

POSITIVE AGEING FOR IRISH TRAVELLERS

2019

DEVELOPING INDICATORS OF POSITIVE AGEING FOR IRISH TRAVELLERS

This report was produced by the Healthy and Positive Ageing Initiative which is led by the Department of Health, with the Health Service Executive, The Atlantic Philanthropies, and the Age Friendly Ireland Programme.

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FOREWORD

Census 2016 signified positive gains in healthy life expectancy and overall life expectancy for people in Ireland as we continue to experience rapid population ageing. However, the census also highlighted gaps in health outcomes and life expectation for minority ethnic groups, including Travellers. Indeed, only 3% of the Traveller population enumerated were found to be 65 years or older. This indicates that healthful ageing for Travellers remains a challenge as a disproportionate number of Travellers continue to die younger and at a faster rate than the majority population.

As acknowledged in the report, other countries have identified the diverse nature of ageing and the particular experiences of minority ethnic groups. In doing so, they have developed innovative solutions and mechanisms to address these gaps through strong baseline indicators based on the recognition that programmes and services for older people must take into account the needs of different groups. In 2013, the first National Positive Ageing Strategy was published in Ireland and as a result, key indicators were developed to monitor progress in positive ageing. However, the indicators were not fit for purpose for all groups, as acknowledged in the report, and therefore there was a clear need to develop a distinct set of positive ageing indicators for Travellers.

We welcome this report, which sets out those indicators based on extensive consultation with Travellers and Traveller organisations. What emerged from that consultation was the need to re-categorise 'Age' and 'Housing' to capture the specific needs of older Travellers who were otherwise excluded from the previous indicators. The new indicators therefore propose to redefine Traveller 'ageing' as 40+, recognising the short lifespan and early ageing of Travellers. It also proposes to redefine 'Housing' to include 'Housing and accommodation,' reflecting the various types of accommodation in which Travellers live.

While this is a positive development towards addressing the specific needs of older Travellers, serious gaps remain. These include the absence of disaggregated data on the basis of ethnicity across all routine data collection systems, a gap which has been highlighted persistently by Pavee Point and by a number of UN treaty-monitoring bodies, European institutions and equality and human rights bodies.

Pavee Point would like to acknowledge the work of Travellers, Traveller organisations and the Healthy and Positive Ageing Team in developing these indicators and urge health policymakers in this area to take on board and implement the recommendations of this report.

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GLOSSARY OF TERMS

AITHS	All Ireland Traveller Health Study
CS0	Central Statistics Office
EQLS	European Quality of Life Survey
EU	European Union
EU-LFS	European Labour Force Survey
EU-SILC	European Survey of Income and Living Conditions
HaPAI	Healthy and Positive Ageing Initiative
HSE	Health Service Executive
NPAS	National Positive Ageing Strategy
PIAAC	Programme for the International Assessment of Adult Competencies
TILDA	The Irish Longitudinal Study on Ageing
WHO	World Health Organisation

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A FRAMEWORK FOR POSITIVE AGEING INDICATORS & DATA

Identified using a consensus process involving a panel of 73 researchers, policy makers and older people

PARTICIPATION

- Employment
- Formal education
- Informal education
- Literacv
- Numeracy
- Political activities
- Voluntary work
- Caring for relatives and children
- Social activities
- Loneliness
- Social support
- Driving
- Public and private transport

HEALTHY AGEING

- Life expectancy
- Healthy life expectancy
- Self-rated health
- Walking speed
- Falls
- Pain
- Chronic disease
- Caregiver stress
- Cognitive impairment
- Smoking
- Alcohol

- Physical activity
- Healthy weight
- Difficulty engaging in work or education due to disability
- Difficulty engaging in leisure due to disability
- Depression
- Life satisfaction
- Sense of control
- Anxiety
- Flu vaccine
- Mammogram

- Unmet need for community care
- Multiple medications
- Home care services
- Difficulty seeing a doctor
- Difficulty going outside the home due to disability
- Difficulty with basic activities
- End of life care services

SECURITY

- Consistent poverty
- Shortage of money
- Housing facility problems
- Housing condition problems
- Keeping house warm
- Access to essential services
- Access to social services
- Neighbourhood social environment
- Elder abuse
- Safety out and about
- Access to recreational and green spaces

CROSS-CUTTING OBJECTIVES

INFORMATION PROVISION

- Internet use
- Confidence filling in medical forms

COMBATING AGEISM

- Positive perceptions of ageing
- Experience of discrimination

SUPPLEMENTARY POSITIVE AGEING INDICATORS FOR TRAVELLERS

New indicators were identified using a consensus process involving 54 representatives from Traveller stakeholder and community groups.

PARTICIPATION

SOCIAL & CULTURAL PARTICIPATION

- Barriers to Traveller identity preserving acts or activities
- Barriers to everyday cultural practices
- Sense of unity and co-operation with family members and neighbours
- Participation in community organisations

HEALTHY AGEING

HEALTHCARE

- Treated with dignity and respect by a healthcare professional
- Medical card coverage
- Use of 'healers' when sick
- Uptake of cancer screening (cervical smear)
- Uptake of faecal occult blood test
- Family or friend to accompany you to medical appointments

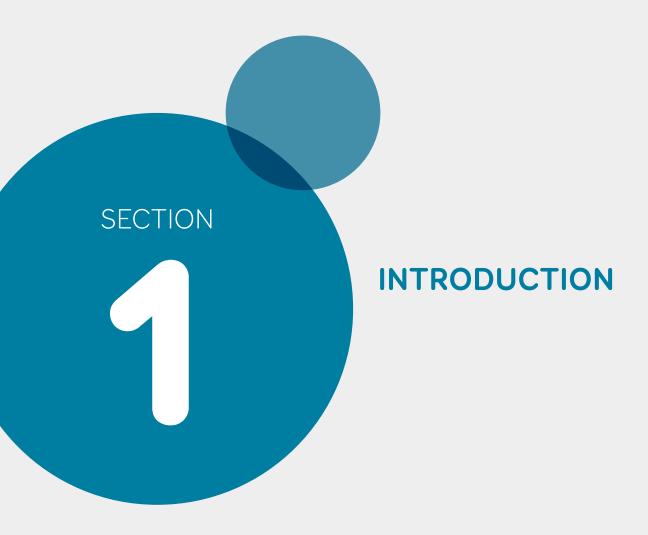
HEALTH BEHAVIOURS

- Functional health literacy
- Adhere to food pyramid recommendations
- Difficulty in reading medication instructions



HOUSING & ACCOMMODATION

- Accommodation security (tenure or land tenure)
- Accommodation facilities: overcrowding; refrigerated food storage; sufficient site drainage; fire safety measures onsite.



