

## *SUNFRAIL: Reference Sites Network for Prevention and Care of Frailty and Chronic Conditions in Community Dwelling Persons of EU countries*



### *D.5.1: Report on patients/final beneficiaries on perception on frailty and multimorbidity.*

Title of the document	Report on patients/final beneficiaries on perception on frailty and multimorbidity.
<b>Deliverable No</b>	<b>5.1</b>
<b>Lead task beneficiary</b>	<b>HSCB</b>
<b>Partners Involved</b>	<b>All</b>
<b>Author</b>	<b>Soo Hun</b>
<b>Status</b>	<b>Final</b>
<b>Date</b>	<b>15/09/16</b>
<b>Type</b>	<b>Report</b>
<b>Dissemination level</b>	<b>Public</b>

## Version History

Date	Version	Author	Description
30/6/16	V0.1	Soo Hun	Draft version
15/08/16	V0.2	Soo Hun	Revised to take into account feedback from lead partner
22/08/16	V0.3	Soo Hun	Further revision from feedback

*This publication is part of the project SUNFRAIL which has received funding from the European Union's Health Programme (2014-2020).*

*The content of this publication represents the views of the author only and is his/her sole responsibility; it cannot be considered to reflect the views of the European Commission and/or the Consumers, Health, Agriculture and Food Executive Agency or any other body of the European Union. The European Commission and the Agency do not accept any responsibility for use that may be made of the information it contains.*

## Table of Contents

Background .....	1
Aim of report.....	2
The Methodology.....	3
Data collection methods and instruments.....	3
Survey Monkey .....	3
Analysis of other studies .....	3
Analysis and summary of relevant studies results.....	5
CPME study .....	5
Excerpts of summary of results and recommendations from study .....	5
MISTRAL .....	6
Gérontopôle Study.....	6
Frailty: Language and Perception Age UK/British Geriatric Society study .....	6
Excerpts from the Executive Summary .....	7
Discussion .....	9
Patient and beneficiaries' perception of frailty and multi-morbidity .....	9
Patient and beneficiaries' expectation of and barriers to services.....	11
Attitudes to Comprehensive Geriatric Assessment (CGA) as a service .....	12
Conclusion.....	13
Suggested areas for focus .....	13
Appendix .....	14
TABLE 1 Summary of responses (CPME Study) .....	15
Table 2 - Studies .....	17

## Background

At the last Steering Group meeting it was agreed that HSCB would conduct as per Task 5.1, an analysis of EIP-AHA initiatives on Patient's/final beneficiaries' perception on frailty and multi-morbidity.

The task involved examining existing EIP AHA initiatives on patient and beneficiaries, eliciting work on from current partners as well as seeking input directly from EIP AHA A3 Action Group.

From the onset we are aware of a number of existing EIP AHA Initiatives on patient and beneficiaries namely work by CPME and MISTRAL. A number of partners were also able to share their recent studies involving patient and beneficiaries. Finally in order to seek input directly from EIP-AHA A3 Action Group members, a questionnaire using Survey Monkey was developed.

## Aim of report

The project SUNFRAIL recognises the importance of patient's/beneficiaries perception and expectations on frailty and multi-morbidity and on services and support related to these conditions. Understanding patient's/beneficiaries perception and expectations in this area is vital as it helps the project to communicate in an optimum way to older people. It is also key to ensuring the model is fit-for-purpose in terms of addressing patient's/beneficiaries frailty and multi-morbidity needs and expectations of services available to them.

Failing to do so may also mean the development of the integrated care model for identifying, prevention and management of frailty and multi-morbidity may overlook key aspects when the model is being tested during the experimentation phase.

The report aims to outline a high level analysis of the results of various studies and highlight those which has particular significance and relevance to enhancing the project's understanding of patient's/final beneficiaries viewpoints, thus to tailor services tackling their needs. Through the analysis it is hoped that the report will also inform project partners' decision on whether to undertake further investigations (qualitative-FGDs).

