

OUR VOICES, OUR RIGHTS

WHAT OLDER PEOPLE SAY ABOUT
THE NORMATIVE ELEMENTS OF THEIR RIGHT
TO AUTONOMY AND INDEPENDENCE



The Global Alliance for the Rights of Older People is a network of about 300 civil society organisations from around the world that have come together to strengthen and promote the rights of older people.

www.rightsofolderpeople.org



Lydia Humphrey/
Age International

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INTRODUCTION

From December 2018 – January 2019, member organisations of the Global Alliance for the Rights of Older People interviewed approximately 100 older people in each of 10 countries to find out their views about key aspects of the right of older people to autonomy and independence. This report of the consultation aims to inform discussions on these rights at the tenth session of the Open-ended Working Group on Ageing in April 2019 and at future sessions.

The countries selected for the consultation are those in a project coordinated by the Global Alliance to promote older people’s rights and empowerment in Africa and Asia. The organisations conducting the survey used a variety of methods to identify older people in their countries to take part. These included attending meetings of older people and contacting individuals directly. Interviewers were encouraged to be inclusive in their thinking and seek out a diverse group of older people to interview.

The interviewers used a questionnaire containing a combination of open and closed questions to find out how important autonomy and independence was to

older people, and how important it was to them for their governments or the United Nations to recognise their rights to autonomy and independence.¹ The responses were uploaded using an online survey tool and analysed by age, gender, disability, rural/urban location and living arrangements.

The findings presented in this report aim to capture the views of the 1,063 older women and men interviewed in the consultation. They are not intended to be representative of the population of older people, either as a whole or in each country.

The report has three main sections:

1. What older people think about different aspects of their autonomy and independence,
2. Analysis of responses by characteristics of participants, and
3. Recommendations on the normative elements of the right to autonomy and independence.

The Annex lists countries that participants came from and the organisations that conducted the consultation.

ABOUT THE PARTICIPANTS

1,063 older people were interviewed:²

571 women
488 men



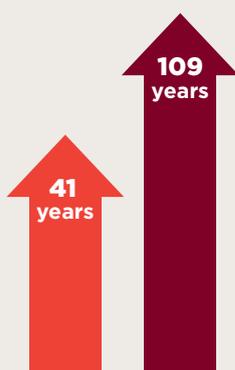
They were from 10 countries:

Bangladesh	Mauritius
Cameroon	Nepal
India	Rwanda
Kenya	Tanzania
Liberia	Uganda



They were aged 41 to 109 years:

1% below the age of 49
11% in their fifties
42% in their sixties
32% in their seventies
12% in their eighties
2% over the age of 90



Nearly half (46%) had disabilities.³

The percentage increased with age:

26% of those in their fifties
34% of those in their sixties
54% of those in their seventies
79% of those in their eighties⁴



Similar numbers lived in urban and rural areas:

48% lived in rural communities⁵
50% lived in urban communities



Their living arrangements varied:

58% lived with multiple family members
16% lived with their spouse or partner only
10% lived alone
5% lived in residential care facilities
3% lived with friends or other community members
2% lived in a refugee camp or state-provided temporary housing
6% answered ‘other’⁶



KEY FINDINGS

Older people value different aspects of their autonomy and independence highly. They want to see their right to autonomy and independence officially recognised by their governments or the United Nations.

This is the key finding from a consultation with 1,063 older people (571 women and 488 men)⁷ in 10 countries in Africa and Asia. Participants were asked about six aspects of autonomy and independence that were discussed at the ninth session of the UN Open-ended Working Group on Ageing in 2018.

