line with coproduction, choice and person centred care principles, individual decisions and preferences for living well must be met and accepted.

People want to be able to access mainstream services and specialist services. Staff must work to encourage external organisations to adapt their services so that older people living with frailty can access and enjoy them meaningfully. Barriers to keeping active currently mean that older people are unable to participate fully. For example, these include socioeconomic factors such as limited transportation, income or cultural or religious factors. For these reasons, an intersectional approach is a necessity to tailor plans to each individual and their circumstances. Alternatives to public or group strength and balance exercises should be available to accommodate any individual's needs.

We suggest that this standard should specifically target interventions for prefrail adults and unpaid carers. For instance, prefrail adults include between 35% and 50% of people over 65 and are a group most likely to benefit from a preventative programme of activity[54]. Unpaid carers should also be empowered and enabled to keep active for themselves in terms of both physical activity and social activity. Keeping active should be a key part of their care planning and include support to access regular respite breaks and access to activities that matter to them.

Standard 6: Nutrition and hydration

18. Do you agree with Standard 6: Nutrition and hydration?

Slightly Agree.

We elaborate on our response in answer to question 19.

19. Do you think there are any necessary changes to Standard 6: Nutrition and hydration that the development group should consider?

Supporting the right environment to support eating and drinking nutritious food is vital. Food is more than medicine: success to appropriately nutritious and healthy food is a basic human right and key to disease prevention[55].

Within international treaties, the link between food and the dignity of the human person is outlined[56]. For example, the right to adequate food is contained within the ICESCR (Internation Covenant of Economic, Social and Cultural Rights) and was recognised by the United Nations Committee on the Economic, Social and Cultural Rights[57]. Food is more than a nutritional need and is inherently important to realising other human rights such as the right to health, the right to an adequate standard of living and the right to social and medical assistance[58].

However, in our My Support My Choice research many people using social care experienced limited choices when it comes to food[59]. Many people, particularly those accessing Self-directed Support via Option 3 (the local council arranges the support) reported being served food at atypical and inconvenient times, that could vary each day (e.g. breakfast at 9am, lunch at 11am).

One person told us that they were offered a range of dietary choices by their care provider each week but that none of them were geared to food commonly eaten by people from their ethnic community[60]. Others highlighted the need to include preparation time for hot food and the importance of the social element of eating with people (including support with eating if required). Many people will have a paid carer provide support

with food but said support is often restricted to a very limited period and food that is quick to prepare and eat.

Stress and anxiety were also caused by the difficulty in accessing food. Many older people struggled with online shopping due to digital exclusion, delivery fees that negatively impacted finances, and access to culturally appropriate foods. For those who did qualify for food parcels provided by their local authority, many found they were not varied enough to meet the nutritional needs of older people[61]. These issues all have a real impact on mental health and wellbeing, demonstrating the negative impact on older people.

Despite being a place of care, undernutrition and malnutrition is common amongst older people in healthcare settings. For those over 65, this is an estimated 32% of admissions[62]. This is almost double the amount for those under 65. This is exacerbated further as undernutrition can be poorly detected by nursing and medical staff.

Every hospital and acute care setting should implement the seven steps to end malnutrition[63]:

- Hospital staff must listen to older people, their relatives and unpaid carers and act on what they say
- All ward staff must become ‘food aware’
- Hospital staff must follow their professional codes and guidance from other bodies
- Older people must be assessed for signs or risk of malnutrition on admission and at regular intervals during their stay
- Hospitals should introduce ‘protected mealtimes’ so that staff cannot carry out routine tests or rounds when patients are eating their meals
- Hospital settings should implement a ‘red tray’ (or coloured tray) system to help those who need assistance in feeding and ensure it works in practice.
- Hospitals should use trained volunteers to assist with eating where appropriate

To mitigate negative experiences, health and social care staff should be trained in identifying people experiencing or at risk of malnutrition and instigating malnutrition prevention techniques. Organisations should improve availability and access to high quality food. We suggest that organisations should embed such training as a compulsory element of any training programmes and CPD schemes for all health and social care staff[64].

Standard 7: Medicines management

20. Do you agree with standard 7: Medicines management?

Slightly agree.

We elaborate on our response in answer to question 21.

21. Do you think that there are any necessary changes to Standard 7: medicines management that the Development Group should consider?