## The Methodology

### Data collection methods and instruments

#### Description of EIP Initiatives on patient beneficiaries

At the initial stage it had been ascertained that there were a number of existing EIP Initiatives that touched upon the area of frailty and functional decline in relation to patient beneficiaries.

#### Survey Monkey

To seek input directly from EIP-AHA A3 Action Group members, a questionnaire using Survey Monkey was developed. We received 6 positive responses (see Appendix I for list). Two (2) of the studies were in relation to validation of screening tools, two (2) were still ongoing, one (1) was focusing on prevalence of frailty for end-stage renal patients. There is only one that focused on a comparative analysis of the expectations of older people concerning nursing care provided and elements of a comprehensive geriatric assessment.

From the questionnaires collected via Survey Monkey, there were two studies that were deemed relevant:

#### *Dr Tomasz Kostka, Department of Geriatrics, Medical University of Łódź*

The study focuses on the comparative analysis of expected demands for nursing care services among older people from urban, rural and institutional environments.

The findings from the study provided some insights into the different expectations on nursing care between older inhabitants of urban areas, rural areas, and those residing in institutions. While the expectations for the provision of nursing care are significantly increased by living alone, they are decreased by having access to care provided by family. Support for families to take care of elderly relatives would appear to be essential for an effective nursing and social care system.

#### *Dr Pasquale Abete, University of Naples Federico II*

This study was a validation of the Italian version of frailty index and has demonstrated that the index is a valid measure of frailty after CGA, has good reliability and includes bio-psycho-social aspects. We do not have information about the types of patients/final beneficiaries who participated in the study.

### Analysis of other studies

#### *CPME - Survey on Health literacy of functional/capacity decline and frailty*

<http://www.cpme.eu/survey/health-literacy-of-functional-decline-and-frailty-related-to-ageing-pilot-questionnaire-for-patients/>

This is a study that generated data on the levels of health literacy of functional decline and frailty for doctors and older patients (60+ year old) in Latvia and Romania. The framework of the present study is the EIP-AHA and it is part of a commitment of the Standing Committee of European Doctors (CPME) and the partners in the present study to understand the health

literacy of functional decline and frailty awareness on prevention of frailty and functional decline.

*MISTRAL - a consortium of 32 organisations from 16 countries led by the University of Aveiro, Portugal.*

The MISTRAL concept on patient empowerment that offers an 'eco-socio-technological approach that empowers individuals with personalised knowledge, empathic support and trust for healthy lifestyles

A number of partners were able to share their recent studies involving patient beneficiaries such as those from:

*Dr Robbert JJ Gobbens, Inholland University of Applied Science, Amsterdam, The Netherlands*

Title of study: Content validation of the Tilburg Frailty Indicator from the perspective of frail elderly. A qualitative explorative study (Andreasena, Lund, Aadahle, Gobbens & Sorensena2015)

The aim of the study is to validate the Tilburg Frailty Indicator on content in relation to the physical, psychological and social domain by exploring the experience of daily life of community dwelling frail elderly. The Tilburg Frailty Indicator is a questionnaire with a bio-psycho-social approach, which measures frailty by 15 questions. A questionnaire about frailty should be in alignment with experiences of frail elderly themselves as a target population is an important source of knowledge in content validation.

*Dr Matteo Cesari, Gérontopôle, Centre Hospitalier Universitaire, Toulouse, France*

Title of study: How older persons perceive the loss of independence: The need for a holistic approach to frailty. (Emile Escourrou, Matteo Cesari, Bruno Chicoulaa, Bruno Vellas, Sandrine Andrieu, Stéphane Oustric 2016). ***Please note that this study is still under review and the findings are preliminary and unpublished.***

The objective of the study is to understand the views of older persons on the risk of loss of independence. The frailty syndrome is associated with the occurrence of negative events; in particular, the loss of independence. Since 2004, the definition of the frailty syndrome has shifted from purely physical criteria to a more comprehensive consideration of the individual, including their psychosocial criteria. In this study, qualitative research methods were used as a complementary approach in order to enrich the existing quantitative results in this area.

