interRAI New Zealand
End of Pilot Report

Pilot title

interRAI Palliative Care Assessment Pilot – Community and Hospice versions

Pilot start and end dates

1 December 2015 – 1 December 2016

Project Manager

Karyn Foley, interRAI Educator, Central Region (formerly Lead Practitioner and System Clinician), Hawke's Bay District Health Board

Pilot Sponsor

Mary Wills, Head of Strategic Planning, Informatics and Finance, Hawke's Bay District Health Board

Organisation/s involved in pilot

Hawke's Bay DHB (HBDHB)
MidCentral DHB (MCDHB)
Canterbury DHB (CDHB)

End of pilot report history

1.1 Revision history

Revision date	Summary of changes	Changes marked
5/4/16	Report tabled at interRAI NZ Governance Board meeting	V1.0
26/9/16	Report reformatted and extended to include new Governance Framework template	V2.0
26/9/16	Circulated to Pilot Project and Steering groups	V2.0
7/10/16	Revised to include comments from Project and Steering Groups and circulated for final comment.	V3.0
10/10/16	Revised to include final comments from teleconference	V4.0

1.2 Approvals

This document requires the following approvals.

Signed approval forms should be filed appropriately in the project filing system.

Name	Signature	Title	Date of issue	Version
Mary Wills		Head of Strategic Planning, Informatics and Finance HBDHB		

1.3 Distribution

This document has been distributed to:

Name	Title	Date of issue	Version
Mary Wills	Project Sponsor	26/9/16	V2.0
Pilot Project and Steering groups	Group members	26/9/16	V2.0
Mary Wills, Kate Grundy, Karyn Foley, Lynda Wheeler	Final draft review teleconference 10/10/16	7/10/16	V3.0

Table of contents

Executive summary

The purpose of the pilot was to test use of the interRAI Palliative Care (PC) assessments for people with a prognosis of less than a year to live who are living in the community or who had been admitted to Hospice or Acute Hospital care and would otherwise have had an interRAI Home Care assessment.

Palliative Care assessments were completed by Needs Assessment Service Co-ordination Agencies (NASC), Palliative Care, Hospice or Hospital Assessors who were already competent and experienced in using the Home Care assessment. The two palliative care assessments from the integrated suite were already available in the interRAI software, to be used for adult clients ages 25-100.

The pilot included both the Palliative Care and Palliative Care Hospice assessments. This pilot report relates only to the pilot of the Palliative Care tool as an additional resource to the interRAI Home Care assessment. Findings from the shorter Palliative Care – Hospice tool have not been progressed as this relates to patients who are imminently dying. Prognosis is difficult and we would not support the use of two tools. We support the use of the Palliative Care assessment.

The pilot's planned benefits were met, these were:

- **Fit for purpose** – assessment items focus on needs of palliative care clients with a particular emphasis on symptom management, psychosocial and spiritual issues and carer stress.

- **Acceptable** – to clients and assessors.

- **Effective** – appropriate palliative, holistic information was made available for care planning, resource allocation and sharing across the continuum of care. Use of the assessments fit easily into the current DHB service delivery models.

- **Efficient** – minimal additional resource is required to train existing interRAI users. Training would be provided as a group for two hours by webinar.

The pilot outcomes also support the New Zealand Triple Aim approach for quality improvement used by the Ministry of Health and District Health Boards (DHBs)in order to improve quality and safety of care for individuals, health and equity for populations and to provide best value for public health system resources.

Quality and safety of care was improved for individuals by having the appropriate clinical, social and psychosocial information available to support individualised care planning in accordance with their needs and preferences. Information is also easily shared electronically with other health professionals involved in the person's care which reduces duplication, promotes teamwork and reduces risk.

Population data is now available for this client group which is more specific to their needs than existing home care data e.g. symptom management. This data can be used for understanding client demographics, service development and other quality initiatives, including the advancement of advanced care planning or supporting family and other carers.

Value for money is demonstrated by the cost effectiveness of the training programme and the potential to use case mix to inform resource allocation and funding models in future.

Context

Palliative care is for people of all ages with a life limiting condition. Palliative and end of life care provides people with humane and dignified support and services as they face a life limiting condition.

The integration of services across primary and specialist care, and between fully-funded public providers and independent private and charitable providers, is understood to be critical components of ensuring people are able to receive the appropriate quality of care.

The Palliative Care Council reported in 2015 that based on the projections of future deaths, providers of palliative care in New Zealand will need to cope with a much greater number of deaths of older people, more people with co-morbidities and potentially a higher prevalence of dementia than in previous years. The implications of more deaths at older ages from frailty and dementia are a cause of concern for the organisation of the health system. If current patterns of end of life care continue, most of the deaths over age 85 would occur in residential aged care facilities after an extended period of care.

There are projected to be 30,610 deaths in the financial year to end June 2015, with 40,790 deaths in the year to end June 2033. This is significant as it is the first time first time that New Zealand breaches the 40,000 deaths a year level. Over the 18 year-period to 2033, the number of deaths each year is projected to increase by 33% from current levels. It is also projected that nearly half (47.2%) of the deaths in 2033 will be of people aged 85 and over.

Evaluation of pilot process and achievements

Overview of progress made during pilot

For the purpose of this pilot, palliative clients who would normally have had an interRAI Home Care assessment were instead assessed using the Palliative Care assessment by Assessors who were already trained and competent in the Home Care assessment. These assessments were tested within the community, hospital and hospice settings across three DHBs – Hawke's Bay, MidCentral and Canterbury. A total of 33 Assessors were trained to use both palliative care assessments.

The pilot scope was limited to use of the Palliative Care assessment in place of the interRAI Home Care, where appropriate. Use of the Palliative Care assessment within aged residential care facilities was out of scope.

interRAI Services provided education and support, including the development of education resources i.e. the Assessors workbook and the training programme which was delivered by the interRAI Education and Support Service in a two hour webinar session. interRAI Services also assisted with communication with stakeholders through three newsletters. Face to face support for education was provided by local interRAI Lead Practitioners who answered any queries and quality reviewed the assessments. Assessors were also required to pass the Assessment and Intelligence Systems (AIS) on line coding quality evaluations.

The provision of additional education in palliative care, as part of the training, was found to be beneficial to Assessors who may have had limited experience in addressing the psychosocial issues of palliative care clients. This consisted of having palliative care experts eg Social Workers available during interRAI Palliative Care training sessions and it was also a pre-requisite for Assessors to complete Advanced Care Planning Training, Level 1, which is a useful resource for communication skills with palliative clients. This training is outside the scope of the interRAI education and support service but could be readily accessed at local level, at a reasonable cost.

Clinical leadership was provided by Dr Kate Grundy, Palliative Medicine Physician, CDHB, who was on the steering group along with representatives from DHB Planning and Funding, NASC, Hospice and interRAI Services.

There was local sector engagement by newsletter and follow up evaluation with organisations and services who were end users of the assessment information and care plans for example, Home and Community Support Service providers, aged residential care and Hospice and Palliative Care teams.

The interRAI Data Analysis and Reporting Service completed the data analysis for the pilot evaluation report (see appendix ii). Additional data from the palliative care assessments not available in the Home Care assessment includes information on life completion and self reported spirituality. Information from the pilot is stored in the national data warehouse which was updated at the time of the software upgrade in November 2015 to include additional items from the Palliative Care assessments not already in the data dictionary.

Enablers

There were a number of enablers that supported this pilot to achieve its aims. The software was already available and adapted for use in New Zealand. All Assessors were competent and experienced interRAI Home Care users, already assessing palliative clients and so required minimal additional training to use the new assessment. Having palliative care and hospice social workers included in the pilot enabled the sharing of knowledge about palliative care issues. The interRAI CAP manual was also found to be a valuable training resource in palliative care issues.

Use across the three DHBs

Implementation of the assessments during the pilot was not consistent across the three DHBs. CDHB had one Assessor trained who resigned from her position in June. CDHB stopped using the palliative Care Hospice tool part way through the pilot.

HBDHB and MDHB continued to use both assessments in the pilot and gathered end user information via a survey about the usefulness of both assessments.

As previously stated this end of pilot report only relates to the pilot of the Palliative Care tool as an additional resource to the interRAI Home Care tool.

There were different business practices and funding models across the DHBs. Normal business practices were applied during this pilot. As not all NASC Assessors were trained in the Palliative Care tools some continued to undertake the usual Home Care assessments with this client group. All HBDHB and MDHB NASC Assessors are now trained in the Palliative Care assessments.

Additional activities undertaken during the pilot

The following additional activities were undertaken during the pilot and found to be effective in supporting education, assessment practice and quality:

- Training resources, local CAPS Guidelines and Palliative care resources were developed.
- Assessors completed Advanced Care Training – Level 1.
- Written resources and training in aspects of palliative care was made available to Assessors.

Direct costs

The following direct costs were required to support this pilot:

- Development of education resource materials and newsletters by interRAI Services provided within current resources.

- Training of Lead Practitioners and Project Group members via webinar session by interRAI Education and Support Service provided within current resources.

- Two hour webinar session to 13 Assessors in a group setting by interRAI Education and Support Service provided within current resources.

- Manuals – coding ($72.82) and CAPs ($79.45) – one per Assessor and Lead Practitioner, provided by interRAI Services from held resources.

- Data analysis by the National Software Services Manager and Data Analysis and Reporting Service was provided within current resources

Implications, including financial and policy, from implementing the tool during the pilot

There were minimal financial implications from implementing these assessments. No changes were made to existing DHB policies.

Communication with stakeholders

There was considerable interest nationally and locally in this pilot with a number of DHBs keen to have access to these assessment tools. A presentation was made to the national HOP Steering Group. Lead Practitioners were updated in interRAI methodology meetings with the requirement to advise Assessors that although the software was available to all DHBs, it should only be used by Assessors involved in the pilot. This was monitored by the National Software Services Manager.