Frailty can be prevented and reversed through programmes like anticipatory care combined with comprehensive multidisciplinary assessment and preventative interventions such as structured medication reviews for 'polypharmacy' to prevent medicine related harm and reduce health and care resources[65]. For example, GPs working jointly with pharmacists undertaking medicine reviews can lead to better outcomes including reduced falls and hospital admissions [66].

So that older people living with frailty, or their unpaid carers, do not have to repeat their medical history, and for the safety of individuals, medications and reviews should be updated and centralised so that prescribing professionals are aware of any changes and effects and outcomes of the medication. Incorrect medication is exacerbated by multiple prescribers, frequent transitions of care, and reduced capacity to recall medications[67]. The World Health Organisation (WHO) has reported that up to 67% of

patients' hospital medication histories contained at least 1 error, with a higher incidence among people aged 65 years and above[68].

Making sure people's medication records are up to date involves engaging the wider healthcare team, caregivers, and health technologies. An up to date medication list can support staff with therapeutic decision making, especially during transitions of care, where there may be time constraints and limited resources.

A key part of this is simplifying medication regimen. The use of multiple medications by older people with frailty is likely to increase the risk of falls, adverse side effects and interactions, hence the need to individualise treatment[69]. This is a person centred approach which enables older people to self manage and stay out of hospital. Home care and community based care services can further support frail older people with managing medication regimens.

For example, most older people are willing to discontinue at least one of their medications if recommended by the prescriber[70]. In the context of frailty, this may assist in maintaining quality of life and minimising medication burden.

Although policy states that a medicine review should take place each month, recognising the high level of vulnerability in this population, we recommend that reviews are conducted routinely and in response to key milestones in care[71].

Older people living with frailty and their unpaid carers are key players in the prevention and early identification of medicine related problems and should be supported to recognise and report poor medicine outcomes. Often medication contains information leaflets that are inaccessible, unclear and written in scientific language. Resources and information on every medication should be proactively provided, in a format tailored to each person's communication needs.

Standard 8: Living and Dying Well

22. Do you agree with Standard 8: Living and dying well?

Slightly agree.

We elaborate on our answer in response to question 23.

23. Do you think that there are any necessary changes to Standard 8: Living and Dying Well that the development group should consider?

Older people living with frailty have said that personal wellbeing, positive relationships and active daily lives contribute to a good life[72].

Reflecting this, and an outcomes based approach, we believe that the Ageing and Frailty standards should incorporate the following statements to enable older people living with frailty to have a full life:

- We have the right to be recognised as who we are, to make choices about our lives including taking risks, and to contribute to society.
- We have the right to continue with day to day and family life, without discrimination or unfair cost, to be accepted and included in our communities and not live in isolation or loneliness.
- We have the right to an early and accurate diagnosis, and to receive evidence based, appropriate, compassionate and properly funded care and treatment, from trained people who understand us and how our ageing and frailty, and associated conditions, affect us. This must meet our needs, wherever we live.
- We have the right to be respected and recognised as partners in care, provided with education, support, services, and training which enables us to plan and make decisions about the future.

Alongside this, we believe that due to the significant pressure on services, the standard should be rephrased to also include Waiting Well. A Waiting Well criterion should focus on providing better information on how to wait well, with material to help people self manage their conditions and signposting to interim support[73]. Waiting Well should be incorporated within individualised care plans so that periods where older people are on waiting lists support their health and wellbeing.

In terms of Dying Well, nobody should find themselves struggling as they approach the end of life. Palliative care should deliver the broadest possible access to available, appropriate, timely and good quality services and support for everyone who would benefit, regardless of where in Scotland they live[74]. It should also support people reaching the end of life who want to die at home to do so. This should include specific duties and obligations on Integration Authorities to plan for and deliver palliative care. Palliative care should be available at any point after someone has received a diagnosis of a terminal or life shortening condition, supporting them to live well and with the best health possible during that time, regardless of how long it may be.

Palliative care must also go beyond managing the direct symptoms and mental health challenges of life shortening and terminal conditions, to support people, as well as their unpaid carers, families and friends, to plan.

Any services supporting older people living with frailty must be accompanied by appropriate levels of resource. This may, for example, help to increase the availability and affordability of care for people living in rural areas people living in rural areas are more likely to find it difficult to access care. This can be due to a lack of provision in their area and the prohibitive costs of travelling elsewhere to access a service.

