

**The Reliability of the Complex Element of the Northern Ireland Single
Assessment Tool for the Health and Social Care of Older People**

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INTRODUCTION

Assessment involves collecting information about a person's circumstances and needs, and making sense of that information in order to decide what support, treatment or care to provide (Slater and McCormack 2005). It is a complex, integrated process consisting of many parts. In March 2001, the Department of Health (DoH, England) published the 'National Service Framework (NSF) for Older People' (NSF for Older People). The central value of the report was that 'just like the rest of us, older people want to enjoy good health and remain independent for as long as possible' (DoH 2001, page 1). One recommendation of the NSF for Older People advocated the implementation of the philosophy of person-centred care when working with older people and implicit within this was a core recommendation for the use of a reliable and valid assessment instrument that would ensure that the person was put at the very heart of the assessment process. The Northern Ireland Single Assessment Tool (NISAT) was developed to address the assessment process as highlighted in the NSF for Older People (DoH 2001).

The NISAT consists of three main parts: the Contact Screening; the Core NISAT; and the Complex NISAT. NISAT also has four additional components: the Specialist Referral, the Specialist Summary and Recommendations, the Carers Support and Needs Assessment, and the GP and Medicinal Practitioner Report. The psychometric property of the Complex NISAT is the focus of this study. The Complex NISAT assessment involves collation of information gathered from the older person through contact screening, core assessment and where appropriate, specialist assessment summaries, carers' needs assessment and input from GP and medical practitioners. Information gathered needs to be coordinated, drawn together and interpreted by a professional assessor. It consists predominately of qualitative data with a quantitative element woven through it. The information is gathered from the aforementioned sources and supplemented by face to face discussion with the older person.

The study involved examining the reliability of information collected by assessors using the complex assessment instrument of the NISAT (will be referred to as Complex

NISAT). Reliability was determined by the level of consistency where assessors identified the same themes when presented with the same evidence. Case studies and trained actors were used to provide the evidence.

The use of case studies is a research strategy which focuses on understanding the dynamics present within a single setting (Huberman and Miles 2002). Case studies typically combine data collection methods such as archives, interviews, questionnaires and observations. The evidence may be qualitative, quantitative or both. For example, Eisenhardt and Bourgeois (1988) combined quantitative data from questionnaires with qualitative evidence from interviews and observations. Case studies can be used to accomplish various aims: to provide description (Kidder 1987); test theory (Penfield 1986); or generate theory (Harris and Sutton 1986). The intention here is in the use of case studies to provide description of a hypothetical older person.

Case studies have been widely used in health care studies, in particular to examine newly developed instruments and classification criteria. Researchers (Skre et al 1991, Marder et al 2003, and Devitt et al 1997) used case studies to inform the development of assessment instruments. Skre et al (1991) used case studies to test the inter-rater reliability of an instrument for psychological classification, and Marder et al (2003) tested the inter-rater reliability of a measure of cognitive impairment based on a case history of hypothetical clients. Both studies found the method to be effective in achieving the study goals

This study also involved the use of trained actors, informed by the case studies. The use of case studies based on simulated patients as portrayed by actors has been used to research studies in communications (Syder 1996), medical health (Hazelkorn and Robins 1996), counseling skills (2000), physiotherapy (Ladyskewsky et al 2000), and psychology (Endicott et al 2002) to test inter-rater reliability. Rosen et al (2004) used actors to test the inter-rater reliability of a depression scale and concluded that actors can effectively portray depressed patients. Experienced assessors could not distinguish between 'patients' and 'actors'. Devitt and colleagues (1997) used five hypothetical case studies with actors portraying scenarios with the aim of examining the inter-rater

reliability of observers rating responses to each case study. The researchers found the method to produce high inter-rater reliability and concluded that the use of standardized scenarios allows the reproduction of the same event for each observer.