Regular teleconferences were held with the project team and three newsletters were sent to local stakeholders to inform them of the pilot and assist understanding of the palliative care assessment clinical information by end users such as aged residential care clinical teams who were receiving new residents with a palliative care assessment.

Processes developed for or during the pilot and their effectiveness

A flow chart was developed to guide Assessors as to which assessment to use when this was found to be beneficial.

Outputs of the pilot

- 160 Palliative Care assessments were completed between 1 December 2015 and 20 September 2016:
  - HBDHB - 87 Assessments.
  - MCDHB – 41 Assessments.
  - CDHB – 32 Assessments.
- 33 Assessors were trained.

- Clinical information used by Assessors and end users to plan care.

- Data from the Palliative Care pilot was transferred into the interRAI National Data Warehouse from the TDHB and CDHB host services. At the time of the software upgrade in November 2015 palliative care items not already included in the national data dictionary were added. Data from the pilot has not been reported on by the Data Analysis and Reporting Service other than for this report.

- There was no impact as this used existing infrastructure and is covered under the annual support and maintenance agreement with Momentum Healthware.

Pilot findings

Summary of pilot outcomes

Several of the planned benefits were evidenced in the evaluation of this pilot. The palliative care assessments were found to be a better fit when compared with the home care assessment as they focus on areas of concern for this population group such as symptom management and psychosocial issues. For people with behaviour issues such as those with brain tumours or dementia it is important for assessors to use the most appropriate tool for the patient's needs at the time - Palliative Care or Home Care assessment. The Home Care assessment includes more detailed assessment of behavioural issues.

The CAPs are palliative care specific and provide more focused decision support for individualised care planning in accordance with the client's needs and wishes. End users such as Home and Community Support Service Providers, Hospice teams and aged residential care Clinical Teams found the palliative care assessments provided more relevant clinical information.

Assessors also found the assessment to be more relevant and appropriate for this client group than the home care assessment. They considered these assessments focused on areas of importance to clients and families and gave them an opportunity to discuss their feelings about their current situation, ensuring that their holistic palliative needs could be care planned. Assessors also reported assessment was less time consuming for the clients and their families at a difficult time, given the items were more relevant to their situation.

Another benefit of piloting these assessments was greater efficiency. Adding the palliative care assessments to the options for already trained home care Assessors was found to require minimal additional training, with the two hour webinar sessions effective in terms of cost and time taken. Assessors were able to complete competency requirements within the required timeframe. The palliative specific assessment also took less time to complete.

The effectiveness of the assessment is demonstrated by reports from Assessors and end users that the clinical information within it was more appropriate to needs of this client group and assists in individualised palliative care planning. Aggregated data is also available to inform service development and quality improvement.

Extent to which pilot achieved its intended aims

The pilot achieved its intended aims within the specified scope. The tool was found by Assessors and end users to be fit for purpose. The training programme developed and delivered by the interRAI Education and Support Service was found to be effective and efficient and all Assessors involved in the pilot met the competency requirements i.e. completed 3 assessments and passed the AIS on line coding competency evaluations. Quality requirements were met through quality reviews undertaken by Lead Practitioners, in line with the normal review process.

Changes made during pilot and the impact of these

CDHB ceased using the Palliative Care – Hospice tool and CDHB's trained Assessor resigned from her position during the pilot so was no longer available to complete palliative care assessments in the community

Coverage of the new tool

NASCs continued in their usual assessment model of so some palliative care clients had a home care assessment during the pilot. Nationally during the period 1/12/15 – 20/9/16 there were 1,232 assessments completed with people who were coded as having end–stage disease with 6 or fewer months to live.

Eight percent of the people assessed identified as Maori; this compares with data published by Hospice NZ which showed 11% of people using hospice services in 2015 were Māori. The Central Region DHBs report that, also in 2015, 6% of people assessed were Māori.

Contribution made by the new tool to service delivery and development

The Palliative Care assessment was found to provide appropriate palliative, holistic and clinical information covering the needs and experience for this client group. The specific CAPS and assessment items support individualised care planning, improve client experience and the provision of health care. The experience of family and other care givers was also taken into account. Assessors increased their understanding of the issues facing this client group and appropriate information was available to other health professionals electronically to support integration of service delivery.

The information from the pilot fills a data gap by providing specific to palliative care information not previously available within the home care assessment. There are items on prognosis, additional pain and symptom items, psychosocial well being in relation to life completion and self reported spirituality, treatment and care programmes received, client's preferences about where they wish to die, their activity preferences and family support availability. This information not only guides care planning for individuals but contributes considerably to our understanding of the overall population. It will be beneficial for service planning and quality improvement initiatives at local, regional and national level.

Qualitative and quantitative measures of benefits from the pilot

Comparison with existing tools

The Palliative Care Assessment is shorter than the Home Care Assessment and is more targeted towards the needs of palliative clients. It focuses on symptoms such as pain, dyspnoea and fatigue and nutrition as well as cognition, mood and activities of daily living. While containing many of the same items as the Home Care assessment there are additional relevant items again around symptom management such as jaundice, hiccups and twitching and also psychosocial well-being such as life completion and self-reported spirituality. It is acknowledged that a number of questions within the Home Care Assessment are inappropriate to ask someone with a short life expectancy, where as those in the Palliative Care Assessment are specifically worded to ensure that relevant issues and concerns are able to be addressed in a sensitive manner.

Assessor experience

Assessors were invited to give their opinions on the Palliative Care assessment by survey monkey. The response rate was 79%. In summary, 100% of respondents considered the Palliative Care assessment to provide adequate information for developing a care plan including the services to be provided. The majority also gave a good or excellent rating to questions regarding the information given in a number of domains e.g. medical issues, social, informal supports and functional performance. Full results of the survey and comments from assessors are available in Appendix I.

Other health professionals experience

Health professionals were also asked if the Palliative Care assessment contained sufficient information to enable their work with the client. It was reported that the client focus is much better in the Palliative Care Assessment than the Home Care one. There is no missing information, as previously and they felt more enabled to plan and deliver the care required.

Assessment findings and use of data

Data from the pilot is available in Appendix II. This shows volumes of assessments completed by month, DHB, ethnicity and age group, as well as findings from some of the assessment items and CAPS and Outcome scores. This population data will be of value to clinicians and health service planners, eg the numbers of people who expressed a wish to die at home and the low numbers who had completed an advanced care plan.

Benefits and Lessons Learned

The following benefits and lessons were identified in the pilot:

For DHBs and other Providers

- The assessment proved to be a more appropriate assessment which supported specialist palliative care planning for individuals.

- Palliative care population data is available to inform service delivery and quality improvements.

- There is potential utility for resource allocation and case mix.

- A number of DHBs are reviewing their palliative care service delivery models at local and regional level. The introduction of a standardised electronic assessment can inform service delivery for individuals and their families across the continuum of care and support integration.

For interRAI Services

- The use of a two hour webinar was found to be an effective means of providing additional training to already competent interRAI Home Care Assessors.

- There was ability to train large numbers of assessors in a group setting.

- The Palliative Care assessment can be added to the Education and Support service offerings for DHBs wishing to introduce this assessment.

- A software enhancement is required to develop the Assessment summary section as already exists in the other interRAI assessments in use in New Zealand.

- The national interRAI data warehouse already includes the additional items from the palliative care assessment.

For the Ministry of Health

- The introduction of a standardised assessment and use of the data available from a national rollout will inform the current review of Adult Palliative Care Services.

- The provision of supporting information for implementation of the Respectful End of Life work stream of the revised Health of Older People Strategy

Activities required to proceed to business case for potential national roll out

In order for this interRAI assessment tool to progress to a national rollout the following activities will need to be undertaken:

Education and support requirements

interRAI Services to consider their capacity to provide Palliative Care assessment training within current resources and fulfil their 2016/17 Outcome Agreement requirements.

Training would be for NASC, Hospital, Hospice and Community Assessors. There are currently 609 Home Care assessors. Further information is required from DHBs as to whether they would want all of their current Home Care assessors trained and over what time period.

Up to 20 Assessors can be trained in a two hour webinar session with additional support provided during and after this session by an interRAI Educator and Palliative Care expert. The training

materials will need to be reviewed by the project group and interRAI Education Services to ensure they are ready for national use. Local education resource is required to provide ongoing support and quality assurance. AIS coding competency evaluations also require annual review as is done for existing tools. The competency requirements will also need to be confirmed. Two or three coding manuals will be required for each office and extra copies of these would need to be funded by the DHB if demand supersedes the volumes of manuals held by interRAI services.

interRAI Services initial analysis is that it will be feasible, within current resources, to manage the education requirements to roll out the Palliative Care assessment to already trained Home Care assessors. Resource requirements will be better understood once DHBs have had the opportunity to express interest in making this assessment available.

The national guide, 'Which assessment to use when', will require review and the addition of the palliative care assessment as a further assessment option.

A planned approach can be developed once numbers to be trained are known.

Software services

A software enhancement is required to develop the assessment summary section to match other assessment tools used in NZ. A quote for this work is included in the software enhancements paper provided to the Board.

Development of a client summary report will need to be costed.

Expected volume of assessments

The expected volume of assessments would need to be confirmed. From data showing the numbers of people assessed who had end stage disease with less than 6 months to live it is estimated that approximately 2500 palliative care community assessments would be completed per year.

Data analysis and reporting requirements

A reporting line for additional items in the palliative care assessment has already been developed by the Data Analysis and Reporting Service and incorporated into the data warehouse. A new suite of reports will need to be developed this can be completed within current resources.

Further engagement with national stakeholders to develop business case

It is recommended that further engagement be undertaken with the HOP Steering Group and other interested stakeholders such as Hospice NZ, Palliative Care Council and the Joint ARC Steering Group.