SECTION 1: INTRODUCTION

Ireland's National Positive Ageing Strategy (NPAS) [3] aims to address the broader social and economic determinants of healthy and positive ageing across the life course. The NPAS draws on the World Health Organisation's (WHO) Active Ageing Framework which highlights action needed on three fronts: participation, health and security. The NPAS has four goals: three based on the WHO's action areas and a fourth which focuses on research. These goals are to:

- Remove barriers to participation and provide more opportunities for the continued involvement of people as they age in all aspects of cultural, economic and social life in their communities according to their needs, preferences and capacities
- Support people as they age to maintain, improve or manage their physical and mental health and wellbeing
- Enable people to age with confidence, security and dignity in their own homes and communities for as long as possible
- Support and use research about people as they age to better inform policy responses to population ageing in Ireland.

The NPAS emphasises that 'older' people are not a homogeneous group, and that everyone has different experiences and expectations of ageing, and these differences can arise due to differences in material resources, level of educational attainment, health status and life experiences (3). As such, as some people get older their risk of poor health, loss of independence, financial vulnerability or social isolation and loneliness will increase at a greater rate compared with others. In acknowledgement of this, the NPAS calls for particular attention to be paid to the need and circumstances of groups in Irish society who have a greater level of vulnerability as they age, including minority groups such as Irish Travellers (3). According to the most recent Census of the Population in 2016 there were 30,987 Irish Travellers resident in the State.

1.1 THE HEALTHY AND POSITIVE AGEING INITIATIVE

A key area of HaPAI's work has involved the development of positive ageing indicators which were published for the first time in 2016 (7). Outcome indicators such as these provide evidence that particular conditions exist or that certain results have or have not been achieved (8,9). During the process of developing these indicators, the NPAS recommended that in order to change mindsets and promote social inclusion, particular attention should be paid to the needs of more marginalised, vulnerable, and hard-to-reach groups of older people, including Irish Travellers.

As part of the consensus process conducted by HaPAI in 2015 to develop the positive ageing indicators for Ireland, a large majority of participants agreed that separate positive ageing indicators for Irish Travellers were important and necessary. Feedback provided in response to open-ended questions collected during the consensus process in 2015 focused on issues of service access, social engagement, social inclusion, accommodation, migration and attachment to place, family experience of trauma, and culturally sensitive measures of material deprivation (10). It was therefore concluded that it was necessary to develop a separate set of indicators for Irish Travellers, which are unique to this group. This can then be used to monitor progress in positive ageing across all groups in society.

1.2 TRAVELLER HEALTH

The All Ireland Traveller Health Study (AITHS) conducted in 2010 remains the primary source of information relating to the health and wellbeing of Travellers in Ireland. Three areas are particularly relevant for healthy and positive ageing: life expectancy, mortality, and the social determinants of health.

Life Expectancy

As of 2010, when the All Ireland Traveller Health Study was carried out, life expectancy for male Travellers was 61.7 years, compared to 76.8 among the general population; life expectancy for female Travellers was 70.1 years, compared to 81.6 among the general population. This means that Travellers have the same life expectancy as that which the general population had from 1945-1947 (males) and 1960-1962 (females). Between 1987 and 2010 life expectancy for male Travellers remained unchanged, while for female Travellers life expectancy increased by 4.8 years. During the same period, for the general population male life expectancy increased 5.2 years and female life expectancy increased 4.4 years (5). In 2018, 13% of the general population were aged 65 or older, compared to just 3% of the Traveller population (4).

Mortality

Rates of death by cancer, cardiovascular disease, respiratory issues and external causes such as accidents are significantly higher for Irish Travellers than the general population (92). The mortality rate due to respiratory disease among male Travellers is 7.5 times higher and for female Travellers 5.4 times higher than the general population. Death due to heart disease and stroke is 3.8 times more prevalent for male Travellers and occurs 4.8 times more frequently for female Travellers. Rates of death by suicide are 6.6 times higher for male Travellers and 4.9 times higher for female Travellers compared to the general population. Finally, compared with the general population, death due to external causes (such as traffic accidents and homicides) is 5.5 times more common among male Travellers and 3.9 times more common among female Travellers (5).

The Social Determinants of Health

As with the majority population, the social determinants of health and wellbeing for the Traveller population are well established and include social, economic, environmental and political conditions (6). As such, the All Ireland Traveller Health Study found a range of adverse conditions, circumstances and resources which negatively impacted the health and wellbeing of the Traveller population, including poor environmental and living conditions; inequity of access to health services; lack of culturally appropriate service provision; individual and institutional racism; social exclusion; and a lack of disaggregated data on the basis of ethnicity to sufficiently monitor, plan and address the health needs of Travellers in Ireland (6).

1.3 INTERNATIONAL APPROACHES TO ETHNIC DIVERSITY IN AGEING POLICIES AND STRATEGIES

There are several examples of international approaches taken to highlight and address the needs and experiences of marginalised groups in healthy and positive ageing strategies and related monitoring frameworks. For example, the European Commission's Active Ageing Index notes the value of the index for differentiating between different groups of older people including ethnic minorities (11). The Global Agewatch Index includes an ethnic identifier to allow for differences in ageing outcomes across ethnic groups to be measured and monitored (12). The World Health Organisation's Global Age Friendly Cities Indicator set was developed with the possibility of disaggregation according to a range of factors, including ethnicity (13).