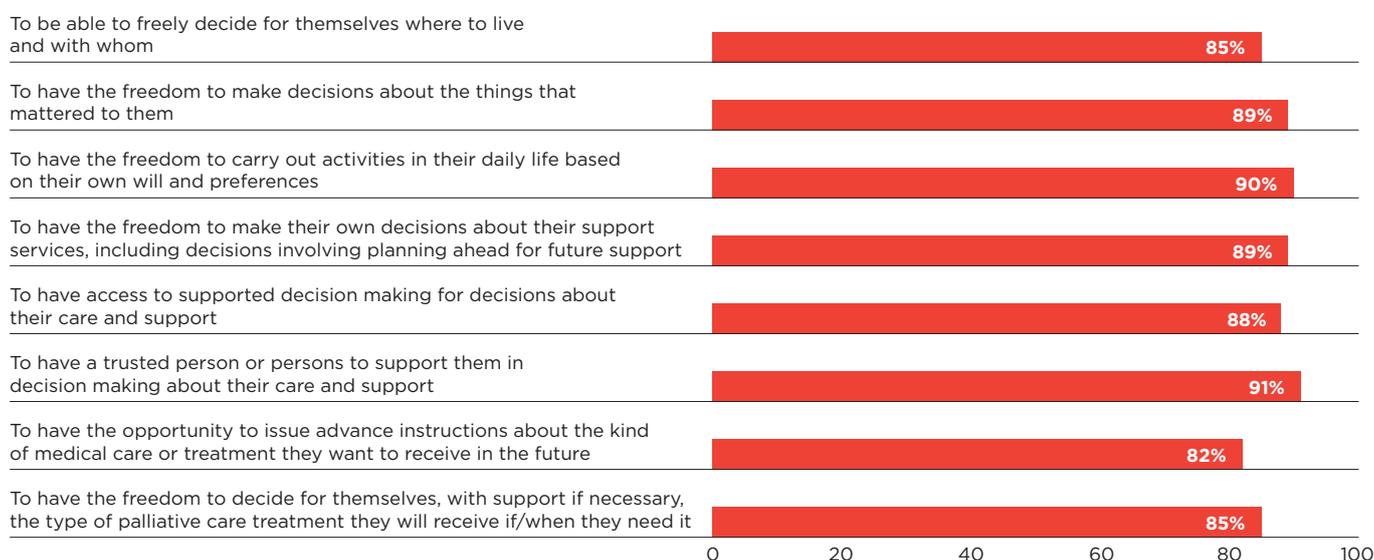
Their responses showed that:

- Older people value different aspects of their autonomy and independence highly, such as deciding where and with whom to live and choosing care and support services. This is important for their dignity and self-esteem, and for respect from others.
- Despite this, a significant proportion of older women and men say they currently enjoy little or no autonomy and independence.

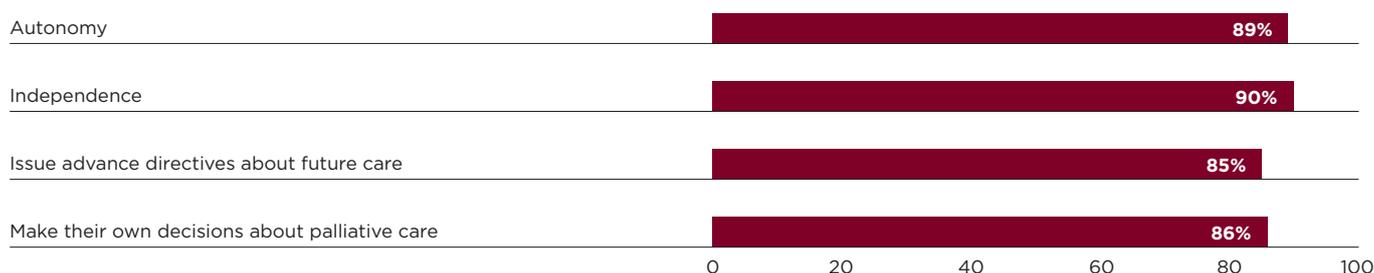
- Older people want to see different aspects of their right to autonomy and independence officially recognised by their governments or the United Nations. They believe this would enhance their dignity and improve their access to services.
- Although some aspects of autonomy and independence – issuing advance instructions about future medical treatment and deciding about the type of palliative care they would receive if they needed it – are new to some participants, the vast majority think these are important and should be recognised as their right.
- Older women and men of all ages and abilities, in different communities and with different living arrangements, attach importance to different aspects of their autonomy and independence and the official recognition of these as rights.

These findings from older people themselves reinforce widespread calls for greater recognition and protection of their rights within a new international instrument. They make an important contribution to the discussion on what the normative elements of the right to autonomy and independence should be, and inform the recommendations on the normative elements of this right presented in this report.