Recommendations

It is recommended that:

- The interRAI Palliative Care tool be introduced as an additional tool to be used by interRAI Home Care assessors.

- Subject to the views of DHBs and other key stakeholders a business case for staged implementation is developed for presentation the interRAI NZ Governance Board.

- The final End of Pilot report be made available directly to Hospice New Zealand and be published on the interRAI NZ website

Appendix I - Survey Monkey Results:

InterRAI New Zealand Palliative Care Pilot – Assessor Survey (79% response rate)

| 1.	**How well did the Palliative Care Assessment Questions provide information on the following Areas?** (no information – excellent information)	
	Medical /Clinical responses	50% good , 50% excellent
	Social Background	10% moderate, 50% good, 40% excellent
	Spiritual	10% moderate, 30% good, 60% excellent
	Cognition	20% moderate, 40% good, 40% excellent
	Informal Supports	10% moderate, 30% good, 60% excellent
	Functional Performance	60% good, 40% excellent
	Comment: • The majority of Assessors found the Palliative Care assessment provided good or excellent information in relation to clients clinical needs	
2.	**When you used the Palliative Care Assessments compared to the Home Care Assessment did it provide adequate information for developing a Care Plan including what services needed to be provided?**	
	Response	100% YES
3.	**Did the Training and the Training Documents you received meet your needs to complete the Palliative Care Assessments?**	
	Response	100% YES
4.	**Were you able to easily identify 'which assessment to use when' using the flow chart e.g. did you know when to use the Palliative Care or Palliative Care Hospice or Home Care/Contact Assessment?**	
	Response	80% - YES 20% - NO
	Comments: • The flow chart was easy to use but the situations were not always straight forward. I ended up using the Palliative Care (not hospice) when in doubt • I needed to get assistance from the Lead Practitioner	
5.	**Can you please explain in the comment box below your experience of using the Palliative Care Assessments compared to the Home Care For the Client Group that the project focused on?** (Did it alter your focus for care planning, time taken to complete, benefits/risks?)	
	Themes: • All respondents mentioned that the Palliative Care Assessments were more relevant and appropriate to the client's situation than the Home Care Instruments • Respondents also focused on how it was less stressful and time consuming for the clients • Most respondents stated that time was spent on questions that focused on the areas that they felt were important for the client and their families such as psychosocial needs • Some respondents thought that the Palliative Care Assessments gave clients the opportunity to discuss their feelings around their current situation. Words used to describe this were holistic and client focused • Some respondents noted that questions/manual gave guidance on how to open discussions • Some of the respondents commented that Care Planning was easier and others said it made no difference	

Appendix II - Data from interRAI Palliative Care – Community Assessments undertaken 1 December 2015 – 20 September 2016.
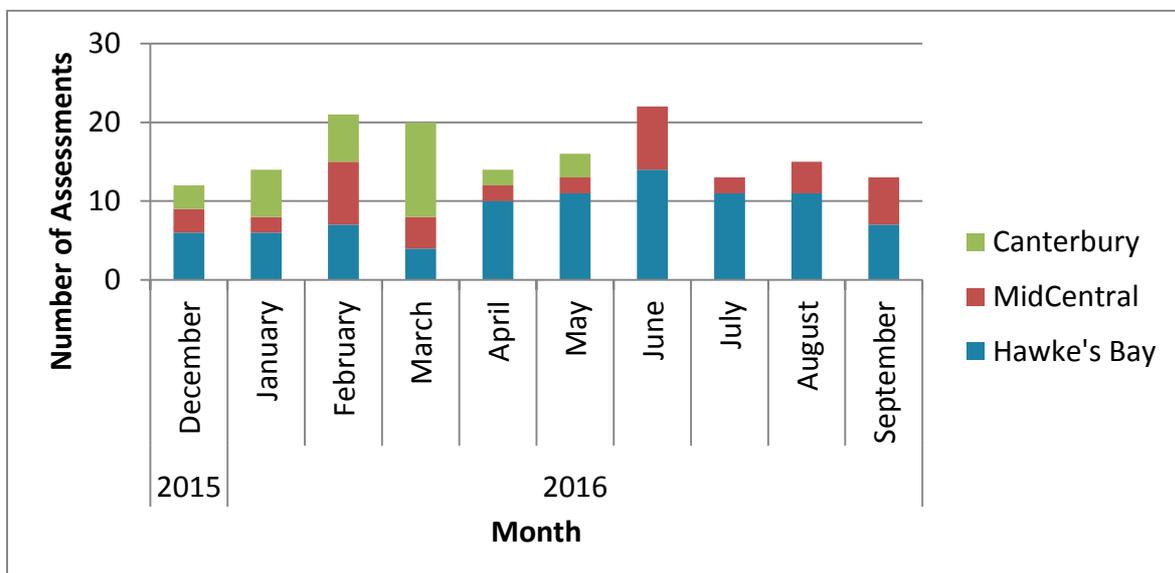
Summary

There were 160 Palliative Care assessments between 01/12/2015 and 20/09/2016. There were 154 distinct clients. 149 clients had 1 assessment, 4 clients had 2 assessments, and 1 client had 3 assessments.
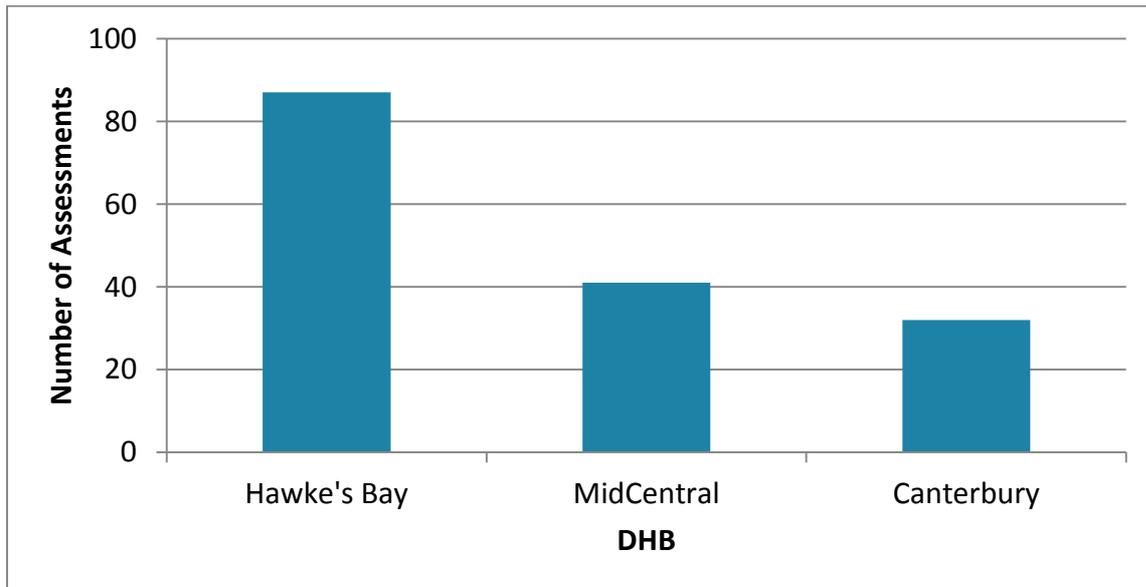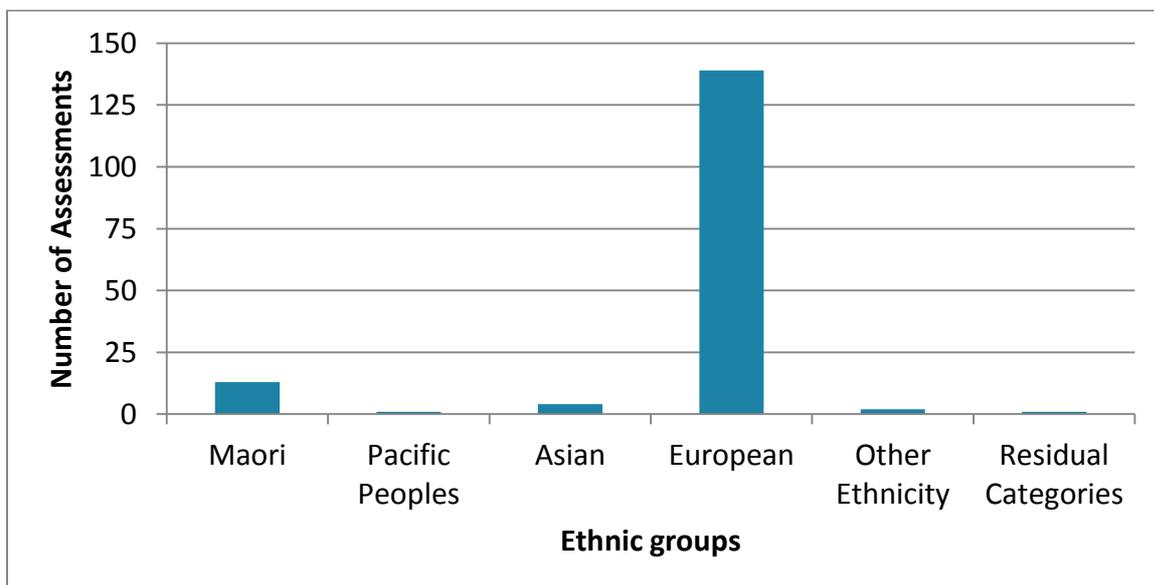
Demographic