Lilford et al (2007) conducted an analysis of the inter-rater reliability reported by studies that used case studies and simulated patients to inform raters' classifications. Lilford et al (2007) reported that case studies and case notes were used in reviews of services conducted in the U.S. (Harvard Medical Practice Study 2004) and Australia (Wilson 1995). The researchers concluded that the studies which used case studies tended to report higher reliability scores, particularly more so with linear quantitative assessment tools than with holistic qualitative assessment instruments.

Reliability is essential criteria for assessment and assessment tools. Case studies have been used extensively in the development of assessment instruments (Marder et al 2003, Devitt et al 1997) as well as the testing of the reliability of assessment tools in areas of health science, such as medical science (Hazelkorn and Robins 1996), psychology (Endicott et al 2002), and physiotherapy (Ladyskewshy et al 2000). They have also been used to test inter-rater reliability (Devitt et al 1997, Lifford et all2007). In this study, the reliability of the Complex NISAT will be tested using case studies as portrayed by trained actors.

METHODOLOGY

Aims

The principle aim of the study was to examine the reliability of the Complex NISAT.

Two measures were calculated:

- The ability of assessors to identify the themes contained in each case study in order to determine the assessors' understanding of the Complex NISAT and its reliability; and
- The total number of themes identified by each assessor provided information on the comprehensiveness of the assessments.

The level of agreement and its statistical significance was calculated for both measures.

Each assessor participated in a short interview following completion of the Complex NISAT to discuss their concerns and issues with the complex NISAT and to help inform the instruments further development.

Design

Trained actors were used to simulate a client's extensive case history; assessors interviewed each trained actor and identified the presenting themes of the case history. A theme was defined as expected health and social care needs/abilities of the older person derived from the case study notes. The reliability of the Complex NISAT was determined by the number of consistently identifying themes across all assessors.

A mixed methods approach was used to inform the testing of the reliability of the Complex NISAT. Quantitative measures were generated to evaluate the reliability of the Complex NISAT and assessors were interviewed to gauge opinions regarding the usability of the instrument. The combination of quantitative and qualitative methods to investigate a single issue or concept may provide an in-depth and comprehensive picture of the phenomenon (Parahoo 1997).

Procedure

The following stages were followed:

- The research team identified measures/themes unique to each case prior to the commencement of the assessment.
- A coding protocol was developed for each case study based on the quantitative measures and qualitative themes contained in each case study. The coding protocol entails assigning labels to text passages that contain reference to specific categories of information (Miles and Huberman 1994). In this study the coding was based on the information contained in the case study.

- The coding protocol informed the development of the scoring matrix, the scoring matrix is a score sheet indicating the presence (or absence) of a measure/theme within an assessment.
- Case studies were used to provide a source of information for assessors to complete the Complex NISAT (Appendix II). Trained actors immersed in the case history acted out the role of the older person.
- Assessors were drawn from a care management background (principally nursing and Social Work), trained in the use of the Complex NISAT, and provided with all information (Core NISAT, Carers' Assessment etc) relevant to the completion of the complex NISAT. Each assessor was given 45 minutes to read through the case history prior to interviewing the actors. The assessors were given 10-15 minutes to interview each actor in order to compliment the information contained in the Core NISAT and have questions relevant to the completion of the Complex NISAT answered.
- The completed assessments were analysed by two researchers.

Measures

Quantitative Measures

The scoring matrix was used to score identified measures/themes in each assessment. Identified and non-identified measures/themes were recorded for each assessor. This was conducted by two researchers independently to ensure the accuracy of the research process. The inter-rater reliability was calculated for each assessor to ensure rigour in the process of identifying themes (Mayan 2001). The level of agreement between researchers was high, indicating consistency in the identification of the same themes, with an average 93% level of agreement (See appendix I).

From the two scoring matrices an agreed data set was developed. The results were analyzed according to the frequency of identified themes for each case study and the number of identified themes by each assessor.

Qualitative Measures

Assessors participated in a short interview to inform the usability of the complex assessment instrument. A semi-structured interview schedule was employed as this allowed the researchers maneuverability and responsiveness within the interview. Three main questions were asked:

1. How did the assessment work?
2. How did it not work?
3. How could it be improved?

Assessors' comments were collected, transcribed and analysed using content analysis to inform the development of the Complex NISAT.