*Frailty: Language and Perceptions - A report prepared by BritainThinks on behalf of Age UK and the British Geriatrics Society*

Separately there was a recent study British Geriatrics Society with Age UK (June 2015) conducted that was relevant to this area of work. BritainThinks was commissioned by Age UK and the British Geriatrics Society (BGS) to undertake qualitative research to gain insights that can be used to help raise awareness of approaches to care that can prevent or minimise the impact of frailty on older people.

Details of the study can be found in the Appendix.

## Analysis and summary of relevant studies results

### CPME study

There was some initial delay in eliciting information - firstly, the link provided by CPME on the results of the study could not be used and presented an error message. (<http://doc.cpme.eu:591/adopted/2014/Background.HLFDF.related.to.ageing.surveys-final.form16.04.2014.pdf>). As co-ordinator was on leave till 21<sup>st</sup> June, a subsequent email sent eventually enabled access to document early this week.

The study analysed 301 responses from 60+ older patients living in Latvia and Romania – most respondents were aged between 65 and 74. The questionnaires included in the CPME study adapted the conceptual HLS-EU model linking health literacy to include the following competencies in relation to information on functional decline and frailty:

- Awareness
- Access
- Understand
- Appraise
- Apply

Table 1 in the Appendix summarises the main results.

### Excerpts of summary of results and recommendations from study

A very high number of patients declared to be aware of age-related functional decline - 76.4% and similarly 75.75% are aware of frailty. However, nearly 22% found it difficult to understand the concept of functional decline and nearly 20% was the same for frailty.

In terms of access to information – a significant percentage of patients found it difficult to access information on functional decline (18.6%). Most respondents however found it easy to access information (46.18%). With regards to frailty the responses were similar ranging from easy (46.51%) to very easy (10.96%) and 18/27% again, a significant percentage that indicated it is difficult to access information.

The main sources of information on functional decline is represented by doctors (54.8%), health broadcasts (22.9%), relatives, friends (20.3%) and journals (19.9%). Concerning frailty the responses were similar; more than half (50.8%) say doctors as a main source of information and instead of journals, magazines were 4<sup>th</sup> in terms of source of information.

Of note is the role of the internet as a means for access to information. In this study 26% above 55 years old indicate to have never used the internet and 20% state not to have access to the Internet. The cohort of patients indicated preference for TV and radio broadcasts as a means to improve awareness of functional decline and frailty. This correlates to the decreased digital access and preferences of the older population. Those who did use the internet for health information and indicated that they were not satisfied with information found, did so primarily because they felt the information was commercially oriented (47%).



The self-declared awareness on functional decline and frailty is high for both patients and doctors in Latvia and Romania (over 70%) but overall levels of health literacy on both functional decline and frailty are determined also by degrees of access, the level of understanding, appraisal and application to reduce functional decline and frailty. All of these components are much lower for patients with over 20% of respondents finding it difficult to access information, understand it or demonstrating knowledge about functional decline and frailty.

For doctors, there is a discrepancy between claiming no problematic awareness, access and understanding and the appraise and apply components as defined in the common background of the study. Only half of the doctors considered a priority to gain some knowledge on functional decline related to ageing and respectively 70% of doctors considered frailty a low priority (all Latvians). Some 24.5% of respondents were not familiar or did not use any of the functional decline assessments scales and 31.9% of respondents were not familiar or did not use any of the frailty assessment scales.

## **MISTRAL**

It has not been possible through web searches to ascertain whether there are any projects that seek to get patient/final beneficiaries' views on frailty and multi-morbidity.

## **Gérontopôle Study**

The study was aimed to explore the views of older people regarding frailty and the risk of loss of independence through a qualitative study, as a complementary approach to the existing quantitative results. The principal objective was to understand the perceptions of older people regarding the risk of loss of independence.

Seven risk factors for the loss of independence were identified in this study: poor mental health, poor physical health, social isolation, no longer leaving home, an unsuitable environment, unsuitable housing, and a lack of resources.