Months
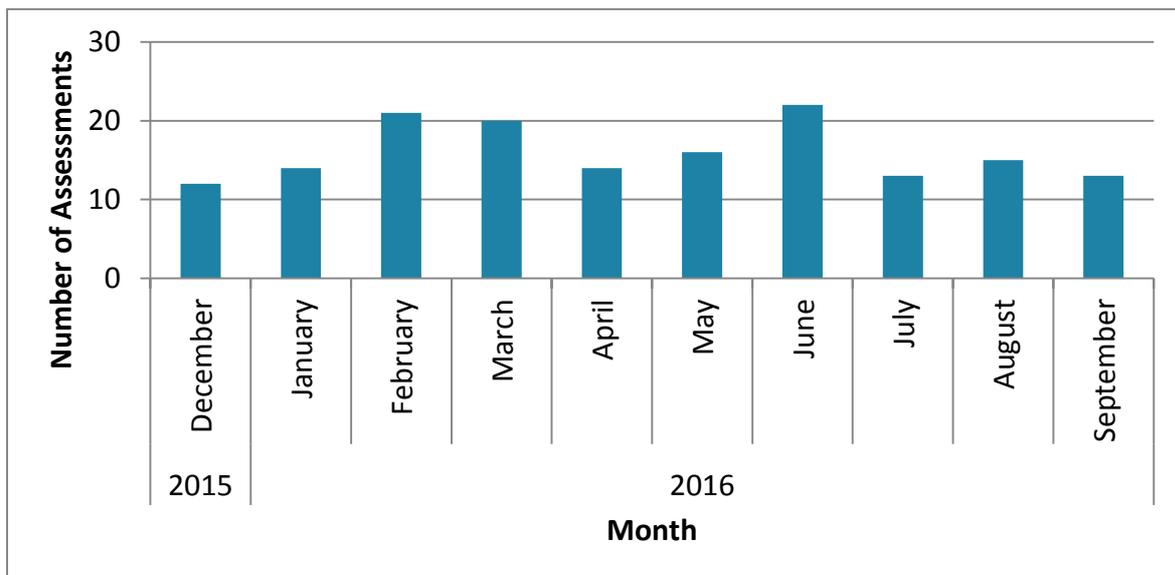
Months and DHB

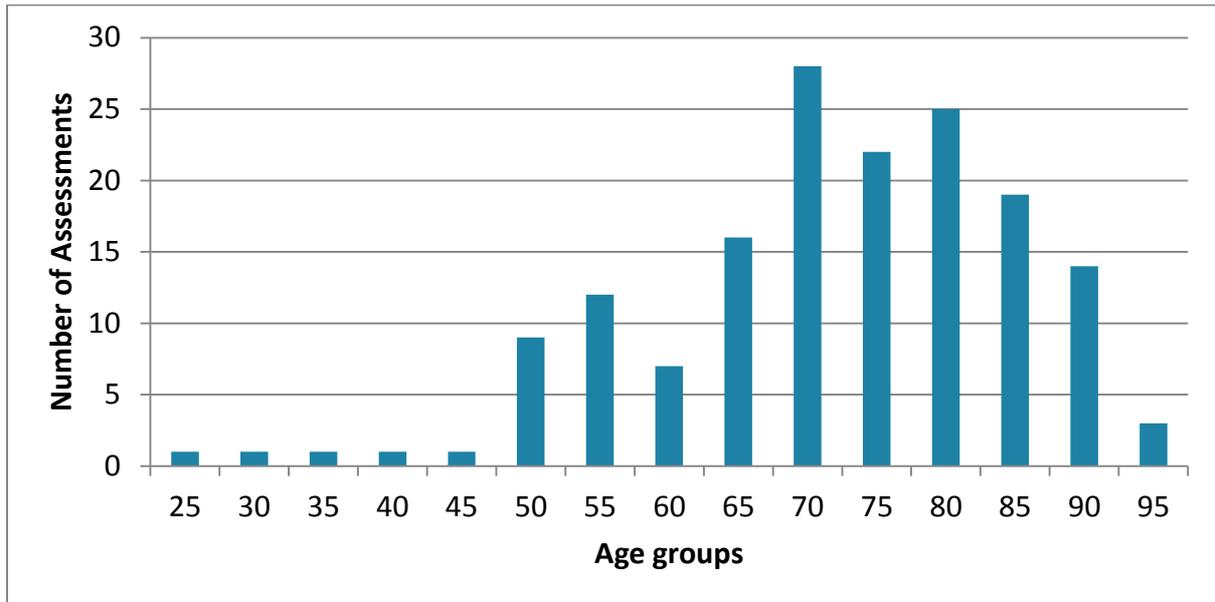N.B. The CDHB Assessor resigned from her position in June 2016

DHBs

Ethnic groups

Note that this is level 1 ethnicity (MELAA is not shown).

Age

Question from Home Care assessment for 01/12/2015 – 20/09/2016

J7c. End-stage disease, 6 or fewer months to live, All DHBs, 01/12/2015 - 20/09/2016

Response	Assessment Count	Percentage
No	27,289	96%
Yes	1,232	4%
Total	**28,521**	**100%**

J7c. End-stage disease, 6 or fewer months to live, Hawke's Bay, MidCentral, Canterbury DHBs only, 01/12/2015 - 20/09/2016

Response	Assessment Count	Percentage
No	4,892	97%
Yes	148	3%
Total	**5,040**	100%

Some NASC assessors in HBDHB and MDHB and all CDHB NASC assessors were not trained in the Palliative Care assessment and so continued to complete Home Care assessments with palliative clients.

Questions from Palliative Care assessment for 01/12/2015 – 20/09/2016

A12a Estimated survival
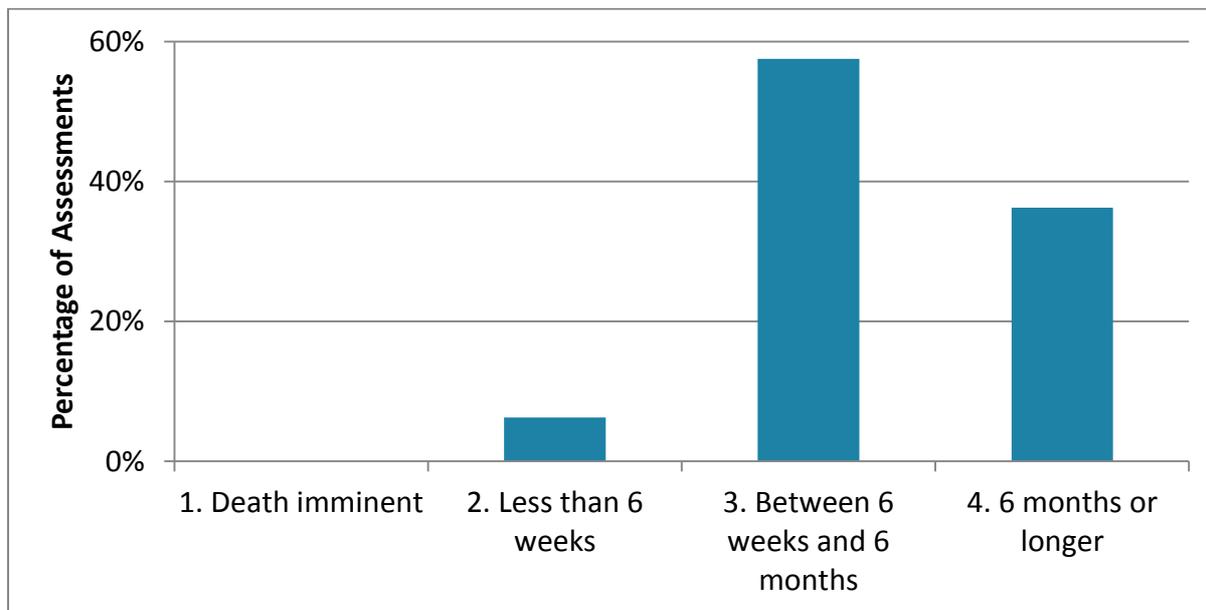
Response	Assessment Count	Percentage
1. Death imminent	0	0%
2. Less than 6 weeks	10	6%
3. Between 6 weeks and 6 months	92	58%
4. 6 months or longer	58	36%

C1b Pain intensity
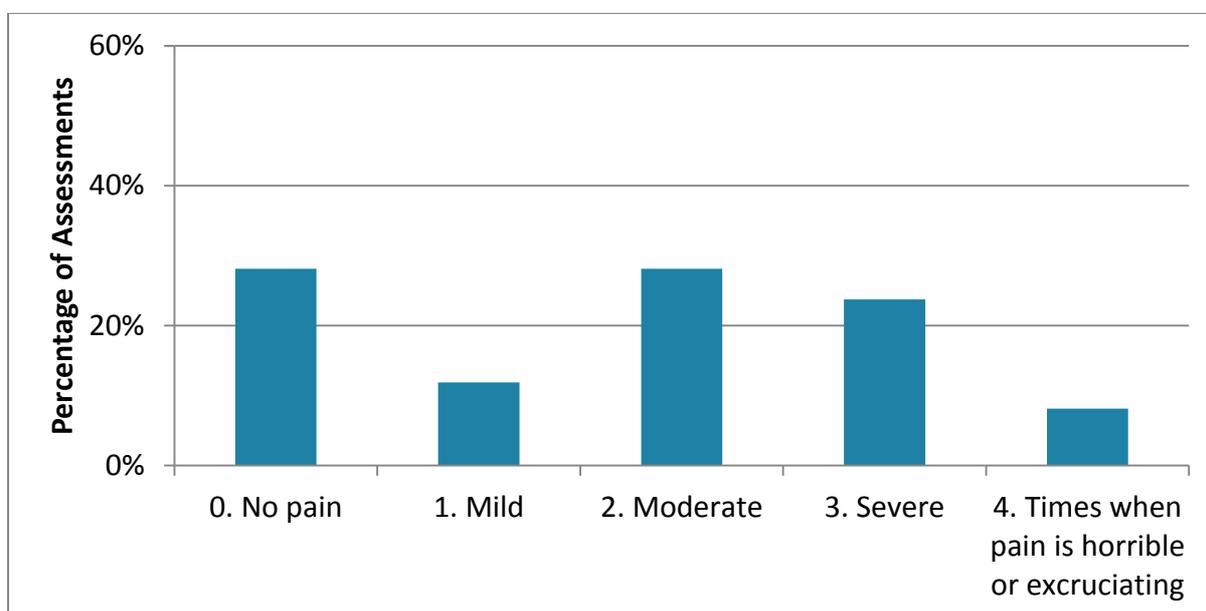
Response	Assessment Count	Percentage
0. No pain	45	28%
1. Mild	19	12%
2. Moderate	45	28%
3. Severe	38	24%
4. Times when pain is horrible or excruciating	13	8%