Sample

Twenty six assessors drawn from all five health trusts in Northern Ireland participated in the study. This represented a mix of nurses (n=12), social workers (n=12) and AHP's (n=2). Inclusion criteria was that the assessor must have experience in completing care management assessment, have received training in the use of the Complex NISAT and be willing to participate.

Each assessor was assigned, randomly, to one of three groups, each focusing on a different case study. Each assessor completed two case studies.

Case Studies

A synopsis of the presenting details of each of the case studies is presented in appendix II. The actors were given the case history to inform their portrayal. The information was also included in Contact and Core NISAT assessments which were given to the assessors before they conducted the interviews.

Data Analysis

A mix of quantitative and qualitative research methods were used in the study. Each required its own particular method of analysis.

Quantitative Data

The quantitative data comprised of set measures and quantified themes. The finding of each was interpreted differently. There were five dichotomous (yes/no) measures contained in the Complex NISAT. Each dichotomous measure had a 50% chance of being scored correctly, by chance alone. Therefore all results for the dichotomous measures begin at a 50% baseline. Scores above 50% indicated a response pattern above chance alone, with scores closer to 100% indicating stronger response patterns well above chance. The level of agreement between assessors was calculated for each quantitative measure and expressed as a percentage score.

The percentage of assessors that successfully identified each qualitative theme was also calculated. The identification of the theme was not predetermined as with the set answers in the dichotomous measures, therefore the chances of themes being identified ranged from 0% - 100%. The number of themes correctly identified was calculated, and examined according to the number of assessors to identify the theme and the number of themes each assessor successfully identified. Both totals were expressed as a percentage.

The percentage was labeled on an ordinal scale of low, moderate or high: percentage agreement above 51% – 75% as low; 75% – 85% as moderate and 86% - 100% as high. The statistical significance for the scores was calculated. An asterix ‘*’ indicates probability at a statistically significant level of <0.05 and a double asterix ‘**’ as <0.01.

Qualitative Data

Assessors participated in a short semi-structured interview after completing the complex NISAT. Assessors’ comments from the interviews were transcribed and the main themes identified using Mayan (2001) guidelines for content analysis. The findings from the content analyses help inform the development of the tool.

RESULTS

CASE STUDY 1

Case study 1 contained twenty one points of measurement. This included a mix of quantitative measurement (shaded row n=5) and qualitative themes (non-shaded, n=16). The statistical significance of each of the results was calculated.