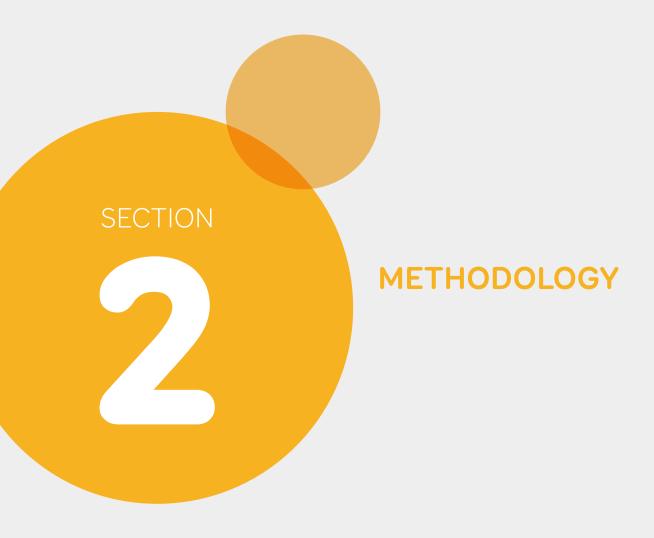
At a national level, in the USA, the Federal Interagency Forum on Aging-Related Statistics published Older Americans Key Indicators of Wellbeing in 2016. This report contained a sub-indicator dedicated specifically to racial and ethnic composition, based on the recognition that programmes and services for older people will require greater flexibility as the population diversifies over time (14). However, this approach is not consistently adopted and, commenting on the Index of Wellbeing in Older Populations, the US Population Research Bureau acknowledges that it fails to reflect the racial and ethnic diversity of the older population of the USA (15).

In Canada, the 'Vision Statement' and 'Five Principles' that seniors and Governments across Canada share and which underpins the National Framework on Aging emphasises that policies and programmes must address the diverse needs, circumstances, and aspirations of various sub-groups within the older population such as age, gender, family status, geographic location, Aboriginal status, official language minorities and ethnocultural minorities, income status, and health status (16). Further, the Alliance for a National Seniors Strategy proposed that any national positive ageing strategy should reflect the increased risk of social isolation and elder abuse which older aboriginal populations face, in particular (17).

The National Strategy for an Ageing Australia recognises the lower life expectancy and significantly lower health status of Aboriginal and Torres Strait Islander peoples. It notes the importance of making separate culturally specific, flexible and innovative arrangements to meet the needs of these marginalised groups [18]. The New Zealand Positive Ageing Strategy recognises the varied health needs of different ethnic groups in the population. It specifically acknowledges the needs of Maori people, their need for care which is culturally safe, and which recognises the importance of whanau (extended family) and kaumata (elders). A key recommendation of this strategy is for quality health services to be provided by Maori, for Maori [19]. These recommendations have permeated New Zealand's Positive Ageing Indicators [2007] which includes Maori Cultural Identity as one of ten key outcome domains [20]. Within Europe, the Dutch policy on the 'elderly', known as Memorandum 64, has been evaluated periodically to examine the extent to which its targets have been achieved. These evaluations have considered the differing contexts for ethnic minority groups and have highlighted how these groups are lagging behind across a range of areas [21].

SUMMARY

In summary, Ireland is among several international and national entities that recognise the disadvantaged position which many minority ethnic groups experience in relation to healthy ageing. The positive ageing indicator set is an important tool to monitor progress under the National Positive Ageing Strategy and the inclusion of indicators that reflect the needs and circumstances of older Irish Travellers in Ireland is an important step towards a 'whole of society' approach to monitoring healthy and positive ageing in Ireland.



SECTION 2: METHODOLOGY

A modified consensus building process was undertaken by the HaPAI to prioritise indicators of healthy and positive ageing for Irish Travellers. The objective of this process was to identify any further aspects of positive ageing that members of the Traveller community considered relevant to this monitoring framework. The intended outcome was the inclusion and/or modification of relevant indicators which can be added to the positive ageing indicators. This process involved four steps which are summarised below.

Figure 1: Process Summary

EXPLORATION ENGAGEMENT REVISION FINALISATION

Exploration

Drawing on a range of academic research, policy documentation, stakeholder research reports and stakeholder position papers on older Travellers and Traveller health, a longlist of over 100 potential indicators for positive ageing for Travellers was developed. This list was screened using the same screening tool that was used in the process to develop the positive ageing indicator set. The screening criteria were:

- the indicator is needed and useful to national stakeholders
- the indicator has technical merit
- it is feasible to collect data for this indicator
- the indicator set is coherent and balanced overall

From the screening process a total of 40 additional indicators were proposed: one under the cross-cutting themes; 11 indicators for Participation; 13 indicators for Security; and 15 for Healthy Ageing. The shortlist of indicators identified at this stage is presented in Appendix 1.

Engagement

Three engagement sessions were undertaken; these used a focus group methodology to gain feedback from expert stakeholders on the shortlist of indicators of positive ageing for Irish Travellers. The expert stakeholders comprised Traveller Community Health Workers and older Travellers.

Across the three engagement meetings a total of 54 Traveller men and women took part from three locations across Ireland: Offaly, Dublin, and Wicklow. Participant details are summarised in Table 1.

Table 1: Participant characteristics

SESSION	PARTICIPANTS	NUMBER
1	Traveller Community Health Workers	20
2	Traveller Community Health Workers and older Travellers	17
3	Traveller Community Health Workers and older Travellers	17
TOTAL		54

 $^{^{2}}$ The screening tool the HaPAI team developed and used is available on the HaPAI website (www.hapai.net).

During the sessions, visual aids were used to provide participants with both the 2016 positive ageing indicators and proposed additional indicators: these posters contained graphics of all the indicators for each positive ageing pillar, e.g. Participation. Participants were invited to discuss the pillar that they felt best placed to provide feedback on: Security, Healthy Ageing or Participation. HaPAI researchers facilitated group discussion using three prompts:

- What is missing?
- What would you change?
- Which indicators are most important?

Under the third discussion point, "which indicators are most important?" participants identified which indicators were most important to them using stickers and a visual aid. Participants were free to put as many stickers as they wished on each indicator but were limited to just ten stickers each. All materials were literacy-friendly to accommodate all literacy levels. Facilitators took detailed notes which were written up immediately following each discussion. The results of the discussion surrounding 'what was most important' were counted by the facilitators. These notes were analysed thematically to capture important issues relevant to positive ageing that were beyond the scope of quantitative indicators.