PERCENTAGE OF PARTICIPANTS SAYING ‘VERY IMPORTANT’ OR ‘IMPORTANT’



PERCENTAGE SAYING THAT OFFICIAL RECOGNITION OF THIS RIGHT IS ‘VERY IMPORTANT’ OR ‘IMPORTANT’



Ben Small/
HelpAge InternationalSion Jones/
HelpAge International

1. WHAT OLDER PEOPLE SAY ABOUT DIFFERENT ASPECTS OF THEIR AUTONOMY AND INDEPENDENCE

1.1 Deciding where and with whom to live

Eighty-five per cent of participants said having the freedom to decide where and with whom to live was very important or important to them. It would give them 'self-respect' and 'self-esteem' and enable them to 'keep their identity'. They could 'control their life' and people would 'respect their decisions'.

'It means nobody can force me out of the place where I live.'

70-year-old woman, Tanzania

'Choosing for myself would mean recognising my dignity.'

72-year-old man, Mauritius

They could 'fulfil their desires', 'exercise their freedom' and live 'comfortably', 'free from stress'.

'Otherwise, it would be like being a caged bird or animal.'

67-year-old man, India

However, 32 per cent said they had limited or no freedom to make such decisions. Sixty per cent said they would like to have more say about where and with whom to live.

Definitions

Autonomy and **independence** are often used interchangeably and are interdependent.

Autonomy is making choices and decisions, with support if necessary, according to one's will and preferences.

Independence is performing activities of daily life and participating in society, with support if necessary, according to one's will and preferences.

1.2 Making decisions about what matters in life

Eighty-nine per cent of participants said that having the freedom to make decisions about the things that mattered to them was very important or important. These included their healthcare; food and clothing; housing; nutrition and exercise; hygiene; work; managing their finances; religious, social and political activities; relationships, family life and the future of their children and grandchildren.

'Nobody likes to live a life depending on others. People should have freedom to live their life according to their wishes.'

68-year-old woman, Nepal

Making decisions about the things that mattered to them 'empowered' them, gave them 'dignity' and 'confidence', and enabled them 'to play all parts of life'. It gave them 'pleasure' and 'satisfaction', and allowed them to 'meet their goals' and 'take responsibility'. It meant they were not 'controlled by others'.

'It means I'm free to decide what's good for me.'

73-year-old woman, Liberia

However, 32 per cent said they had limited or no freedom to make such decisions.

Eighty-nine per cent said it was very important or important that their government or an international organisation such as the United Nations officially recognise their right to autonomy about the things that mattered to them.

'The international laws which are designed to protect our rights would definitely make our country's laws stronger, better and more effective.'

66-year-old woman, India

Recognition of their right to autonomy, they said, could 'influence the public and bring about a change in society' and make their rights 'real' and 'effective'. It would help 'maintain their individuality', 'safeguard their freedom' and 'honour their wishes'. It would also 'set standards' and 'provide guidance'.

'It gets to prove that I am a citizen in my country.'

70-year-old woman, Cameroon

1.3 Autonomy and independence in everyday activities and participation in society

Ninety per cent of participants said it was very important or important to carry out everyday activities based on their own will and preferences. However, 36 per cent said they had limited or no freedom to do this.

Having freedom to carry out everyday activities as they wished was part of being 'human'. It made them feel 'integrated into the community', 'helpful in society', 'competent' and 'accomplished'.

'It's very important because it connects me with other people living in my community.'
65-year-old woman, Rwanda

'My life becomes mine and my wishes remain as I wish.'
87-year-old man, Kenya

Ninety per cent of participants said it was very important or important that their government or the United Nations officially recognise their right to independence to carry out everyday activities based on their own will and preferences.

'Everybody, including people living in a [residential care] home, has rights. Even if we are living under the control of others we still need independence. This is what our government should know.'
90-year-old woman, Mauritius

Recognition, they said, would mean that older people were 'valued' and 'accepted' more. They would be able to 'live freely as they had done when they were young'. The government could be held 'accountable', and 'what is officially recognised works better.'