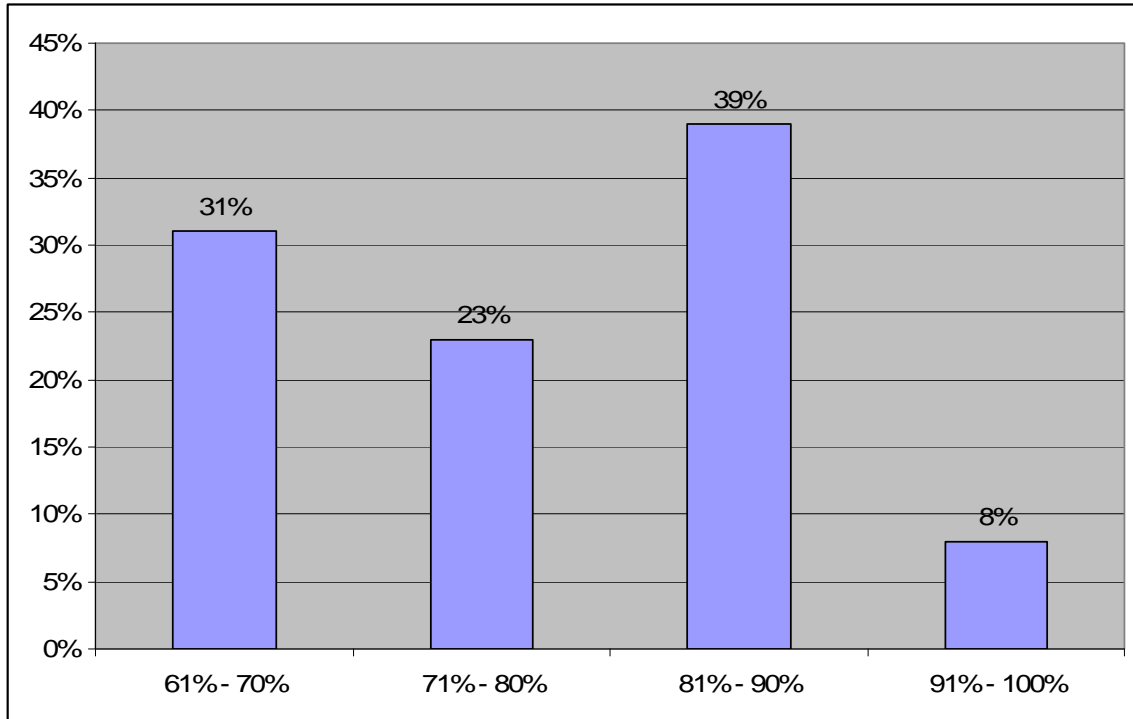
	Percentage	Reliability	
Client participation	100%	High	**
Client Awareness	100%	High	**
Decision making Facilities	100%	High	**
Change in physical health	100%	High	**
Mobility – getting upstairs	77%	Moderate	**
Mobility – get to toilet	71%	Moderate	NS
Mobility – O2 therapy	77%	Moderate	**
Ability to conduct daily tasks	100%	High	**
Changes in mental health	100%	High	**
Isolation	94%	High	**
Risks	88%	High	**
Carers Assessment	100%	High	**
Accommodation issues	88%	High	**
Assistance required with ADL's	59%	Low	NS
Independence	53%	Low	NS
Lack of family assistance	59%	Low	NS
Friendships	77%	High	*
Vulnerable Adult	100%	High	**
Legal Financial Arrangements	100%	High	**
Control over finance	71%	Moderate	NS
Payments advice	71%	Moderate	NS

Table 1. Case Study 1 Reliability Scores

There was a broad range of scores for both the measures and quantified themes. Fifteen (71%) of the measures were scored above 75% agreement between assessors and were statistically significant. Six of the measures failed to achieve statistical significance yet 3 of the measures had reliability scores above 70%. All of the quantitative measures had high reliability, all at a statistically significant level.

Almost two thirds (62%) of the themes were scored above 85% with 9 of the scores having 100% agreement. A further 5 themes (24%) were classified as having moderate

reliability. Only 3 themes (14%) were scored as having low reliability and should be examined for further amendment.



Graph 1. Percentage of identified themes for case study 1

The number of themes correctly identified by each assessor was calculated and converted to a percentage score ranging from 0% to 100%. The percentage of successfully identified themes by assessors is displayed in graph 1. An average of 77.5% of the themes was identified by the assessors. Overall, two thirds (69%) of the assessors identified 70% or more of the themes, with almost half (47%) identifying 80% or more. Eight percent identified 90% or more of the themes. Examination of graph 1 highlights variability in the scoring between assessors.

CASE STUDY 2

Twenty seven potential themes were identified for case study 2. The number of identified themes was summed for all the assessors and the agreement between assessors was calculated for each of the measures and expressed as a percentage score.