Importantly, these standards should incorporate any experiences and outcomes of unpaid carers. Unpaid carers have noted the importance of ‘intrapersonal’ factors to them living well but they had much lower levels of satisfaction with life[75]. Some reported feeling overwhelmed and/or

depressed, while others reported feeling high levels of stress due to their caring roles, feeling trapped, and feelings of guilt.

Challenges to living well for carers include the lack of available respite, their change in role, not having time or resources to participate in activities for themselves and a lack of physical and mental health support[76]. Organisations and staff should deliver interventions to mitigate any barriers that unpaid carers might experience.

Standard 9: Care in hospital

24. Do you agree with Standard 9: Care in hospital?

Slightly agree.

We elaborate on our response in answer to question 25.

25. Do you think that there are any necessary changes to standard 9: Care in hospital that the Development Group should consider?

Whilst we agree that hospitals and hospital care should be equitable, compassionate, and safe, as with the other standards, they should also be human rights based and person centred.

Hospital admissions should not be seen as inevitable, and any stays in hospital should be as short as possible with delayed discharge only occurring when an absolute necessity to prevent further deterioration.

Staff across organisations must be trained in identifying frailty. Awareness of some of the symptoms associated with frailty, such as delirium, is very variable among acute hospital staff. For example, a survey found that only 53% of UK hospital doctors were confident in identifying frailty[77]. Only 38.1% of the doctors received frailty identification training, with 67.9% agreeing they want more[78].

There are certain areas where there is a training gap including the different grades of frailty, malnutrition assessment and interpretation, and guidance on screening tools with clear instructions on accessibly communicating them to different audiences[79]. Alongside this, training is also needed on what to do after frailty is identified in terms of how to manage frailty[80].

Research has found that most people attending an emergency department already know the outcomes they want[81]. Their concerns mostly focused on:

- Autonomy
  People want to understand and be informed of their condition, treatment and care plan. Their choices and decisions should be independent, or supported by their unpaid carers, and adhered to. People want to feel heard by professionals and that their lived experiences are respected. They want to feel safe going home and managing their health issues.

- Function
  People want to be able to look after themselves, get around their environment and continue their activities. They want to feel better from illness, injury or low mood. People want support for caring for loved ones, and for those who care for them.

It is vital that this standard, and the Ageing and Frailty Standards as a whole, incorporate the outcomes that people using hospital and frailty services want and have the right to.

When planning for discharge, older people living with frailty may require complex support networks, both formal and informal, to support them in their own homes. Comprehensive discharge planning is likely to be beneficial in improving care, reducing length of stay and reducing readmissions[82]. Discharge planning should commence as early as possible once the decision to admit an older person to hospital has been taken but must not compromise adequate assessment.

Frail older people may also need a holistic assessment of their home circumstances before discharge. Doing this will enhance personal satisfaction and reduce the risk of readmissions, and the need for long term care. To facilitate a more detailed assessment of selected older people, joint working between hospital services and timely access to therapy staff and social services support is crucial[83].

If a patient is not severely unwell but is unable to stay in the community, it is good practice and better for people with frailty to transfer care to responsive community services rather than admission to hospital[84]. This could be either a rapid response type ‘hospital at home’ or a community based intermediate care service.

Comprehensive training of staff managing the care of older people in emergency settings is paramount to the safe and effective delivery of care. This should not be restricted to medical staff, but all health care staff, social services and community teams involved in older peoples’ care. Wherever possible and appropriate, this training should be undertaken jointly.

Without data to demonstrate good quality and/or gaps in service provision, it is impossible to plan or run medical services effectively[85]. Good quality diagnostic data about older people's presentation, diagnosis and treatment is vital to inform service provision, audit and research.

Older people living with frailty and other cooccurring conditions may not be able to communicate details about their health, social care and wishes for treatment which may be recorded elsewhere. This includes communication or sensory needs. Services should be able to exchange data about older people with other systems, especially primary care as this reduces the risk of prescribing errors. It is essential to share adequate and appropriate information between services to facilitate health and social care management and address safeguarding issues.

Standard 10: Delirium, dementia, and cognition

26. Do you agree with Standard 10: Delirium, dementia, and cognition?

Slightly agree.

We elaborate on our response in answer to question 27.

27. Do you think that there are any necessary changes to Standard 10: Delirium, dementia, and cognition that the Development Group should consider?