'Few women in my society enjoy such freedoms. Government recognition would help.'
67-year-old woman, India

1.4 Deciding about care and support services

Eighty-nine per cent of participants said it was very important or important to make their own decisions about care and support services, including planning ahead for future support. It was important for them 'to decide if it is necessary or not' since they were 'best to judge' what support services they needed.

'It means I have a choice to accept what I want and refuse what I do not want.'
90-year-old woman, Uganda

Deciding about their care and support would give them 'self-respect' and 'choice'.

'Without freedom of choice, I couldn't get the care service I wanted.'
75-year-old man, Bangladesh

However, 44 per cent said they had limited or no freedom to make such decisions. Fifty-eight per cent said they had access to little or no information about their options for care and support services. Ninety-one per cent said they would like to have access to more information.

Definitions

Care and support refers to the support a person needs to live a dignified, autonomous and independent life. It is sometimes called 'long-term care'. Support services offer people assistance in carrying out activities of daily life, such as taking medication, washing, eating, dressing, or getting around. Support services can also enable people to participate in their community and in society. For example, they may support people to go shopping, visit friends, go to worship, vote, and take part in groups or other events. Care and support also includes support with making decisions.

1.5 Supported decision-making

Eighty-eight per cent of participants said it was very important or important to have access to supported decision-making about their care and support. However, 50 per cent said they did not have access to supported decision-making. Eighty-five per cent said they would like more support in making decisions about their care and support.

Ninety-one per cent said it was important to have a trusted person or persons to support them in making decisions about their care and support. However, 38 per cent said they did not have access to such a person.



Issuing advance instructions about their future medical treatment, or care and support, was a new concept to many participants. Only 14 per cent had issued any advance instructions. Seventy-three per cent said they had no access to any information about their options for doing so. Nonetheless, 82 per cent said it was very important or important to have the opportunity to issue advance instructions about the kind of medical care or treatment they wanted to receive in the future.

'I can arrange care and treatment service as per my choice.'

75-year-old man, Bangladesh

'It means I can tell my children or family what to do when something serious happens to me, like a serious illness or death.'

58-year-old man, Liberia

Eighty-five per cent said it was very important or important that their right to issue advance instructions about their future care should be recognised by their government or the United Nations.

'This will bring about the introduction of this right to many older people in my country and also other countries where this right is not given at village level.'

65-year-old woman, Tanzania

Recognition of this right would lead to 'better treatment' and could prevent family 'difficulties' or 'problems'. Older people could 'plan', feel 'empowered' and be given 'their dignity'. Their decisions would be 'honoured', giving them 'a sense of security'.

'With the medical complications I have, advance directives [instructions] would give me confidence in my treatment.'

62-year-old woman, Uganda

Definitions

Supported decision-making allows people to maintain their autonomy and independence by choosing different types of support to assist them to make their own decisions and choices.

A trusted person is an individual that an older person chooses to ask for advice or other types of support before making a decision. This could be a friend, family member or someone else the older person trusts.

Advance instructions are instructions about the kind of medical treatment or care a person wants to receive in the future. They are often in the form of a written, legal document, for example, a 'living will' or 'advance directive'.

1.6 Deciding about palliative care

The concept of palliative care was new to many participants. Sixty-three per cent said they did not have access to palliative care if and when they needed it and 18 per cent did not know if they did or not. Sixty-five per cent said that they had no access to information about palliative care options.

However, 85 per cent said it was very important or important to decide for themselves, with support if necessary, the type of palliative care they would receive if they needed it. Freedom to choose their palliative care would 'reduce their stress', knowing they would 'receive trusted care'. They could 'plan for a better end of life'. They would 'suffer less' and 'die without pain'. They could 'participate' and 'choose the right care options'.

'I can decide what is best for me without any restriction.'

65-year-old woman, Nepal

'I am free, even at the end of my life.'

66-year-old man, Cameroon

Eighty-six per cent of participants thought it was very important or important that their government or the United Nations officially recognise their right to make their own decisions about their palliative care. Recognition would mean their 'decisions as an older person' were 'important and matter for others'.

'It equalises us with the other cohorts of age groups.'

78-year-old man, Kenya

Official recognition would 'improve policies' and older people 'would be included in government plans'. 'Hospitals would know they had that right'. Services would be 'affordable' and 'available without discrimination of any kind'.