Revision

The results of the engagement phase informed how the shortlist of indicators was revised. Indicators were added that were important but missing from the proposed set; indicators were removed that were not considered to be important; and indicators were re-worded to capture wider issues and/or to make the indicator easier to understand.

Although only those indicators which had at least four priority dot stickers were considered for inclusion in the final set of indicators, the rate of prioritisation was much higher for some. For example, one indicator was marked as a priority 24 times (cumulatively, across all three consultations). A total of 32 indicators were prioritised for finalisation. This included three indicators that were not included in the initial longlist:

- Percentage of Travellers aged 40+ who report feeling a sense of unity and co-operation with family members and neighbours
- Percentage of Travellers aged 40+ who have a friend or family member to accompany them to medical appointments
- Percentage of Travellers aged 40+ who report feeling secure in their accommodation (tenure or land tenure).

Finalisation

The last steps of the process were to compare and adjust any of the indicators in terms of existing data; where there was no current data source, to prepare for future data collection; and to align the wording and content of indicators to existing and forthcoming data sources. Data from three sources was assessed during this step: Census of the Population; the All Ireland Traveller Health Study; and the Healthy Ireland Survey.



SECTION 3: RESULTS

Details of the process undertaken are summarised in Figure 2.

Figure 2: Detailed process summary

EXPLORATION

100 indicators identified and screened by HaPAI

ENGAGEMENT

40 indicators discussed and prioritised by stakeholders

REVISION

32 indicators proposed by stakeholders

FINALISATION

Age ranges adjusted,
18 indicators
aligned with
current framework,
14 new indicators
proposed

3.1 REVISIONS

Of the 32 indicators prioritised by stakeholders, two major revisions were made. Firstly, according to the AITHS, average life expectancy for Travellers is 17% lower than that of the settled population. The NPAS indicators are reported for those aged 50+ and reducing this age by 17% results in a lower age limit of 41.5 years. This age was rounded down to simplify current and future reporting. Secondly, the indicator domain 'Housing' was re-named 'Housing and accommodation' following feedback gathered during the engagement process about the variety of accommodation in which Travellers live. Additional items were added to the list of facility problems that make up the headline indicator: overcrowding (rooms per person); adequate refrigerated food storage; sufficient site drainage; and adequate fire safety measures onsite.

Several indicator-specific adjustments were made to a small number of these 32 indicators to align them with the positive ageing indicator set so that they would be comparable. For example, nine individual indicators for accommodation were collated under 'percentage of adults aged 40+ with accommodation facility problems', and 'percentage of adults aged 40+ with accommodation condition problems' on the basis that additional information on specific types of problems can be provided when reporting the headline indicator. This approach was also taken to report chronic conditions in a single indicator ('percentage of Travellers aged 40+ with chronic conditions') and disabilities in a single indicator ('percentage of Travellers aged 40+ with a disability').

3.2 NEW INDICATORS

Of the 32 indicators that were prioritised by stakeholders, 14 indicators were new and were not present in the Positive Ageing Indicators in 2016: three for Participation, 10 for Healthy Ageing, and one for Security. Of these 14 new indicators, the three that were given the highest priority by stakeholders were:

- Percentage of Travellers aged 40+ who reported being treated with dignity and respect by a healthcare professional in the past 12 months (Health care domain, prioritised by 17 participants)
- Percentage of Travellers aged 40+ who report barriers to Traveller identity preserving acts or activities in the past 12 months (Social and cultural participation domain, prioritised by 14 participants)
- Due to the proposed inclusion of the 'overcrowding' item (prioritised by 24 participants), Percentage who have accommodation facility problems.
- All new indicators are summarised by NPAS pillar in Tables 2-4 below.

Table 2: New Participation indicators

NPAS DOMAIN	PROPOSED ADDITIONAL INDICATORS	PRIORITISED BY
SOCIAL AND CULTURAL PARTICIPATION	Percentage of Travellers aged 40+ who report barriers to Traveller identity preserving acts or activities in the past 12 months	14
	Percentage of Travellers aged 40+ who report barriers to everyday cultural practices such as keeping animals	10
	Percentage of Travellers aged 40+ who report feeling a sense of unity and co-operation with family members and neighbours	11
	Percentage of people aged 40+ who engaged with a community organisation in the past 12 months	10

Table 3: New Healthy Ageing indicators

NPAS DOMAIN	PROPOSED ADDITIONAL INDICATORS	PRIORITISED BY
HEALTHCARE	Percentage of Travellers aged 40+ who reported being treated with dignity and respect by a healthcare professional in the past 12 months	17
	Percentage of Travellers aged 40+ who are eligible for a medical card but don't have one	9
	Percentage of Travellers aged 40+ who use a healer when they are sick (some, most, or all the time)	9
	Percentage of Traveller women aged 40+ who have undergone a cervical smear test in the past 2 years	6
	Percentage of Travellers aged 40+ who have had a faecal occult blood test in the past 2 years	6
	Percentage of Travellers aged 40+ who have a friend or family member to accompany them to medical appointments	4
HEALTH BEHAVIOURS	Percentage of Travellers aged 40+ who have functional health literacy difficulties	7
	Percentage of Travellers aged 40+ who adhere to food pyramid recommendations	4
	Percentage of Travellers aged 40+ who report difficulty in reading medication instructions	4

Table 4: New Security indicators

NPAS DOMAIN	PROPOSED ADDITIONAL INDICATORS	PRIORITISED BY
HOUSING AND ACCOMMODATION	Percentage of Travellers aged 40+ who report feeling secure in their accommodation (tenure or land tenure)	7
	Percentage of Travellers who have accommodation facility problems – new categories added: overcrowded (rooms per capita) (24); adequate refrigerated food storage (6); sufficient site drainage (4); adequate fire safety measures onsite (4).	6-24

Several Positive Ageing Indicators that were reported in 2016 were selected by more than 10 participants and are therefore considered to be highly important for future comparison.