Preventative and early intervention approaches to dementia are essential for people to remain in their own homes and communities for longer periods[86]. They will have higher quality of life where they might otherwise have been institutionalised.

Effective prediagnosis and postdiagnosis support is important to personal wellbeing and the wellbeing of unpaid carers[87]. This offers an opportunity for early intervention and prevention, to consider and manage any impact of diagnoses. However, it has been found that there are often significant periods between receiving a dementia diagnosis and becoming eligible for formal health and social care services, without any interim support available.

Post diagnosis support should be delivered and accessible for each individual and their unpaid carer(s) at a minimum of one year after diagnosis. The success of the post diagnostic support service that is provided for one year by professional and highly trained staff is undisputed and helps people recently diagnosed with dementia, along with unpaid carers and families, understand the illness, access supports and services, and to plan for their future yet this is not implemented across universally across Scotland[88].

Such support must be easily accessible from one initial point of contact, timely and appropriate. People should know and understand where and how they can access such support, without being directed to multiple organisations or teams before receiving the help they need.

This reflects the Five Pillars of Post Diagnostic Support, a framework that allows people to live well with dementia[89]:

1. Planning for future decision making
2. Supporting community connections
3. Planning for future care
4. Peer support
5. Understanding the illness and managing the symptoms

Delirium, along with depression and dementia, is the most common mental health problem for older people in hospital. Approximately 20% to 30% of people on hospital medical wards have delirium, as well as 10% to 50% of people who have surgery[90]. In long term care settings, delirium affects less than 20% of individuals, but the percentage tends to rise with age.

Despite this, it is poorly detected and recorded with 33 to 66% of cases undiagnosed or misdiagnosed[91]. Failed detection in acute care setting increase mortality, and lengthens hospital stays. Low detection and recording are hampered by a limited availability of information on previous mental health assessment. It may not be possible for professionals to tell whether the cognitive impairment they have detected is different from the usual state.

Adequate support at home is critical in allowing older people to live independently, and these initial findings suggest a particularly important role for home care among older people with dementia[92]. People across Scotland have indicated that there is still an almost automatic default to care home care in some areas, particularly for frail older people[93]. This is

contrary to a human rights based approach. Moving into a care home must always be the informed choice of the person requiring care and support.

Standard 11: Mental Health

28. Do you agree with Standard 11: Mental health?

Slightly agree.

We elaborate on response in answer to question 29.

29. Do you think that there are any necessary changes to Standard 11: Mental health that the Development Group should consider?

Considering mental health in conjunction with ageing and frailty is essential. This follows the Scottish Government's A Fairer Scotland for Older People framework as for older people chronic loneliness is harmful to mental and physical health, and tackling social isolation and loneliness is fundamental to a thriving older age[94].

Whilst we are encouraged that older people will have their mental health assessed and supported, the Standard phrasing needs to be changed to demonstrate the importance of prioritising mental health to the same level as physical health. This should occur throughout someone's journey with health and social care services.

In our own research, for example, the ALLIANCE found that some felt GPs did not prioritise mental health over what they considered to be more 'urgent' physical issues[95]. Older people also told us that they lose a range of mental health support services when they turn 65 and felt that they had been pushed out of services. Participants all agreed that statutory service provision before the pandemic for older people was easier to access than it is now.

As with the identification and assessment of physical health, staff should be trained on how to actively look for and identify mental ill-health or issues and facilitate referrals to relevant support services that understand ageing, frailty and mental health[96].

The ALLIANCE, Age Scotland, See Me, and Voices Of eXperience (VOX) held a consultation event to discuss older adults' mental health and their experiences of mental health and social care services both before and during the COVID-19 pandemic[97].

Both loneliness and isolation were mentioned by participants as important to understanding older people's experiences of mental health. People also discussed that feelings of loneliness and isolation are caused by different reasons, meaning that the response to tackle them requires nuance[98]. For example, telephone befriending services made some people feel supported but certainly did not work for everyone. Practical activities were also seen as important to tackling feelings of isolation.

The word 'stoicism' was used by several participants to describe older people to emphasise what is seen as a generational difference and additional barrier to accessing support and services; it was also used to describe older people feeling that they did not want to 'be a bother' or a 'burden' especially when "others are having such a terrible time and the NHS is overstretched."

Stigma is clearly an issue for older people experiencing poor mental health who may struggle to ask for help. Some reported fear in coming forward in case they were deemed to have lost the ability to make decisions for themselves, therefore losing control over their own lives.