## **Frailty: Language and Perception Age UK/British Geriatric Society study**

This study is of particular interest because the research objectives chimes and seemed to be a close match with the particular SUNFRAIL aim of understanding patient's/final beneficiaries perception of frailty and expectations/barriers to services. It examines the views of the older people and their informal carers as well as non-specialist HCPs on:

- Definition of the term 'frailty'
- Their awareness and experiences of preventative strategies and specialist health care services
- HCPs' perceptions around older people's care and the role of older people specialists
- The optimum way to communicate to older people on this issue

The research was designed to identify ways of supporting older people to:

- Identify with the concept of 'frailty' (if not the word)
- Engage with preventative strategies and frailty services (with support from healthcare professionals (HCPs) and informal carers)

- Play a role in accessing services (such as those providing the Comprehensive Geriatric Assessment), that are designed to help them

## Excerpts from the Executive Summary

### *Responses to the language of 'frailty'*

- 'Frailty' as a clinical concept has a very different meaning to the way it is understood and used amongst general public audiences and non-specialist health care professionals (HCPs).
- For these audiences, frailty is related to those people who are approaching the end of their lives, malnourished and highly dependent on care. These associations mean that the word 'frail' is understood to refer to an irreversible state rather than something that could be improved or exist on a spectrum. However, these audiences took a slightly different view when considering some of the specific symptoms associated with the clinical condition of frailty (but not labelled as such), where there was a greater appreciation of being able to get better or worse over time.

### *The concept of frailty*

- The older people spoken to did not identify with the term 'frail':
  - Older people do not use the word 'frail' or the phrase 'living with frailty'
  - The key barriers to identifying with the word 'frail' itself speak to a deep fear of losing independence, dignity and control over one's life
  - Older people do, however, recognise the experience of living with frailty
  - Older people do not primarily define themselves in terms of an overall state of 'frailty'
    - Instead, the experience of living with frailty is understood as comprising a number of specific challenges and specific solutions
  - Older people articulate their physical and mental wellbeing in terms of being able to complete everyday tasks independently
    - While older people tend to accept that it will become harder to complete these tasks as they get older, as the ability to do these things without significant support start to slip out of reach entirely, this can act as a 'trigger point' to accessing care/support services.
- Understanding this context, it is possible to position the concept of frailty in such a way as to encourage older people to identify with it, for example by:
  - Avoiding using the term 'frail' or any other all-encompassing term, but rather, use specific examples of living with frailty in order to drive self-identification
  - Using language that resonates with older people's desire to maintain or return to a level of independent living
  - Being clear that that identifying the problem is the best way to get solutions in place to help older people to achieve their goals
- Non-specialist health care professionals tend to describe an older person's wellbeing in terms of their functionality, which chimes strongly with older people's conceptions of 'frailty'.

### *Attitudes to support*

- When older people begin to find everyday tasks harder to complete, their first instinct tends to be to find their own solutions
  - Medical professionals are not seen by older people as the first port of call for receiving help with everyday challenges

- Once they move past a certain ‘trigger point’, however, some older people then become much more open to external support.
- For older people and informal carers, information about accessing preventative strategies and frailty services are received in the context of:
  - Beliefs that many elements of frailty are an inevitable or unavoidable part of ageing, but that losing one’s independence is not
  - A mixed awareness amongst these audiences of the main risks for frailty
  - A mixed awareness of the range of available preventative strategies and frailty services
  - The attitudinal barriers that older people have to engaging with strategies and services.
- In specific reference to Comprehensive Geriatric Assessment (CGA)
  - Older people in our sample were unaware of CGA, and awareness among informal carers and non-specialist health care professionals was only marginally higher
  - The name ‘Comprehensive Geriatric Assessment’ was disliked by older people spoken to; however, older people do feel that it is a good idea in principle, despite reservations about the time, effort and what it would entail in practice.