'It shows respect for our right to die in dignity.'

59-year-old man, Rwanda

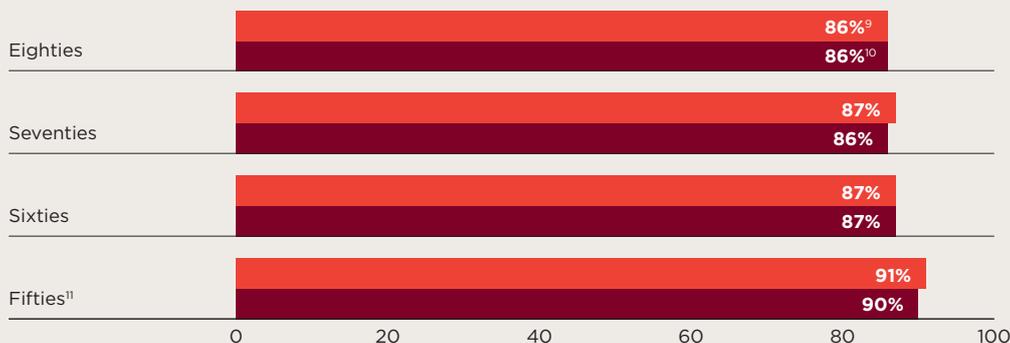
Definition

Palliative care is the active holistic care of individuals across all ages with serious health-related suffering due to severe illness, and especially of those near the end of life. It aims to improve the quality of life of patients, their families and their caregivers.⁹

2. ANALYSIS OF RESPONSES BY CHARACTERISTICS OF PARTICIPANTS

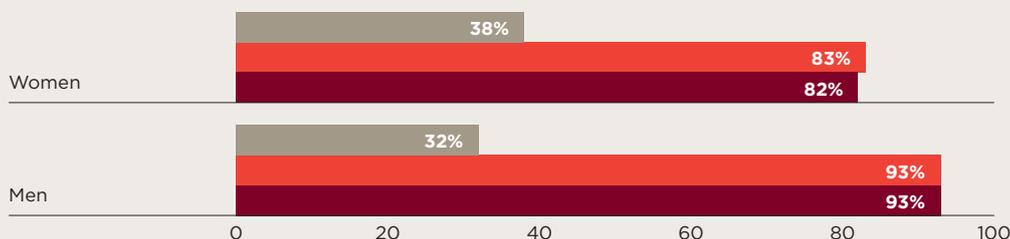
An analysis of responses by different characteristics of participants shows that both older women and men, of different ages and abilities, in different communities and with different living arrangements, value their autonomy and independence highly and want official recognition of this right.

AGE



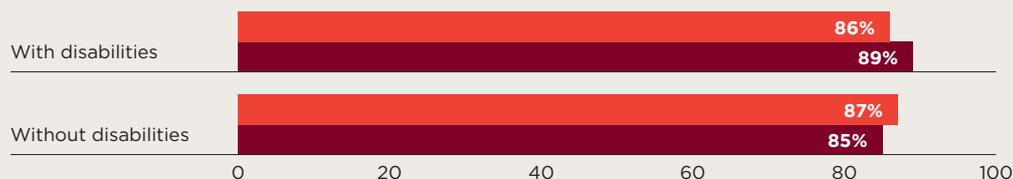
A high percentage of participants in every age group said that their autonomy and independence was very important or important, as was official recognition of their right to this.

GENDER



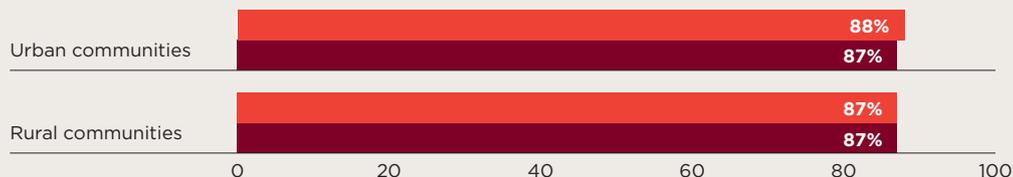
Around one third of both women and men said they had limited or no autonomy and independence. A high percentage of both women and men (slightly higher for men) said that their autonomy and independence was very important or important, as was official recognition of their right to this.