C1f When pain is present
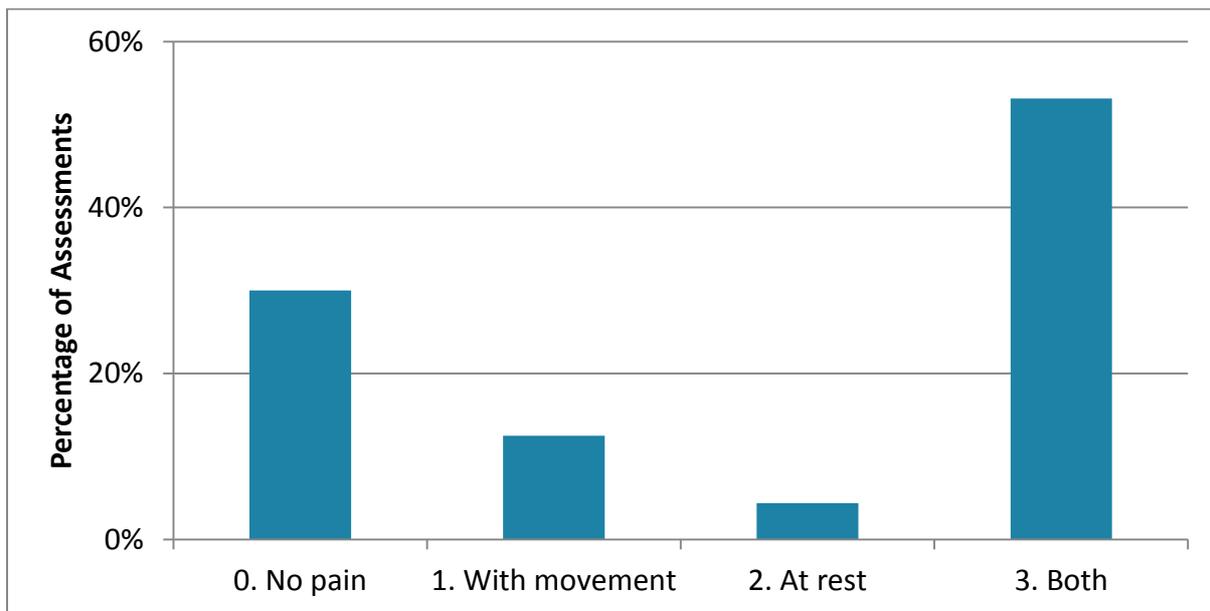
Response	Assessment Count	Percentage
0. No pain	48	30%
1. With movement	20	13%
2. At rest	7	4%
3. Both	85	53%

C6 Problem frequency
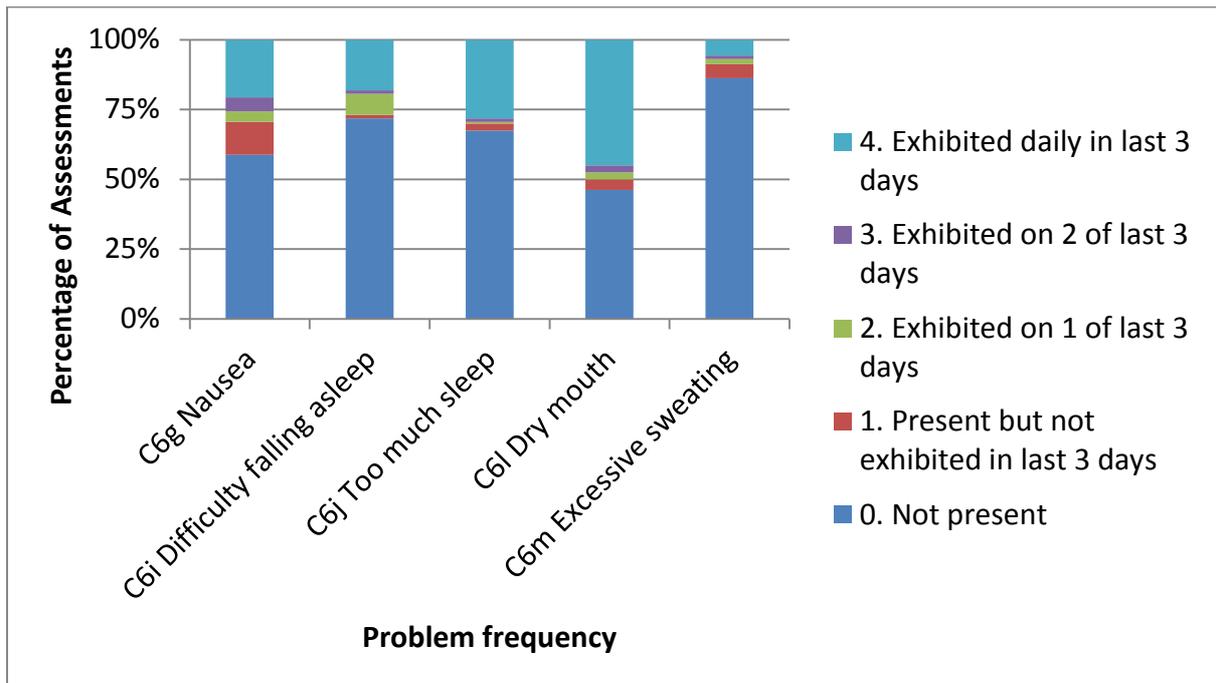
I1 Life completion = 1. Yes
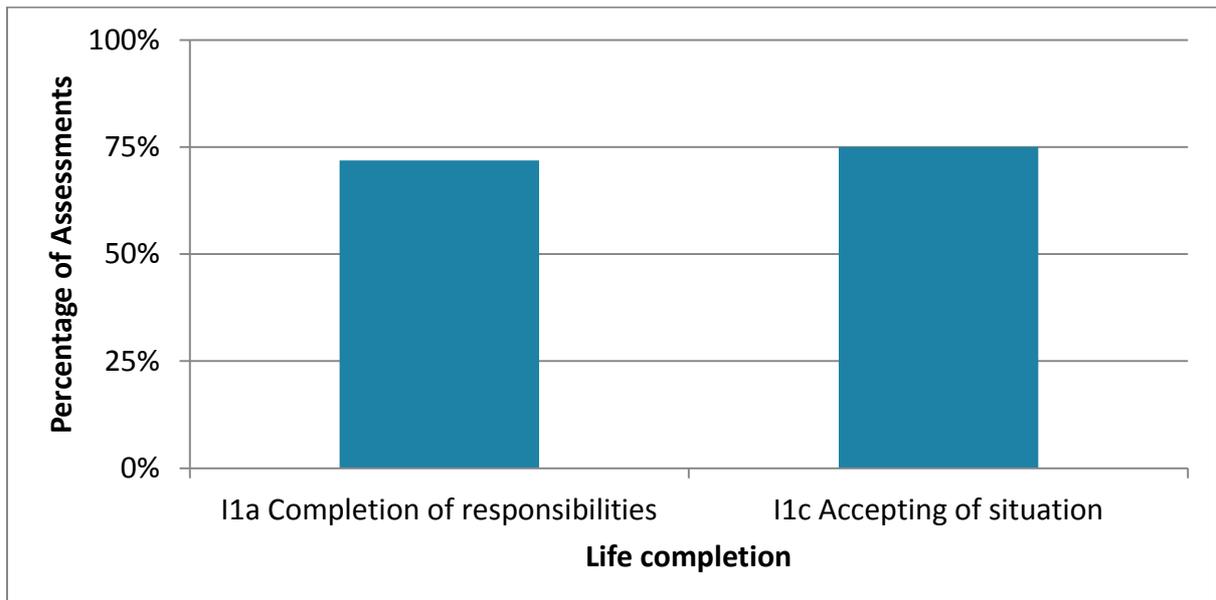
I2 Self-reported spirituality
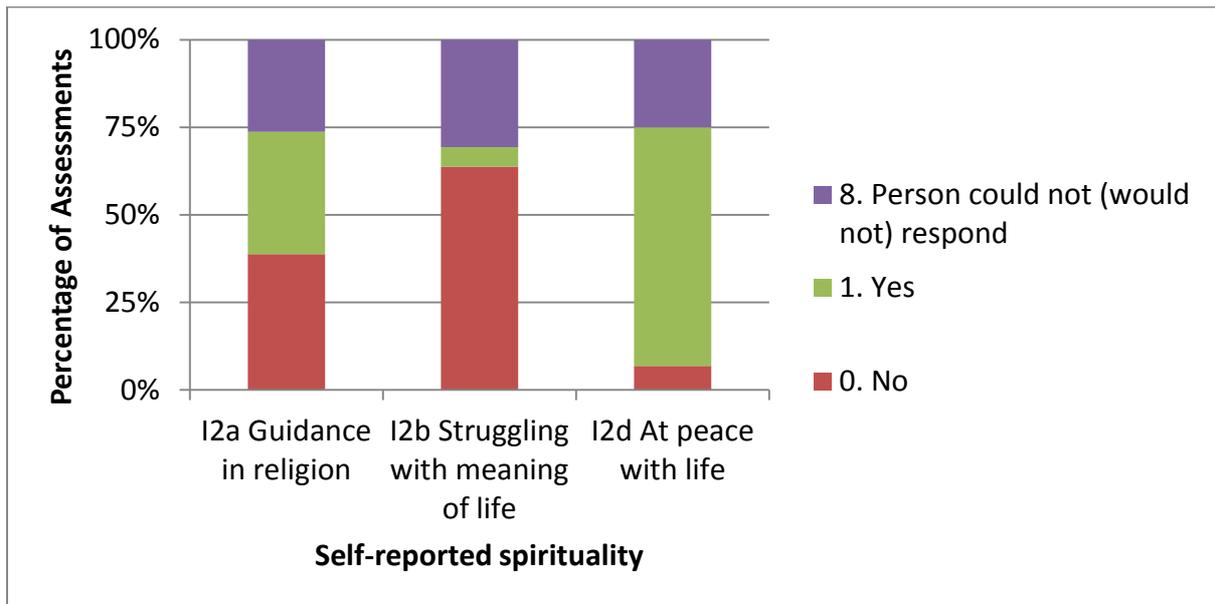
Note that "I2b Struggling with meaning of life" is an inverse of the other questions