## Discussion

Based on the above analysis made, there are studies that provide useful and relevant information about patient/final beneficiaries' perception of frailty and multi-morbidity, that influence their expectation of and any barriers to the services.

### Patient and beneficiaries' perception of frailty and multi-morbidity

There are a number of the studies that do provide insights to patient/final beneficiaries' perception of frailty and multi-morbidity, e.g. CPME's, Gerontopole's and Age UK/BGS studies.

Findings from other studies cover validation of the screening tools or frailty index whilst informative, do not appear to provide adequate information about patients and their perception of frailty and their expectations of services – to the level that enables us to be in a position to develop and validate the integrated model for frailty and multi-morbidity.

The qualitative Age UK/BGS study in particular does provide some useful responses to the language of "frailty" and further explores the concept of "frailty". It also examines the attitudes toward prevention and management of frailty, in terms of accessing care and services from the perspectives of the older people themselves, non-HCP perceptions and informal carers.

From a language perspective, those consulted within the study not only did not identify with the term 'frailty', they showed a strong aversion to the term 'frail'. It was reported that the introduction of the word tended to evoke a strong and often emotional reaction in older people, particularly older men, including several research participants who expressed incredulity or offence at the term. Carers too viewed this as being extremely serious although their reactions were less emotionally charged.

These strong negative associations meant that the word 'frailty' was understood to mean an irreversible state that some older people enter into in the very final stages of their lives. It was assumed that frailty means a total loss of independence, and there was no sense that frailty exists on a spectrum or is a state that once can move in and out of. An older person having a fall, breaking their leg and experiencing limited definition of frailty was not synonymous with participants of frailty, primarily because it was neither seen as permanent state, nor as linked to end of life.

The study also shows that older people were acutely aware of their own position on the 'independence scale' (a scale developed using participants' own definitions and experience of independent living – moving up the scale indicates a reduced ability to complete tasks independently with Stage 1 being the 'most independent' to Stage 5 being 'losing independence entirely'), and any change in their capabilities. However their understanding and awareness of risk factors associated with clinical definitions of frailty tended to be low, even among frail older people. Some risk factors were recognised e.g. chronic illness, recuperating from acute illness or operations and poor diet. Other risk factors however, such as being overweight and unhealthy lifestyle choices in younger age were generally unrecognised.

Older people showed great consistency in the language they used to describe the experience of different stages of the independence scale from:

- Stage 2: Being able to do everyday tasks to maintain the status quo with some minor adaptations or 'light touch' support ("*Getting slower*", "*Feeling tired*", "*Lacking in strength*")
- Stage 3: Being almost or totally unable to do the everyday tasks important to maintaining the status quo without significant support ("*Struggling*", "*Feeling frustrated*", "*Feeling low*", "*Finding things tough*")
- Stage 4: Becoming almost or totally unable to manage personal hygiene without significant support ("*Losing control*", "*Not coping*", "*Feeling vulnerable*", "*Feeling weak*")
- Stage 5: Losing independence entirely and becoming totally reliant on support ("*Giving up*")

There were also references to 'trigger point' on the spectrum (that is transition from stage two up to stage three), which typically centred on words and phrases that referred to their mood and state of mind. This in itself was interesting in that it reflected a commonly expressed belief in the interviews, that the process of ageing is dependent on one's attitude and outlook on life as much as on one's physical state. Words like feeling 'frustrated', 'low' and that the older people were 'struggling' emerged as words that resonated particularly strongly.

Within the study it was also interesting to note that non-specialists HCPs and carers were attuned to the fact that having an independent lifestyle is the biggest motivator for older people in terms of taking action to safeguard their health and wellbeing. Moreover, they tended to feel strongly that it was their role to support older people in this goal as far as possible.

In line with older people themselves, this group also preferred to articulate an older person's wellbeing in terms of their 'functionality', measured by the extent to which everyday tasks can be completed independently.