DISABILITY



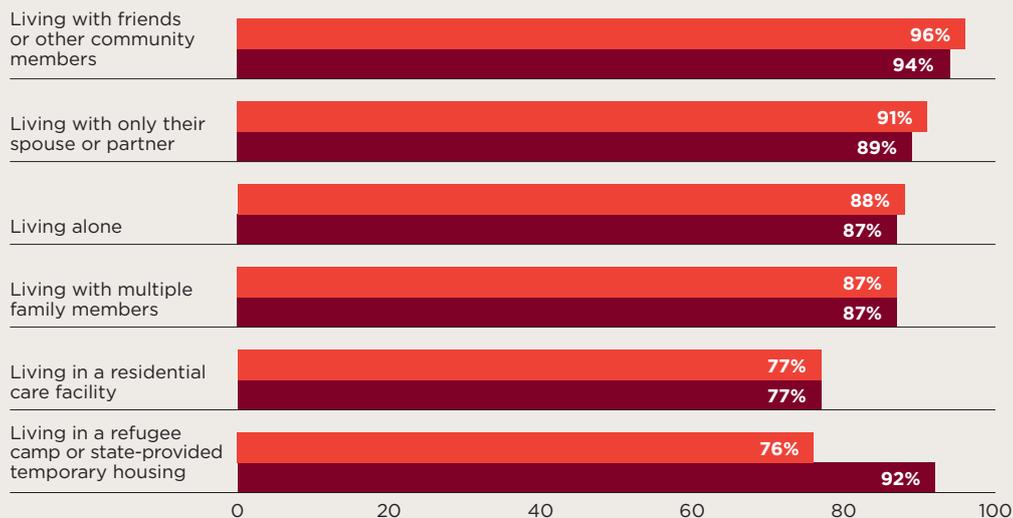
An almost equally high percentage of participants with and without disabilities said that their autonomy and independence was very important or important, as was official recognition of their right to this.

URBAN AND RURAL COMMUNITIES



An almost equally high percentage of participants living in urban and rural communities said that their autonomy and independence was important or very important, as was official recognition of their right to this.

LIVING ARRANGEMENTS



A high percentage of participants in every living arrangement said that their autonomy and independence was very important or important, as was official recognition of their right to this.

KEY TO ALL GRAPHS

- Have limited or no autonomy
- Autonomy and independence is important or very important
- Official recognition is important or very important

3. RECOMMENDATIONS ON THE NORMATIVE ELEMENTS OF THE RIGHT TO AUTONOMY AND INDEPENDENCE

Older people have the right to autonomy and independence in all aspects of their lives in line with their will and preferences and on an equal basis with others. Older people say officially recognising, promoting and protecting this right is important to them.

The following recommendations on the normative elements of the right to autonomy and independence are informed by what older people said in this consultation, and build on existing international human rights standards. They are intended to inform discussions on the normative elements of a possible new international instrument on the rights of older people at sessions of the Open-ended Working Group on Ageing.

Definitions

Normative elements are the different elements (components) that form the content of a human rights standard (also called a norm).

International human rights standards are set out in international human rights treaties. Each standard is the minimum level of how all humans should be treated. If these standards are met, people should be able to live a life of dignity.

On an equal basis with others means giving everyone equal opportunities to enjoy their rights. Everyone has the same human rights. Older people should have the same opportunity to enjoy their human rights as everyone else.

3.1 Deciding where and with whom to live

Older people have the right to:

- Choose where and with whom to live on an equal basis with others
- Access a range of support services which are available on an equal basis in home, community and residential settings in order to support their dignified, autonomous and independent living and inclusion in the community where they choose to live.

3.2 Making decisions about what matters in life

Older people have the right to:

- Make decisions, to determine their life plans and to lead dignified, autonomous and independent lives in line with their will and preferences and on an equal basis with others
- Have their decisions respected
- Be recognised as individuals under the law and take legal action on an equal basis with others.

3.3 Autonomy and independence in everyday activities and participation in society

Older people have the right to:

- Access to a range of care and support services to enable them to live dignified, autonomous and independent lives and be fully included in the community
- Full, effective and meaningful participation in family, social, cultural, economic, public and political life and educational and training activities.