Wishes regarding where to die
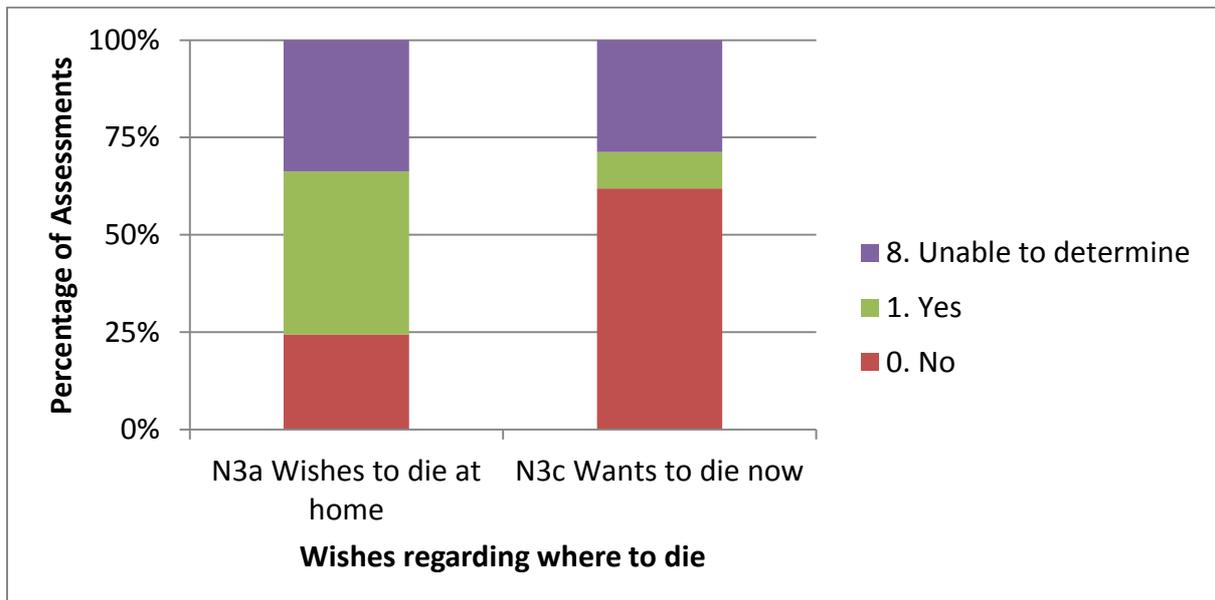
EPOA = 1. Yes / ACP = 1. Completed
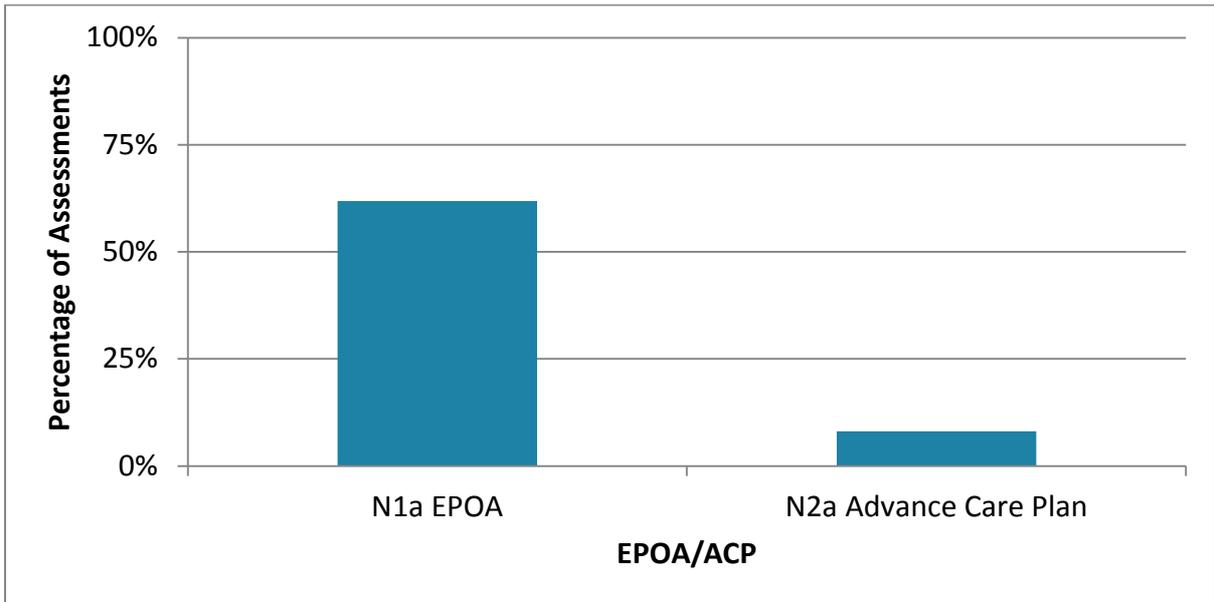
O1 In last 24 hours how long was any family member, significant other, or friend with the person
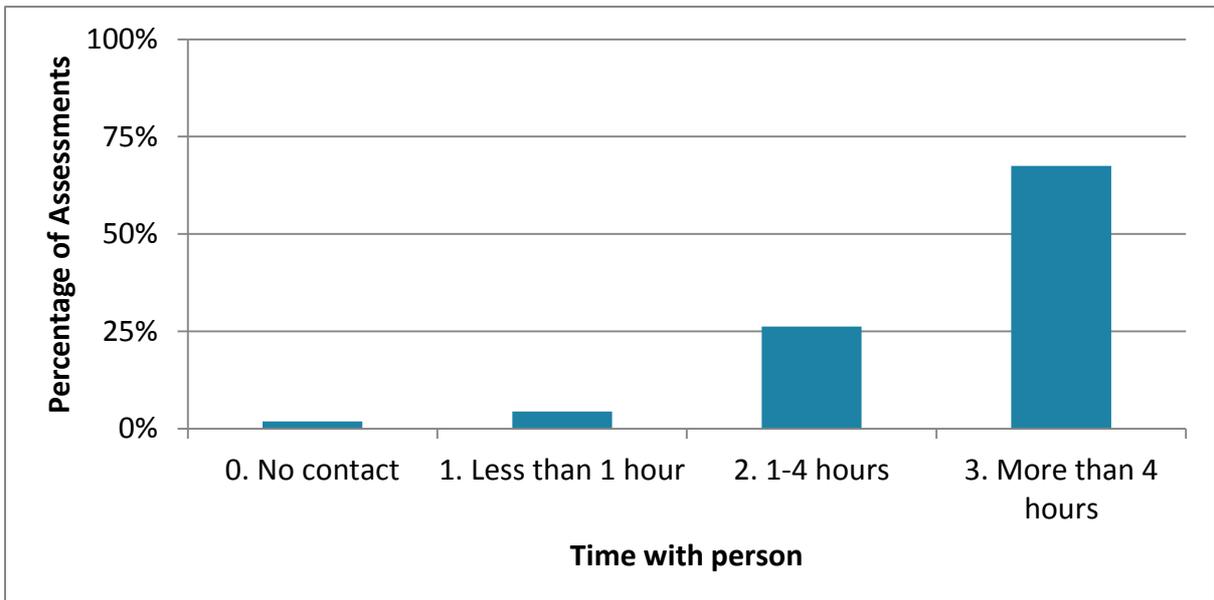
Social Supports
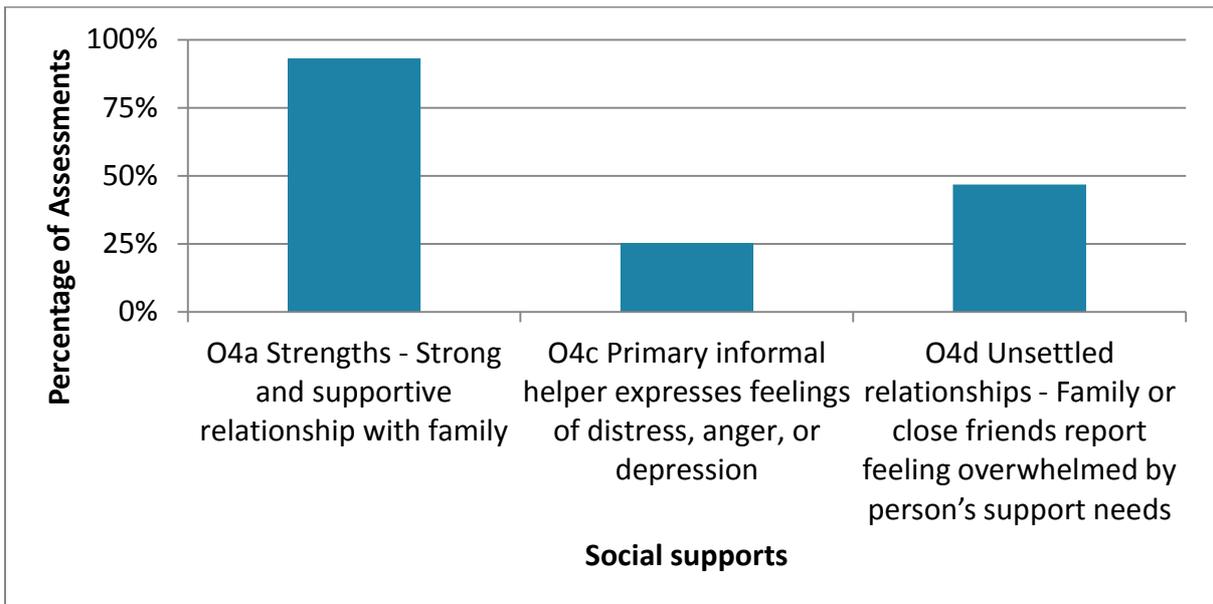
Note that for question O4c there were 6 non-responses where the person did not have an informal helper. The percentage has been calculated from total responses of 154 for this question only.