## Patient and beneficiaries' expectation of and barriers to services

We also have some relevant information on patient and beneficiaries' expectation of and barriers to access for "frailty" services. The studies indicate these are linked to patient and beneficiaries awareness and understanding of concepts of functional decline and frailty; the CPME study indicates patients have awareness but less understanding of the concepts of functional decline and frailty. Also for many the first point for access to information is through doctors, however, if only half of the doctors considered a priority to gain knowledge on functional decline and respectively majority of doctors considered frailty a low priority, they may not be fully aware of availability of such services.

The Age UK/BGS study indicates the older people would not automatically look for external sources of support on experiencing the clinical symptoms of frailty. Even those who might look for support would not consider the GP to be the most appropriate port of call in the first instance.

The study summed up older people's perception of frailty and mixed awareness of a range of available preventative strategies and frailty services points to a limited understanding by patients in two areas. Firstly, understanding of what "frailty" services may look like: among some older people, impressions of available support tended to veer towards the extreme (i.e. in-home carers and care homes, which both represent a real loss of independence), with limited awareness of any less invasive forms of support). Secondly, the belief that clinical conditions take a precedence over general physical and mental "wellbeing": some of the older people in the study dismissed terms such as 'wellbeing' and 'quality of life' as 'self-indulgent' or 'airy-fairy'. There was a common belief that doctors who tended to be highly respected and who older people rarely know well, should not be 'bothered' with non-clinical conditions. Consequently their first instinct when they notice a reduction in their capabilities would be to look for their own solutions/self-identified coping mechanisms rather than external sources of support. This and 'making my own decisions' was seen as critical for maintaining independence and avoiding 'spiralling' into long-term care. Older people also reported the importance of 'keeping up appearances' and a reluctance/stigma to admitting there is a problem to the outside world.

For some, only when the coping mechanisms were no longer adequate, they became more open to external support. This was much true of those who had received some form of external support previously as they had a more nuanced understanding of support, namely that they recognise that support is not solely extreme or invasive and can offer practical solutions to help them maintain their independence.

In contrast, older people who had less nuanced understandings of external form of support tended to say they would continue to try and manage for themselves. They were less likely to have had direct exposure to in-home support in the past, though were not necessarily any less likely to have received medical treatment. Some with chronic conditions reported feeling that they receive 'more than enough attention' from HCPs as it is and that any decline in their independence was an inevitable and natural consequence of their condition. This group tended to perceive support as being synonymous with a total loss of independence and free choice and as such, aim to avoid for as long as possible, even if they find themselves moving up the 'spectrum' of frailty.

Informal carers in this study were also highly conscious of barriers to accessing support or services among their older relatives. This group of people tended to have a strong sense of, and interest in older people's holistic health and wellbeing, even if they did not necessarily use that language.

Notably, this included older informal carers such as spouses of older people who tended to take the view that an older person's ability to complete day-to-day task independently is of interest and importance to medical professionals. They recount instances where they made themselves responsible for older people accessing frailty services including making appointments, accompanying the older person to the appointment and advocate on their behalf on their health and wellbeing challenges.

### **Attitudes to Comprehensive Geriatric Assessment (CGA) as a service**

As an aside there was also further work on patient's as well as non-specialist HCPs attitude towards of CGA as a service. The study found that awareness of CGA was extremely low amongst all audiences: both patients/informal carers as well as non-specialist HCPs. The title "Comprehensive Geriatric Assessment" itself emerged as a major barrier to public engagement ultimately their understanding of the approach such as the length and complexity of the three words, the inclusion of the word 'geriatric' (generally associated with very old people nearing ends of their lives) and finally, the acronym CGA did not communicate of what the service entailed and was easily forgotten.

However, despite objections to its name public audiences could identify several positive aspects of the service in principle i.e. the comprehensive, holistic and joined-up in its approach.

Whilst the involvement of specialists were seen as a positive feature of CGA, there was notable confusion as to whether the 'specialists' were medical consultants such as cardiologists, or specialists in support of older people e.g. geriatricians, occupational therapists and district nurses. The former tended to be received more favourably and seen as an opportunity to see real experts who could identify potential health problems as a preventative measure.