Table 5: Priority given to the positive ageing indicators 2016

PILLAR	THEMES		NUMBER OF PARTICIPANTS
PARTICIPATION	ACTIVE CITIZENSHIP AND VOLUNTEERING	Percentage of people aged 50+ who provide care to an older relative or disabled relative	10
HEALTHY AGEING	PHYSICAL HEALTH	Life expectancy at 65	12
	ADAPTION TO DISABILITY AND ILLNESS	Percentage of people aged 50+ who report difficulties with activities important for independent living such as shopping and cooking, due to a health or memory problem	10
	POSITIVE MENTAL HEALTH	Percentage of people aged 50+ with moderate and severe levels of depression	10
		Percentage of people aged 50+ with moderate and severe levels of anxiety	10
	SOCIAL CARE	Percentage of people aged 70+ living in the community in receipt of home care services in the previous 12 months	11
	CARERS	Percentage of carers aged 50+ who report high levels of stress or distress	11

3.3 FURTHER THEMES ON POSITIVE AGEING

There were several recurring themes throughout discussions surrounding indicators and aspects of positive ageing. These areas, experiences, and issues are relevant to future studies on Traveller health and wellbeing and social inclusion. Each theme is described under the relevant NPAS pillar; however, it should be noted that some of these themes go beyond the current circumstances of older Travellers and included family, community, and intergenerational issues. It is beyond the scope of this report to conduct an in-depth thematic analysis of these themes; therefore, they are presented here in a summary way only.

Participation

- Intergenerational contact
- Cultural participation and cultural expression

Healthy ageing

- Access to services and service experience
- Mental health
- Women's health and wellbeing
- Healthy diet
- Food safety

Security

- Accommodation standards
- Accommodation availability and overcrowding
- Access to essential services such as health and postal services



4.1 CURRENT AND FUTURE DATA COLLECTION

A review of current data sources showed that there is not currently available data for nine of the 14 additional indicators prioritised for Travellers and the most recent data available for the remaining five indicators is from the AITHS (2010) (Tables 6-8).

Table 6: New Participation indicators and data

NPAS DOMAIN	NPAS DOMAIN PROPOSED ADDITIONAL INDICATORS	
SOCIAL AND CULTURAL PARTICIPATION	Percentage of Travellers aged 40+ who report barriers to Traveller identity preserving acts or activities in the past 12 months	No current source
	Percentage of Travellers aged 40+ who report barriers to everyday cultural practices such as keeping animals	No current source
	Percentage of Travellers aged 40+ who report feeling a sense of unity and co-operation with family members and neighbours	No current source
	Percentage of people aged 40+ who engaged with a community organisation in the past 12 months	No current source

Table 7: New Healthy ageing indicators and data

NPAS DOMAIN	PROPOSED ADDITIONAL INDICATORS	DATA SOURCE
HEALTHCARE	Percentage of Travellers aged 40+ who reported being treated with dignity and respect by a healthcare professional in the past 12 months	Baseline AITHS (40+)
	Percentage of Travellers aged 40+ who are eligible for a medical card but don't have one	Baseline AITHS (40+)
	Percentage of Travellers aged 40+ who use a healer when they are sick (some, most, or all the time)	Baseline AITHS (40+)
	Percentage of Traveller women aged 40+ who have undergone a cervical smear test in the past 2 years	Baseline AITHS (40+)
	Percentage of Travellers aged 40+ who have had a faecal occult blood test in the past 2 years	No current source
	Percentage of Travellers aged 40+ who have a friend or family member to accompany them to medical appointments	No current source
HEALTH BEHAVIOURS	Percentage of Travellers aged 40+ who have difficulty understanding and acting on health information	No current source
	Percentage of Travellers aged 40+ who adhere to food pyramid recommendations	No current source
	Percentage of Travellers aged 40+ who report difficulty in reading medication instructions	Baseline AITHS (40+)

Table 8: New Security indicators and data

NPAS DOMAIN	PROPOSED ADDITIONAL INDICATORS	DATA SOURCE
HOUSING AND ACCOMMODATION	Percentage of Travellers aged 40+ who report feeling secure in their accommodation (tenure or land tenure)	No current source
	Percentage of Travellers who have accommodation facility problems – new categories added: overcrowded (rooms per capita); adequate refrigerated food storage; sufficient site drainage; adequate fire safety measures onsite.	Census (rooms per capita)

The tables in Appendix 3 provide an overview of all the positive ageing indicators reported in 2016 for the general population, and the current level of data available for each indicator for Travellers. To summarise, comparable data for 32 indicators is not currently available. Further, the most recent data for 10 indicators is from the All Ireland Traveller Health Study, collected in 2010. Up-to-date information for comparison and monitoring is therefore required.

At present, the following survey data sources that are used to construct the positive ageing indicators do not contain an ethnic identifier:

- Irish Health Survey
- The Irish Longitudinal Study on Ageing (TILDA)
- European Quality of Life Survey (EQLS)
- Programme for the International Assessment of Adult Competencies (PIAAC)
- European Survey of Income and Living Conditions (EU-SILC)
- European Labour Force Survey (EU-LFS)
- Health Service Executive (HSE) Elder Abuse Services
- Health Service Executive (HSE) National Screening Service

The Census of the Population is a key source of information on Irish Travellers and allows for comparison with other groups in Irish society. While the numbers of Travellers have steadily increased in the national census since the introduction of the ethnic/cultural background question in 2006, it is acknowledged Travellers are largely under-enumerated in the national Census. To address this gap, Pavee Point has worked in partnership with the Central Statistics Office [1] to develop the capacity and confidence of enumerators to effectively engage with Travellers during the census and ensure that all Traveller homes are visited; and (2) to generate awareness amongst Travellers and Traveller organisations about the importance of the census and in voluntary self-disclosure.

It is worth noting that there are several up-to-date health data sources that contain information on ethnicity, including Irish Travellers: the Health Information Quality Authority (HIQA), the Health Research Board (various reporting systems), the Drug Prevalence Survey, the National Cancer Registry Board, and the Healthy Ireland Survey. Further details of these sources, datasets, and the ethnic identifiers that are used are summarised in Appendix 4.

In terms of data that have the potential to capture positive ageing outcomes on a regular basis, the National Cancer Registry, the Census of the Population, and the Healthy Ireland Survey all contain an ethnic identifier (either 'Traveller' or 'Irish Traveller'). Further options should be explored in terms of ensuring data coverage and use of ethnic identifiers in national data sources and national surveys.