CAPs
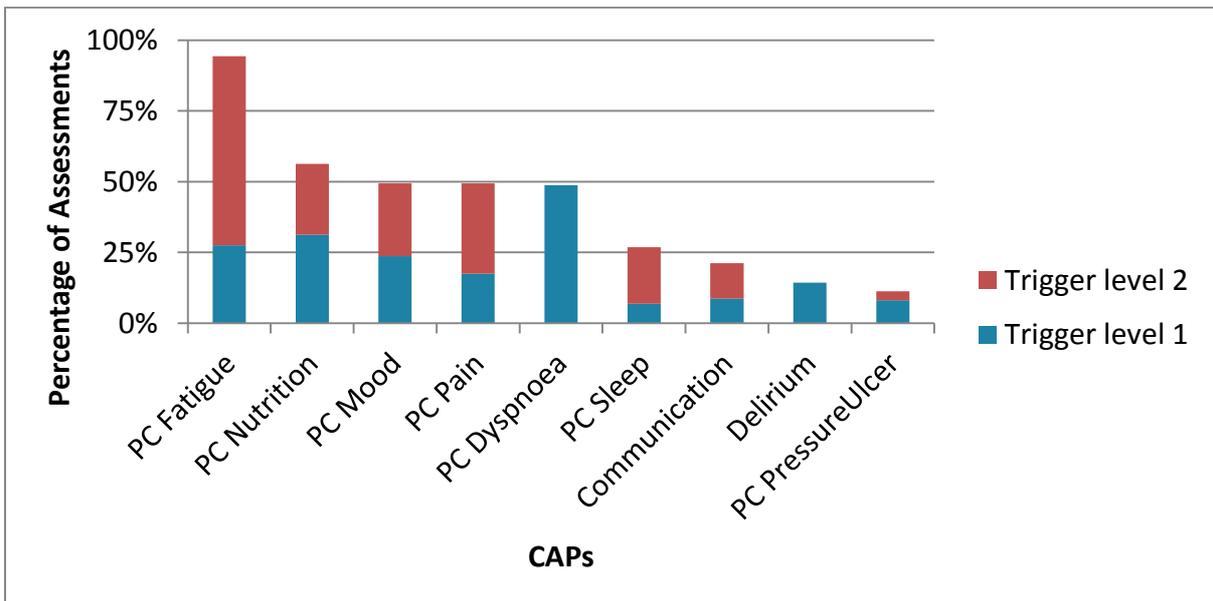
Note that "not triggered" is not shown in the chart. PC Dyspnoea and Delirium only have one trigger level.

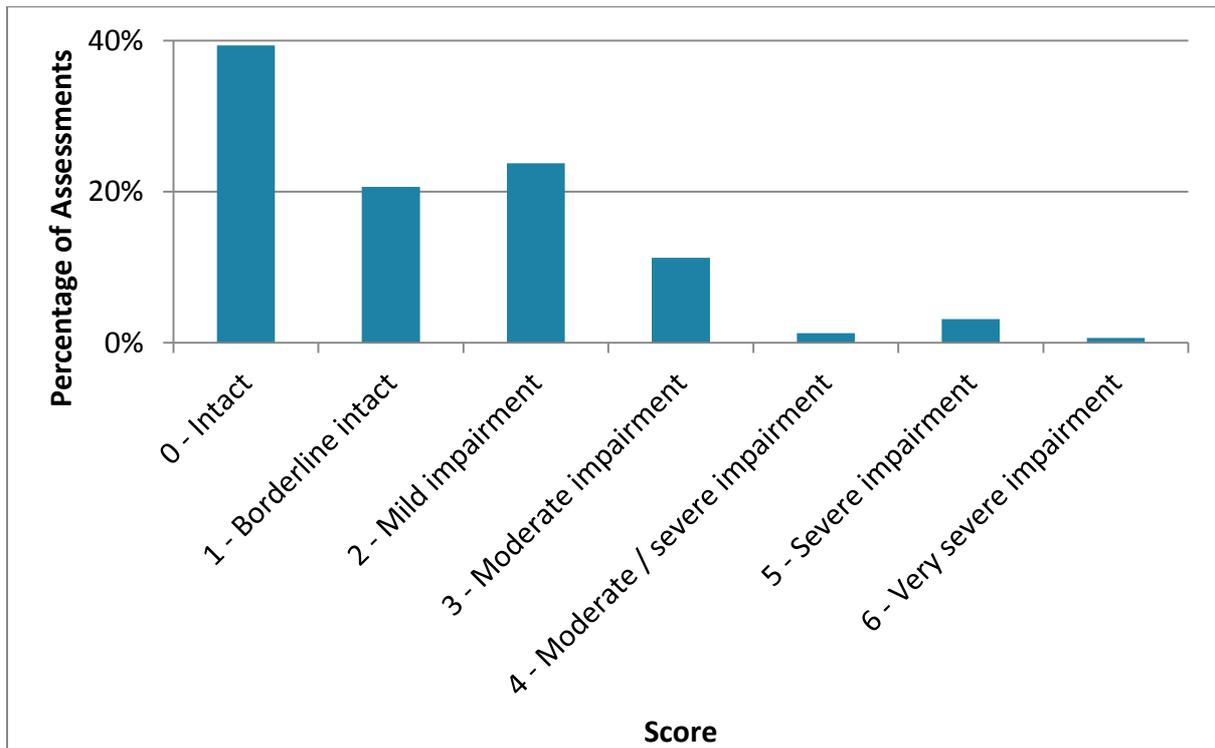## Outcome scales

ADL Hierarchy
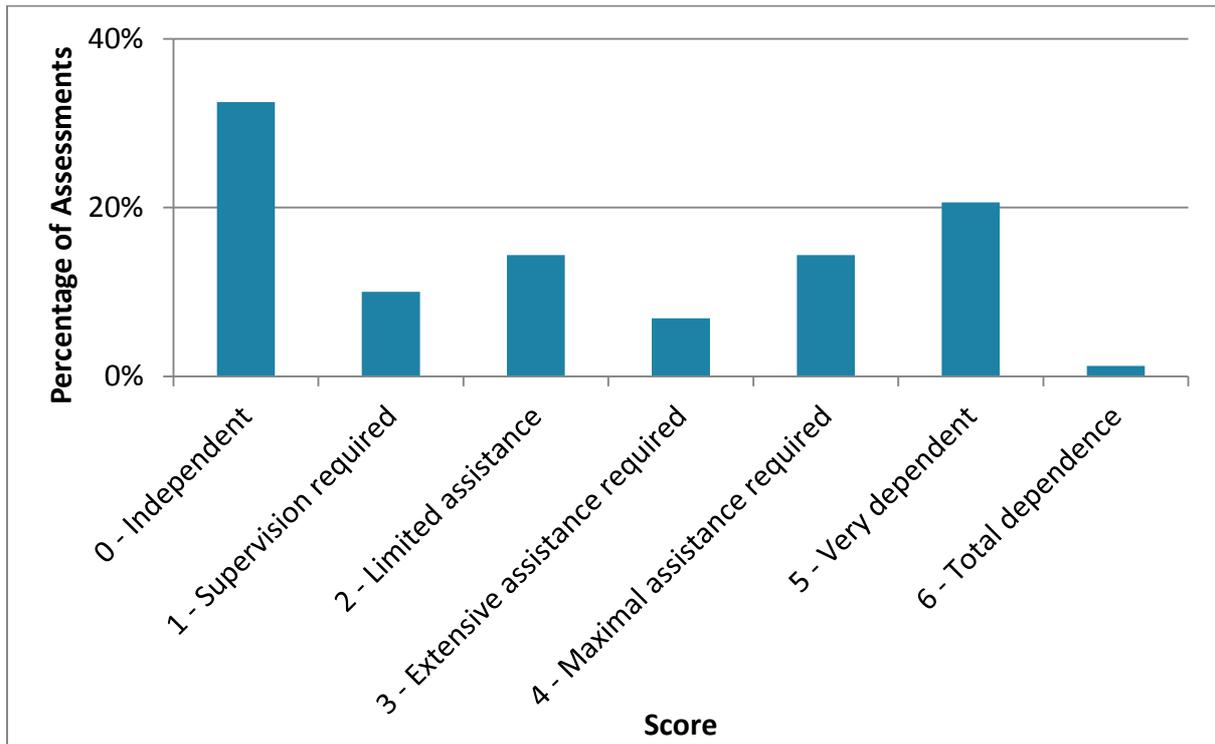
ADL Short Form
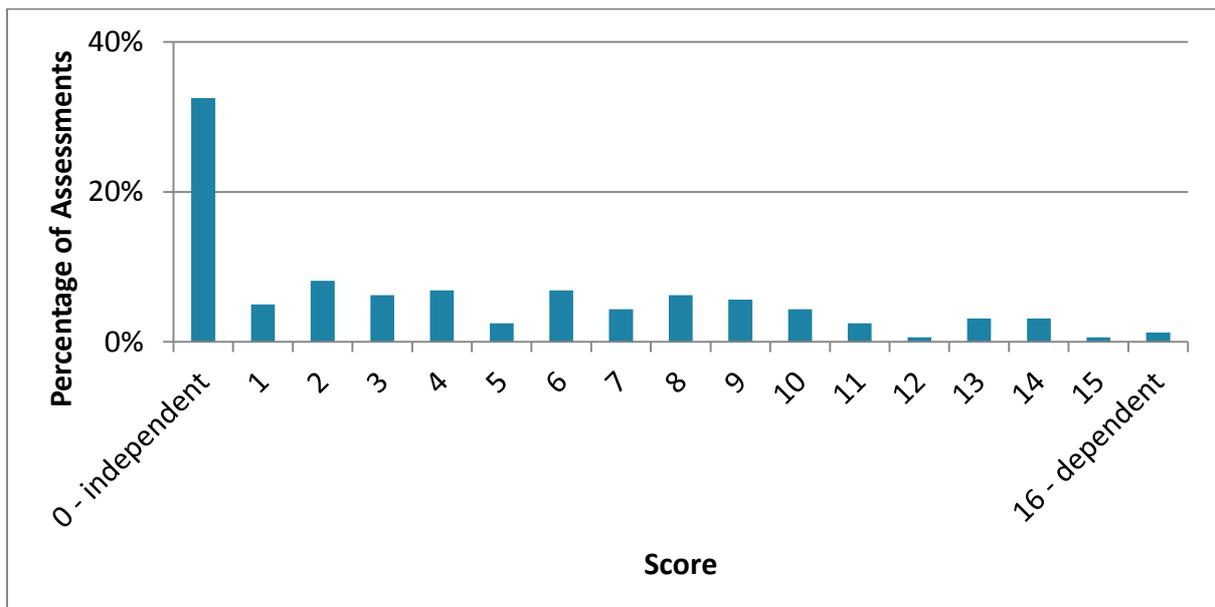
CHESS