Specialist mental health services for older people are crucial not only for the delivery of treatment but also for training and liaison with other health

and social care providers. According to best practice guidelines, such services show greater effectiveness than non specialist services in community settings, general hospitals and care homes[99]. Unless people with multiple conditions are to attend multiple services, which is neither person centred nor efficient, a single, joint working comprehensive service will be needed.

However, Audit Scotland found that there is a lack of data on unmet need and service provision and that the Scottish Government does not have oversight of most adult mental health services due to such lack of information[100]. Audit Scotland also found that:

- The quality of care or the outcomes for people receiving it is not measured.
- Focus is on waiting times for psychological therapies to assess how adult mental health and wellbeing services are performing.
- Complications and delays in developing services that focus on individual needs due to a fragmented system and complex accountability measures.

Loneliness and isolation are also real struggle for unpaid carers, who often struggle to access support for themselves which negatively impacts their mental health. Lack of respite was reported to be a key issue for older people's and their unpaid carer's mental health. Most unpaid carers are women and finding out how to best support this group's mental health is essential. This should be highlighted within the Ageing and Frailty Standards.

30. Do you feel that anything is missing from the standards?

We recommend that the following additions are made to the Ageing and Frailty Standards:

Health Inequalities

We are concerned that the draft standards do not mention health inequalities specifically.

A key way to reduce health inequalities in older age is to reduce the inequalities in society across the life course[101]. There is a social gradient in healthy ageing that is rooted in inequality. The lower a person's social status, the more likely they are to enter older age in poor health and die younger than people from higher social classes. Health inequalities in older age are mostly a result of the social patterning of chronic diseases such as heart disease, stroke and cancer, however, a significant proportion of older people are affected by the damaging impact of living in poverty.

Health inequalities can also be perpetuated by stigma and discrimination. Independent Age argues that older people suffer the 'double whammy' of discrimination both because of their age and because of their mental health needs[102]. This is compounded when people have intersectional characteristics.

Global research suggests that older people are stereotyped as ill, dependent and incompetent. This is reinforced when being cared for as professionals accept and internalise negative attitudes towards old age. In healthcare doctors are less likely to give the correct diagnosis or treatment to older people than to younger ones[103].

From conducting our My Support, My Choice thematic studies, for example, the ALLIANCE knows that there are groups of individuals who are excluded from decision making or have received unequal access and treatment[104]. If coproduction and collaboration was taking place across the board, experiences such as these should not have occurred.

The ALLIANCE have heard from people with different protected characteristics or other seldom heard communities who described applying to SDS as being a bureaucratic battle, where they did not understand what

their options were due to communication barriers; were told SDS was “too complex to administer” because of their homelessness status; faced lengthy waiting times; or received no information at all[105].

Implementation, service gaps and barriers to access and support disproportionately impact individuals from groups who are either already marginalised and seldom reflected in policies or are in most need of social care support and services. For example, none of the Black and minority ethnic My Support My Choice research participants received information about the four SDS options before their needs assessment, and many said they had never heard of such an assessment[106].

Caring Places and Age Friendly Environments

As noted throughout the draft standards, people must be cared for in environments that meet their needs and outcomes. We believe that there should be a dedicated standard with a focus on place and/or environment especially considering the effect it has on older people living with frailty and dementia.

For older people, a poor environment affects both their physical and mental health and contributes to social isolation and loneliness being a major public health issue. Age friendly communities also enable ageing in place, which respects a person’s choice and preference of where they want to live and age and enables older people to live longer in their homes and communities[107].

In practical terms**,** age friendly environments are free from physical and social barriers and supported by policies, systems, services, products and technologies[108]. This includes organisational environments like health and social care settings. These supports promote health, building physical and mental capacity across the life course and enable people to continue to do the things they value.

Inclusive communication

Several of the standards contain criterion looking at information. We believe that there should be a dedicated standard focusing on inclusive communication and accessible information.

Work should be done to dismantle communication barriers faced by older people so they can find out about health and social care support quickly and easily. This would include widening the pool of professionals who are informed about relevant services for each individual and can encourage people to access it, streamlining information processes and clear signposting, and ensuring people have access to information in a range of formats and languages as detailed above.