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APPENDIX 1: SHORTLIST OF INDICATORS

The following indicators were shortlisted during the 'exploration' phase and were reviewed during the 'engagement' phase of the process.

Table A1: Shortlist following 'exploration' phase

CROSS-CUTTING

INFORMATION ACCESS

Percentage of people aged 40+ who have difficulty accessing information on health

PARTICIPATION

EDUCATION AND LIFELONG LEARNING

Percentage of people aged 40+ with a low level of educational attainment

Percentage of people aged 40+ who report difficulty in understanding health campaigns and health messages

Percentage of people aged 40+ who consider the ease of understanding the medical card application form as 'good' or 'very good'

Percentage of people aged 40+ who report difficulty in reading medication instructions

Percentage of people aged 40+ who have difficulty understanding and acting on health information

SOCIAL AND CULTURAL PARTICIPATION

Percentage of people aged 40+ who experienced discrimination based on their age and/or other factors in the past 2 years, whether individual or institutional

Percentage of people aged 40+ who experienced, in the past 12 months, the ability to fully engage in important cultural practices such as nomadism, casual trading and animal-keeping

Percentage of people aged 40+ who report positive experiences of Traveller identity preservation in the past 12 months

Percentage of people aged 40+ who report experiences of intergenerational conflict in the past 12 months

Percentage of people aged 40+ who report feeling a sense of unity and co-operation with family members and neighbours

Percentage of people aged 40+ who had the opportunity to socialise with older travellers (40+) at least once in the past month

ACTIVE CITIZENSHIP AND VOLUNTEERING

Percentage of people aged 40+ who engaged with a community organisation in the past 12 months

SECURITY

HOUSING/ACCOMMODATION

Percentage of people aged 40+ who report feeling secure in their accommodation tenure or land tenure

Percentage of people aged 40+ who report living with shortage of space (overcrowded conditions)

Percentage of people aged 40+ who have access to a piped water supply

Percentage of people aged 40+ who have sewerage facilities

Percentage of people aged 40+ who have a direct mains electricity supply

Percentage of people aged 40+ who have the ability to adequately store and refrigerate foods

Percentage of people aged 40+ who have central heating

Percentage of people aged 40+ who report living in accommodation which is free of damp and mould

(For those who live in Traveller-specific accommodation sites) Percentage of people aged 40+ who report that their accommodation site has sufficient drainage

Percentage of people aged 40+ who have access to refuse collection services at least monthly

Percentage of people aged 40+ who report living in accommodation which is free of pest infestation

Percentage of people aged 40+ who report having adequate fire safety measures in place in their accommodation (including wider accommodation site)

(For those who live on group accommodation sites) Percentage of people aged 40+ who report that their accommodation site has sufficient amenities (footpaths, public lighting)

HEALTHY AGEING

PHYSICAL HEALTH

Percentage of people aged 40+ who report difficulty with pain, breathing, or any other chronic illness or condition

Percentage of people aged 40+ who have suffered from a chronic respiratory disease in the past 12 months

Percentage of people aged 40+ who have suffered from a cardiovascular disease or illness in the past 12 months

Percentage of people aged 40+ who have suffered from diabetes in the past 12 months

Percentage of people aged 40+ who have suffered from high blood pressure in the past 12 months

Percentage of people aged 40+ who have been diagnosed with high cholesterol in the past 12 months

Percentage of people aged 40+ who report a difficulty with basic physical activities such as walking, climbing stairs, reaching, lifting or carrying

Percentage of people aged 40+ who experienced an injury in the past 12 months

HEALTH BEHAVIOURS

Percentage of people aged 40+ who adhere to food pyramid recommendations

HEALTH CARE

Percentage of people aged 40+ who, in relation to their most recent experience being treated by a HCP in the past 12 months, report being treated with respect and dignity

Percentage of people aged 40+ who have a friend or family member to accompany them to medical appointments

Percentage of people aged 40+ who are eligible for a medical card but don't have one

Percentage of women aged 40+ who have undergone a cervical smear test in the past 2 years

Percentage of people aged 40+ who have had a faecal occult blood test in the past 2 years

Percentage of people aged 40+ who sometimes, most times, or every time they're sick, use a healer/curing person

APPENDIX 2: SHORTLIST OF INDICATORS, POST-ENGAGEMENT

The following shortlist of indicators resulted from the 'engagement' phase of the process. The number of participants who prioritised each indicator is also presented. These indicators were then finalised.

Table A2: Finalised supplementary set of Indicators for Healthy and Positive Ageing for Travellers

PARTICIPATION

EDUCATION AND LIFELONG LEARNING	FREQUENCY OF PRIORITISATION
Percentage of people aged 40+ with a low level of educational attainment	11
Percentage of people aged 40+ who report difficulty in reading medication instructions	4
Percentage of people aged 40+ who have difficulty understanding and acting on health information	7
SOCIAL AND CULTURAL PARTICIPATION	FREQUENCY OF PRIORITISATION
Percentage of people aged 40+ who experienced discrimination based on their age and/or other factors in the past 2 years, whether individual or institutional	19
Percentage of people aged 40+ who experienced, in the past 12 months, the ability to fully engage in important cultural practices such as nomadism, casual trading and animal-keeping	10
Percentage of people aged 40+ who report positive experiences of Traveller identity preservation in the past 12 months	14
Percentage of people aged 40+ who report feeling a sense of unity and co-operation with family members and neighbours	11
Percentage of people aged 40+ who had the opportunity to socialise with older travellers (40+) at least once in the past month	8
ACTIVE CITIZENSHIP AND VOLUNTEERING	FREQUENCY OF PRIORITISATION
Percentage of people aged 40+ who engaged with a community organisation in the past 12 months	10

SECURITY

HOUSING/ACCOMMODATION	FREQUENCY OF PRIORITISATION
Percentage of people aged 40+ who report feeling secure in their accommodation tenure or land tenure	7
Percentage of people aged 40+ who report living with shortage of space (overcrowded conditions)	24
Percentage of people aged 40+ who have access to a piped water supply	8
Percentage of people aged 40+ who have sewerage facilities	8
Percentage of people aged 40+ who have a direct mains electricity supply	11
Percentage of people aged 40+ who have the ability to adequately store and refrigerate foods	6
Percentage of people aged 40+ who have central heating	4
Percentage of people aged 40+ who report living in accommodation which is free of damp and mould	8
(For those who live on group accommodation sites) Percentage of people aged 40+ who report that their accommodation site has sufficient drainage	4
Percentage of people aged 40+ who report having adequate fire safety measures in place in their accommodation (including wider accommodation site)	4