However, there were barriers that the people felt would make them unlikely to seek the service in practice including that:

- Inability to understand links between a seemingly disparate collection of services
- Concern and confusion on how to access the service – how long the assessment would take, which specialists to see and what effort required on their part
- Lack of clarity on end goal and ultimate benefit of the assessment

## Conclusion

The Age UK/BGS study research objectives would appear to resonate most closely to the aims of this task on understanding patient/final beneficiaries' perception and expectations on frailty and multi-morbidity. The findings were of high relevance and the insights were credible and consistent with other studies.

## Suggested areas for focus

The Age UK/BGS study also suggests useful pointers to take into consideration for developing of the SUNFRAIL integrated care model especially in patient engagement activities.

In order to encourage older people to engage with preventative strategies and frailty services, it will be important to:

- Build on existing beliefs that 'living with frailty' is not an inevitable or irreversible part of getting older and emphasise that it is possible to maintain independence by engaging with strategies and services
- Build on existing awareness of the risk factors for frailty, but raise awareness of lesser-known risk factors such as being overweight
- Provide a comprehensive overview of services and solutions that are available and how to access them, particularly less invasive, smaller scale services that demonstrate that getting 'support' doesn't mean going into a care home
- Raise awareness of Comprehensive Geriatric Assessment (CGA) and clarify the value that it offers
- Encourage older people to talk to their HCPs and to enquire about services to which they are entitled, and also require HCPs to engage older people on the topic, using language that resonates with older people in order to assess needs and help put services in place.

However whilst being very relevant, the study did have some limitations:

- Sample size was small (<15 for older people, 5 x informal carers)
- Did not include any older people living in care homes or sheltered accommodation
- No older person with a frailty score above 8, as measured on the Rockwood Frailty Scale was included.

In order to move forward to the experimentation phase, partners within the project should consider the above information gleaned from the studies are adequate and meets their needs for the development of the model from identification, prevention to management of care; as well as for the design of the experimentation phase.

Project partners in deciding whether the need to conduct further investigations (qualitative-FGDs) is necessary may also wish to address the limitations of the study e.g. older people living in care homes or sheltered accommodation.







## Appendix

**Appendix - TABLE 1 Summary of responses (CPME Study)**

Health literacy			Functional decline	Frailty
Awareness			76.4% of respondents are aware of functional decline	75.75% (aware of frailty)
Access	Source		10.3% do not know or access information on functional decline	10.6% do not know or access information on frailty
	Type		18.6% difficult access and 14.62% did not know or cared	18.2% difficult access and 10.3% did not know or cared
Understand			21.93% found it difficult to understand the concept	19.93% found it difficult to understand the concept
Appraise	Look for information		44.85% of respondents seek information frequently but also a significant percentage never seeks information (11.63%) or rarely seek information (37.54%).	
	Trusted sources		A very high percentage indicate the doctor as the most trusted source of health information (79.4%), followed by health broadcasts, a more traditional source of digital information (31.2%), nurses (21.9%), pharmacists (20.6%)	
	Judge relevance		41.6% indicated functional decline is very relevant for their health condition and 35.55% judged it as important. This is a very high importance attached to the condition.	81.73%, a slightly higher percentage of respondents, of respondents gave judged frailty important and very important to their health condition.
	Gain knowledge		69.76% respondents gave high and very high priority to gain knowledge on functional decline.	66.77% respondents gave high and very high priority to gain knowledge on frailty
	Reversibility			37.54% considered pre-frailty reversible, in line with the preferences to seek information on the condition. 35.55% did not consider frailty reversible.
Apply	General knowledge		Patients most often communicated about functional decline and frailty with family (59.5% - 179 respondents), then with doctors (50.2% - 151), and then with relatives/friends/neighbours (34.9% - 105).	
	Healthcare	Regular physical activity or exercise	Most respondents stated they did walk for 30 minutes more than three times a week (28.6% - 86 respondents).Yet an alarming percentage (15% - 45 respondents) answered “no” to this question. It should be noted that 40.2% of the interviewed respondents failed to answer this question. Most respondents did not walk 60 minutes at all (24.6% - 74 respondents). 23.9% (72) stated they did walk 60 minutes at least three times a week. It should be noted that 23.9% of the respondents did not answer this question. 32.9% (190) of the respondents stated their daily routine included some form of physical exercise more than three times a week. It should be noted that 36.9% (111) respondents did not check this answer	
		Increased weakness	Most respondents responded they did feel weaker (23.59% - 71 respondents) or they thought they might have become more weak (29.57% - 89). Only 59 (19.6%) responded “no” and other 18 (6%) failed to give an answer.	
		Consult doctor	Most respondents had consulted a doctor regarding their weakness (81.4% - 149 respondents). 4.4% (8 respondents) did not respond to this question.	
		Recurring tiredness	Most respondents declared they felt more tired in general (31.56% - 95 respondents) or they thought they felt more fatigue (30.56% - 92 respondents).	
		Physical pattern changes	Most respondents (33.6% - 101) did not feel a change in their balance. The percentage of respondents feeling a negative change in their mobility was slightly higher (25.2% - 76) than that of respondents who felt that nothing had changed in their mobility (23.9% - 72) or were unsure (23.3% - 70). Most respondents stated they felt stiffness, especially in the morning (34.9 % - 105 respondents). Most respondents declared they did not drop objects (40.9% - 123). Most respondents declared the time they needed for their daily activities was not prolonged (26.9% - 81 respondents). Most respondents stated they did not need a prolonged time to cross the street (34.2%).	