To promote human rights, choice and person centred care, any information should be freely available and provided proactively or at the first point of contact with health and social care services. It should follow the Principles of Inclusive Communication, be high quality, accessible and provided in individually tailored formats (e.g. hard copy and digital; face to face; community languages; large print; Braille; Easy Read; BSL; electronic notetakers; captions; Alt text) at every stage of their journey through services no matter their age, disability, gender, religion, socioeconomic status, ethnicity, or cultural background[109]. Such information should be coproduced by older people with lived experience and unpaid carers.

In our My Support My Choice research, we found that older people found it difficult to find out about these services available to them, how to access them and confusion over what was available to them[110]. This is particularly pertinent to older people who have sensory loss or impairments[111]. Others found that they were signposted or referred to multiple services before they received answers to their questions or the support they required.

Language barriers have also presented a challenge in terms of accessing information and support. This can also lead to people whose first language is not English being excluded from decision making and solutions. For example, information about vaccines in different languages has only more

recently become widely available, and it is also difficult for those who have literacy issues[112].

Robust data gathering, monitoring and evaluation

Whilst the standards reflect what we are aiming for, in most areas of ageing and frailty, we do not know to what extent they are being realised due to a lack of data gathering, monitoring and evaluation[113].

A way to enable realisation of the standards would be to proactively collect and share disaggregated data between services. By improving gathering, transparency and recording gaps, there will be a clearer pathway to implementing the Ageing and frailty Standards in such a way that establishes equal access and availability, by exposing who services are not reaching and enabling the evaluation of outcomes that are met.

The ALLIANCE welcomed the Scottish Government's Health and Social Care Data Strategy to support social care providers to streamline data gathering[114]. Yet, as acknowledged by the Government, the system remains fragmented with little mention of the need for disaggregated data gathering and intersectional analysis.

Data sharing

We have also heard from members and people with lived experience that such fragmentation has resulted in them having to repeatedly retell their medical information, history, and care needs. This reflects a lack of continuity and sharing across healthcare and other services and leads to disengagement or retraumatisation.

Data sharing should also not be restricted to health and social care staff working directly for public sector organisations. It is important that third sector organisations providing services to people should have access to data where it is appropriate, and the assessment of appropriate access should be in dialogue with and led by the person accessing support.

Accountability

The standards state that organisations, multidisciplinary teams and staff will be responsible for delivering the standards. However, the standards should specify who they are targeted to and where responsibility lies for achieving and evaluating them. Accountability is a key element of a rights based approach.

In our joint focus group with Healthcare Improvement Scotland, we heard from participants who described the landscape as confusing, that they do not know where to go for specific types of support and how to complain about the services they are receiving[115].

Complaints mechanisms should be available and accessible to anyone using health and social care, so they are able to realise their right to the highest attainable standard of health and care.

About the ALLIANCE

The Health and Social Care Alliance Scotland (the ALLIANCE) is the national third sector intermediary for health and social care, bringing together a diverse range of people and organisations who share our vision, which is a Scotland where everyone has a strong voice and enjoys their right to live well with dignity and respect.

We are a strategic partner of the Scottish Government and have close working relationships with many NHS Boards, academic institutions and key organisations spanning health, social care, housing and digital technology.

Our purpose is to improve the wellbeing of people and communities across Scotland. We bring together the expertise of people with lived experience, the third sector, and organisations across health and social care to inform

policy, practice and service delivery. Together our voice is stronger, and we use it to make meaningful change at the local and national level.

The ALLIANCE has a strong and diverse membership of over 3,500 organisations and individuals. Our broad range of programmes and activities deliver support, research and policy development, digital innovation and knowledge sharing. We manage funding and spotlight innovative projects; working with our members and partners to ensure lived experience and third sector expertise is listened to and acted upon by informing national policy and campaigns and putting people at the centre of designing support and services.

We aim to:

- Ensure disabled people, people with long term conditions and unpaid carers voices, expertise and rights drive policy and sit at the heart of design, delivery and improvement of support and services.
- Support transformational change that works with individual and community assets, helping people to live well, supporting human rights, self management, co-production and independent living.
- Champion and support the third sector as a vital strategic and delivery partner and foster cross-sector understanding and partnership.

Contact

Billi Allen-Mandeville
E: billi.allen-mandeville@alliance-scotland.org.uk

Rob Gowans, Policy and Public Affairs Manager
E: rob.gowans@alliance-scotland.org.uk

T: 0141 404 0231
W: http://www.alliance-scotland.org.uk/

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