HEALTHY AGEING

PHYSICAL HEALTH	FREQUENCY OF PRIORITISATION
Percentage of people aged 40+ who report difficulty with pain, breathing, or any other chronic illness or condition	5
Percentage of people aged 40+ who have suffered from a chronic respiratory disease in the past 12 months	4
Percentage of people aged 40+ who have suffered from a cardiovascular disease or illness in the past 12 months	11
Percentage of people aged 40+ who have suffered from diabetes in the past 12 months	11
Percentage of people aged 40+ who have suffered from high blood pressure in the past 12 months	8
Percentage of people aged 40+ who have been diagnosed with high cholesterol in the past 12 months	11

HEALTH BEHAVIOURS	FREQUENCY OF PRIORITISATION
Percentage of people aged 40+ who adhere to food pyramid recommendations	4
HEALTH CARE	FREQUENCY OF PRIORITISATION
Percentage of people aged 40+ who, in relation to their most recent experience being treated by a HCP in the past 12 months, report being treated with respect and dignity	17
Percentage of people aged 40+ who have a friend or family member to accompany them to medical appointments	4
Percentage of people aged 40+ who are eligible for a medical card but don't have one	9
Percentage of women aged 40+ who have undergone a cervical smear test in the past 2 years	6
Percentage of people aged 40+ who have had a faecal occult blood test in the past 2 years	6
Percentage of people aged 40+ who sometimes, most times, or every time they're sick, use a healer/curing person	9

APPENDIX 3: POSITIVE AGEING INDICATOR DATA FOR IRISH TRAVELLERS

Table A3: Participation indicators and data

NPAS DOMAIN	KEY INDICATORS IN 2016	2016 DATA FOR TRAVELLERS		NOTES
EMPLOYMENT AND RETIREMENT	Employment rate in the population aged 50+	63%	CSO Census (40+)	
	Percentage of people aged 50+ who engaged in political activities in the past 12 months	21%	No current source	
ACTIVE	Percentage of people aged 50+ who did unpaid voluntary work in the previous 12 months	17%	No current source	
CITIZENSHIP AND VOLUNTEERING	Percentage of people aged 50+ who provide care to children and/or grandchildren	32%	CSO (40+)	CSO Census equivalent 40+ 'regular unpaid help'
	Percentage of people aged 50+ who provide care to an older relative or disabled relative	13%	No current source	
	Participation rate in formal education and training in Ireland among people aged 25-64	6.5%	CSO census (40+)	
EDUCATION AND LIFELONG LEARNING	Participation rate in informal education and training in Ireland among people aged 50+	8%	No current source	
	Percentage of adults aged 55-65 with low literacy	61%	No current source	CSO Census: Percentage of people aged 40+ with a low level of educational attainment
	Percentage of adults aged 55-65 with low numeracy	63%	No current source	
SOCIAL AND CULTURAL PARTICIPATION	Percentage of people aged 50+ who engage in one or more social leisure activity at least once a week	85%	No current source	
	Average self-reported loneliness among people aged 50+	7.1%	No current source	
	Percentage of people aged 50+ with at least one supportive relative or friend	93%	Baseline AITHS (40+)	

NPAS DOMAIN	KEY INDICATORS IN 2016	2016 %	DATA FOR TRAVELLERS	NOTES
TRANSPORT	Percentage of people aged 50+ who drive	72%	No current source	
	Percentage of people aged 50+ who rate public transport in their area as good or excellent	49%	No current source	
	Percentage of people aged 50+ who rate private transport in their area as good or excellent	59%	No current source	

Table A4: Healthy Ageing indicators and data

NPAS DOMAIN	KEY INDICATORS IN 2016	2016 %	DATA FOR TRAVELLERS	NOTES
	Life expectancy at age 65.	21.1%	No current source	Change to age 50. Calculated from Census and life tables
	Healthy life years at age 65.	18.4%	No current source	Change to age 50. Calculated from Census and life tables
	Percentage of people aged 50+ with good (or better) self-rated health.	12.3%	CSO Census (40+)	
PHYSICAL HEALTH	Percentage of people aged 50+ who report any physical disability.	11.4%	No current source	
	Percentage of people aged 50+ who have a chronic disease.	80%	CSO Census (40+)	
	Percentage of people aged 65+ reporting a fall in the previous year.	15%	CSO Census (40+)	
	Percentage of people aged 65+ who have a slow walking speed.	61%	CSO Census (40+)	
	Percentage of people aged 50+ who report severe or moderate pain most of the time.	27%	No current source	Equivalent in Census: % reporting pain (disability section)
	Percentage of people aged 50+ who have a chronic disease	61%	Baseline AITHS (40+)	
BRAIN HEALTH	Percentage of people aged 50+ who show evidence of mild cognitive impairment.	36%	None	

NPAS DOMAIN	KEY INDICATORS IN 2016	2016 %	DATA FOR TRAVELLERS	NOTES
ADAPTATION TO DISABILITY AND ILLNESS	Percentage of people aged 50+ whose ability to work, or participate in social or leisure activities, are reduced due to disability	15%	CSO Census (40+)	
	Percentage of people aged 50+ with difficulty dressing, bathing or getting around inside the home, due to disability	6.8%	CSO Census (40+)	
	Percentage of people aged 50+ with difficulty going outside home alone to shop or visit a doctor's surgery, due to disability.	9.0%	CSO Census (40+)	
HEALTH BEHAVIOURS	Percentage of people aged 50+ who report current smoking.	17%	Baseline AITHS (40+)	
	Percentage of people aged 50+ who report problematic alcohol use.	14%	None	
	Percentage of people aged 50+ with medium and high physical activity levels.	67%	None	
	Percentage of people aged 50+ who are underweight*, overweight and obese. (*not reported in 2016)	44% overweight 35% obese	None	
POSITIVE MENTAL HEALTH	Percentage of people aged 50+ with moderate and severe levels of depression.	9%	No current source	
	Percentage of people aged 50+ who report high life satisfaction.	82%	No current source	
	Percentage of people aged 50+ who report a sense of freedom and control over their lives.	67%	No current source	
	Percentage of people aged 50+ with moderate and severe levels of anxiety.	9.2%	No current source	
HEALTHCARE	Percentage of women aged 50-69 who have had a mammogram in the previous 2 years.	71%	Baseline AITHS (40+)	
	Percentage of people aged 65+ who have had a flu vaccine in the previous 12 months.	69%	No current source	
	Percentage of people aged 50+ who experienced any difficulty in seeing a doctor in the past 12 months.	18%	No current source	
	Percentage of people aged 50+ who report unmet need for a community care service	19%	No current source	
	Percentage of people aged 50+ who are taking 5 or more medications.	27%	No current source	