		Psycho-cognitive intellectual patterns	Most respondents stated it was more difficult for them to recall certain information (34.9%). Most respondents declared they did not find it difficult to find their way to a destination (58.8%). Most respondents felt there was nothing changed in their laughing or smiling pattern (52.8% - 159). Most respondents stated they were not crying more easily (44.9% - 135). Most respondents felt that nothing had changed in their performance of regular intellectual tasks (46.2% - 139). Most respondents felt that nothing had changed in their understanding of instructions/ directions (46.8% - 141). Most respondents felt that nothing had changed in their performance of mathematical tasks (40.5% - 122).
		Weight loss that patient cannot explain	Most respondents did not notice any weight loss (69.77% - 210 respondents).
	Disease prevention and health promotion	Measures to prevent functional decline related to ageing	<p>Most respondents considered that all the listed measures should be taken to prevent age-related functional decline and frailty (44.2% - 133). Of course, TV and radio programs are preferred. The listed measures in the options for response were:</p> <p>a) TV and radio programs on the issue to increase awareness on the subject matter and education for healthy lifestyle</p> <p>b) Hotline where the public can call to ask questions about different resources available (e.g. where to get transportation to different services, access to buildings, what health and social services are available for the elderly, etc.)</p> <p>c) Increase physicians' awareness and knowledge with regards to available screening and treatment approaches</p> <p>d) Increase awareness of the younger generation to help them recognise, be sensitive</p>

**Table 2 - Studies**

Title of Study	Document
CPME Doctors' and older patients' health literacy of functional decline and frailty – Results from Latvia and Romania	 cpme.2014-102.HL.s tudy.Fraily.functione
Content validation of the Tilburg Frailty Indicator from the perspective of frail elderly. A qualitative explorative study (Andreasena, Lund, Aadahle, Gobbens & Sorensena2015)	 Content validation of the Tilburg Frailty Ind
How older persons perceive the loss of independence: The need for a holistic approach to frailty (Emile Escourrou, Matteo Cesari, Bruno Chicoulaa, Bruno Vellas, Sandrine Andrieu, Stéphane Oustric 2016) <b><i>Please note that this study is still under review and the findings are preliminary and unpublished.</i></b>	 How older persons perceive the loss of ir
Frailty: Language and Perceptions – Report prepared by BritainThinks for Age UK/BGS study	 Age-UK---BGS---Frail ty-Final-Report.pdf