This is a measure of health stability based on a diagnosis of end stage disease, change in Activities of daily living (ADL) status and decision making as well as signs and symptoms such as dyspnoea and weight loss.
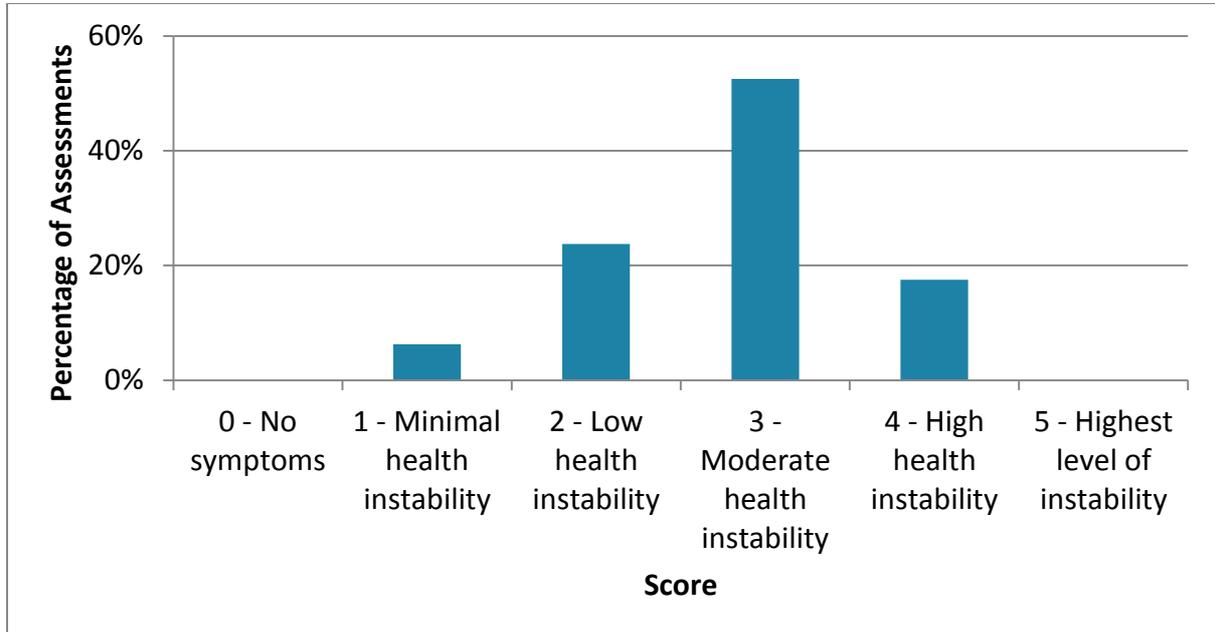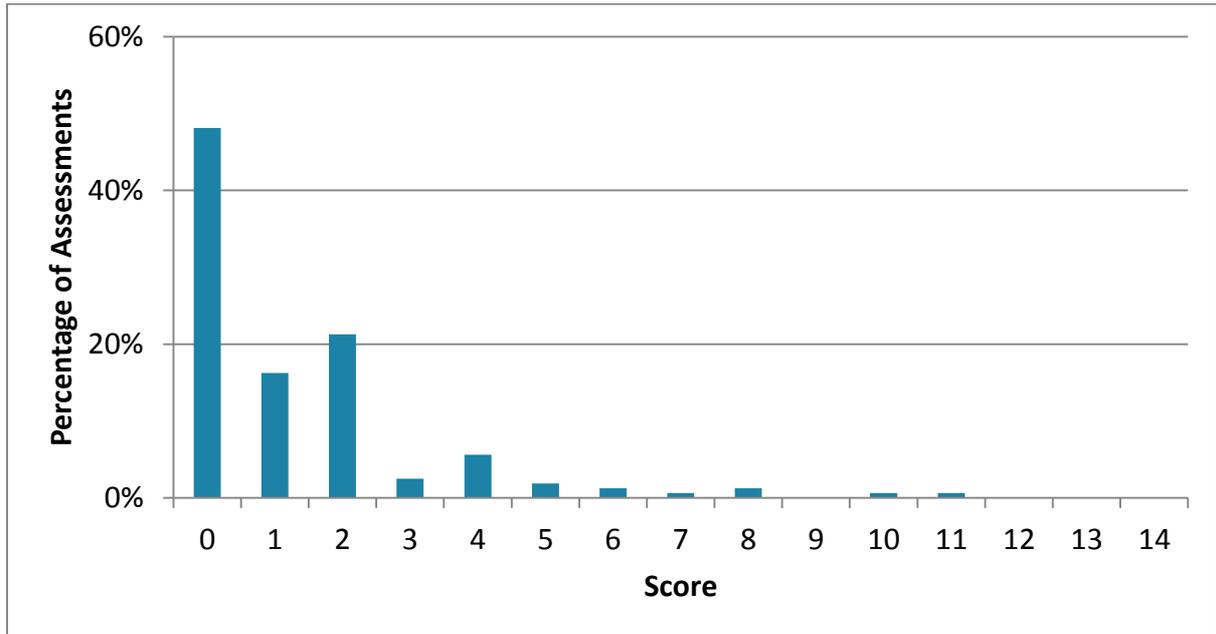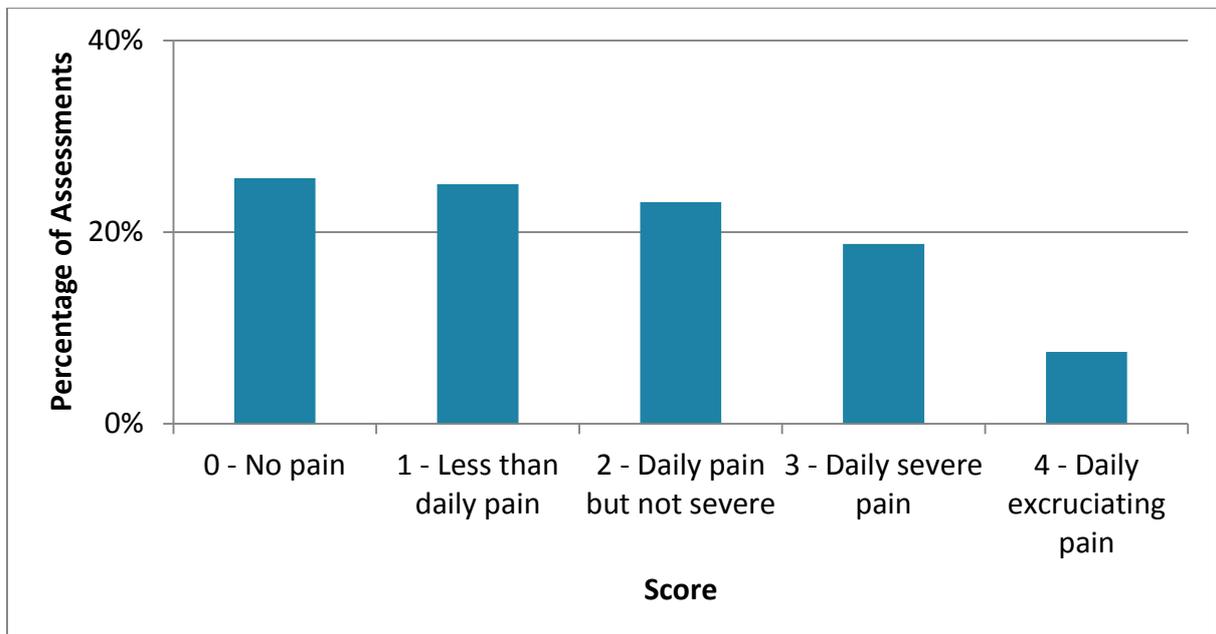

CPS

Cognitive performance scale

DRS

Depression rating scale

Pain

Pressure Ulcer Risk