NPAS DOMAIN	KEY INDICATORS IN 2016	2016 %	DATA FOR TRAVELLERS	NOTES
SOCIAL CARE	Percentage of people aged 70+ living in the community in receipt of home care services in the previous 12 months	14%	No current source	Change age to 60+
CARERS	Percentage of carers aged 50+ who report high levels of stress	27%	No current source	Change age to 40+

Table A6: Security indicators and data

Table Ao: Security Indicators and data					
NPAS DOMAIN	KEY INDICATORS IN 2016	2016 %	DATA FOR TRAVELLERS	NOTES	
FINANCIAL SECURITY	Consistent poverty rate for people aged 50+.	2.1%	No current source		
	Percentage of people aged 50+ who report that a shortage of money stops them from doing the things they want to do.	19%	No current source		
	Percentage of people aged 50+ who have housing facility problems.	12%	Baseline AITHS (40+)		
HOUSING/ ACCOMMODATION	Percentage of people aged 50+ who have housing condition problems. (Includes pests, noise from neighbours, structural cracks or subsidence, rot, damp, difficulty heating home and leaks)	48%	Baseline AITHS (40+)		
	Percentage of households with an adult aged 50+ who are unable to keep their house warm.	8.8%	No current source		
AGE-FRIENDLY PUBLIC SPACES	Percentage of people aged 50+ who experience difficulty accessing essential services.	14%	No current source		
	Percentage of people aged 50+ who experience difficulty accessing social or recreational facilities	11%	No current source		
	Percentage of people aged 50+ who experience difficulty accessing green spaces	9.2%	No current source		
	Percentage of people aged 50+ who report high levels of neighbourhood social capital.	66%	Baseline AITHS (40+)	Alternative indicator is single item on trust in other people, as a component of neighbourhood social capital.	

NPAS DOMAIN	KEY INDICATORS IN 2016	2016 %	DATA FOR TRAVELLERS	NOTES
PERSONAL SAFETY	Percentage of people aged 50+ who feel that it is safe to walk alone after dark in their local area.	72%	No current source	
ELDER ABUSE	Number of confirmed cases of elder abuse (most recent year).		No current source	National data source changed to National Safeguarding Office for 2018

 Table A6: Cross-cutting indicators and data

INDICATOR DOMAIN KEY INDICATORS IN 2016		2016 %	DATA FOR TRAVELLERS
COMBATING DISCRIMINATION	Percentage aged 50+ who reported that they felt discriminated against because of their age	45%	No current source
	Percentage of people aged 50+ who perceive ageing as a time of personal growth	73%	No current source
ACCESS TO INFORMATION	Percentage of people aged 50+ who use the internet	48%	CSO Census (40+)

APPENDIX 4: ETHNIC IDENTIFIERS IN CURRENT DATA

Table A7: Data sources and ethnic identifiers

DATA SOURCE	IDENTIFIER RESPONSE OPTIONS	NOTES	
	White:IrishIrish TravellerAny other White background		
HEALTH INFORMATION AND QUALITY AUTHORITY	Black or Black Irish: • African • Any other Black background	These are the same as the CSO Census categories. CSO plans to change	
	Asian or Asian Irish: Chinese Any other Asian background	categories in the next Census (2021).	
	Other, including mixed background: • Other, write in description		
	White:IrishIrish TravellerAny other White background		
CENSUS OF THE POPULATION	Black or Black Irish: • African • Any other Black background	CSO plans to change categories in the next	
	Asian or Asian Irish: Chinese Any other Asian background	Census (2021).	
	Other, including mixed background: • Other, write in description		
HEALTH RESEARCH BOARD (National Psychiatric Inpatient Reporting System – NPIRS; National Ability Supports System – NASS; National Drug Treatment Reporting System – NDTRS; National Drug-related Deaths Index – NDRDI)	 White Irish White Irish Traveller (NPIRS only) Irish Traveller (NASS, NDTRS, and NDRDI) White Roma (NPIRS) Roma (NDTRS and NDRDI) White other Black African Black other Asian Chinese Asian other Other, including mixed backgrounds 		

DATA SOURCE	IDENTIFIER RESPONSE OPTIONS	NOTES
	 White: Irish Irish Traveller British Roma Any other White backgrounds (specify) 	
DRUG PREVALENCE SURVEY	Black or Black Irish: AfricanAny other Black backgrounds (specify)	
	Chinese:Any other Asian background (specify)Other, including mixed background (specify)	
	White:IrishIrish TravellerAny other White background	
HEALTHY IRELAND SURVEY	Black or Black Irish: AfricanAny other Black background	
	Asian or Asian Irish: Chinese Any other Asian background	
	Other, including mixed background: • Other, write in description	

Further Departments, bodies and agencies that include an ethnic identifier within their administrative system and survey data are:

- Pobal, Social Inclusion and Community Activation Programme (SICAP) & Tús (inclusion of Roma)
- Maternity services (Maternal & Newborn Clinical Management System) (inclusion of Roma)
- Irish Prison Services (inclusion of Roma)
- Probation Services
- Dept of Education and Skills (Primary online database and Post-Primary online database) (inclusion of Roma)
- Higher Education Authority (Equal Access Survey)
- PASS Dublin Region Homeless Executive
- SOLAS
- Health Protection Surveillance Centre.

DEVELOPING INDICATORS OF POSITIVE AGEING FOR IRISH TRAVELLERS

2019