Abir Abdullah/Age International



Ben Small/HelpAge International

3.4 Deciding about care and support services

Older people have the right to:

- Information about all aspects of their care and support needs and services
- Choice and control over their care and support services, and the right to support to enable them to exercise this right
- Give and withdraw at any time their free, prior, ongoing and informed consent to all aspects of their care and support services
- Control over the planning, delivery and monitoring of their care and support
- Make legally binding documents on the type of care and support they would like and who provides it, should it be required at a future point in time
- Designate one or more trusted persons to assist them to make decisions, based on their instructions, will and preferences, about their care and support services.

3.5 Supported decision-making

Older people have the right to:

- Support to enable them to make their own decisions and choices in line with their will and preferences
- Designate one or more trusted persons to assist them to make decisions based on their instructions, will and preferences
- Make legally binding documents to express their instructions, will and preferences in advance
- Participate in, and challenge, any decisions that interfere with the exercise of their autonomy and independence.

3.6 Deciding about palliative care

Older people have the right to:

- Timely access to information about all aspects of their health and palliative care treatment options
- Give and withdraw at any time their free, prior, ongoing and informed consent to their palliative care treatment, and any other health matters
- Access to palliative care in a setting that is consistent with their needs, will and preferences, including, but not limited to, in the home, in hospices, in hospital, and in other care and support settings
- Support with decision-making about their palliative care, including the right to appoint one or more trusted persons to assist them to make decisions based on their instructions, will and preferences
- Make legally binding documents that set out their instructions, will and preferences around medical interventions, palliative care and other support and care at the end of life, including the place where palliative care services are provided.

Older people also have the right to safeguards to enable them to exercise all aspects of their right to autonomy and independence. They also have the right to justice including access to complaint or other accountability mechanisms and redress when their right is denied.

ANNEX: LIST OF COUNTRIES AND ORGANISATIONS

The consultation took place in Bangladesh, Cameroon, India, Kenya, Liberia, Mauritius, Nepal, Rwanda, Tanzania and Uganda.

We would like to thank the following member organisations of the Global Alliance for the Rights of Older People for their support in conducting the consultation with older people:

Resource Integration Centre (RIC), Bangladesh

Association Camerounaise pour la Prise en charge des Personnes Agées (ACAMAGE), Cameroon

Centre for Gerontological Studies (CGS), India

Karika, Kenya

Center for Community Advancement and Family Empowerment (CECAFE), Liberia

Droits Humains Ocean Indien (DIS-MOI), Mauritius

Ageing Nepal, Nepal

NSINDAGIZA Organisation, Rwanda

The Good Samaritan Social Service Trust (GSSST), Tanzania

Uganda Reach the Aged Association (URAA), Uganda

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1. The full questionnaire can be found at www.rightsofolderpeople.org/wp-content/uploads/2019/02/Questionnaire-final-12-December-2018.pdf
2. 3 respondents skipped this question and 1 answered 'I prefer not to say'.
3. Based on their answers to the set of six Washington Group Questions www.washingtongroup-disability.com/washington-group-question-sets/short-set-of-disability-questions
4. Age cohorts 49 and younger and 90 and older were excluded from this analysis due to the small number of respondents in these cohorts.
5. 50% urban, 47.7% rural, 1.7% other, 0.3% don't know, 0.3% prefer not to say.
6. 'Other' included living in makeshift shelters, slums, an 'abandoned house', 'behind the community church' and having 'no fixed place' to live.
7. 3 respondents skipped this question and 1 answered 'I prefer not to say'.
8. International Association for Hospice and Palliative Care <https://hospicecare.com/what-we-do/projects/consensus-based-definition-of-palliative-care/definition>
9. Percentages in these graphs are based on an average taken from a number of questions about the level of importance attached to different aspects of autonomy and independence.
10. Percentages in these graphs are based on an average taken from a number of questions about the level of importance attached to official recognition by the government or the United Nations to different aspects of autonomy and independence.
11. Age cohorts 49 and younger and 90 and older were excluded from this analysis due to the small number of respondents in these cohorts.