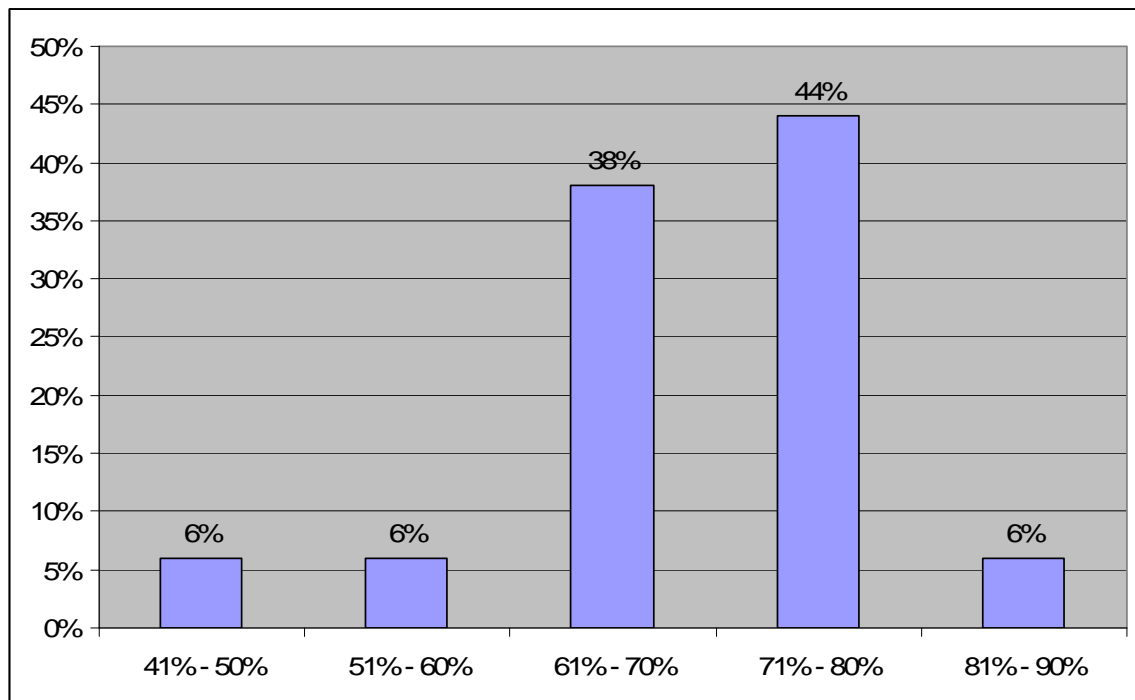
	Percentage	Reliability	
Person participation	100%	High	**
Person awareness	92%	High	**
Decision-making facilities	100%	High	**
Personal Care	100%	High	**
Incontinence	56%	Low	NS
Risk of choking	69%	Low	NS
Walking	56%	Low	NS
Wandering	81%	Moderate	**
Changes in Mental health	88%	High	**
Fear and agitation with strangers	94%	High	**
Reduced involvement	56%	Low	NS
Aggression with others	94%	High	**
Risks	94%	High	**
Changes in physical health	81%	Moderate	**
Respite care	75%	Moderate	*
Caring issues	100%	High	**
Quality of care	94%	High	**
Assistive technologies	94%	High	**
Carers Assessment	100%	High	**
Living arrangements	94%	High	**
Living changes	56%	Low	NS
Support network	63%	Low	NS
Family connections	63%	Low	NS
Vulnerable adult	85%	High	**
Legal Financial arrangements	50%	Low	NS
Power of attorney	81%	Moderate	**
Benefits and payments	56%	Low	NS

Table Two. Case Study Two Reliability Scores

Table 2 highlights the main themes to be identified from case study 2. Overall 80% of the 27 themes were identified by all assessors. The number of identified themes varied considerably within the assessment. Nineteen percent (n=5) of the themes were identified by all assessors. Examination of the results shows that 52% of the themes identified by the majority of assessors had high reliability, and a further 15% of themes as

moderate reliability, with all results at a statistically significant level. Four of the five quantitative measures were scored as high reliability and as having statistical significance.

A third of the themes did not achieve high reliability scores or statistical significance. These themes require further examination as potential areas of amendment.



Graph 2. Percentage of identified themes for case study 2

Twenty two qualitative themes were contained in case study 1, assessed by 16 assessors. The number of correctly identified themes was calculated according to each assessor. A summary of the percentage of successfully identified themes according to assessors is displayed in graph 2. An average of 69% of the themes were identified by the assessors. It is clear from the findings that there was considerable variability in the number of themes identified by assessors. The majority of the assessors (44%) identified between 70% - 80% of the themes. However half of the assessors failed to identify more than 70% of the themes.

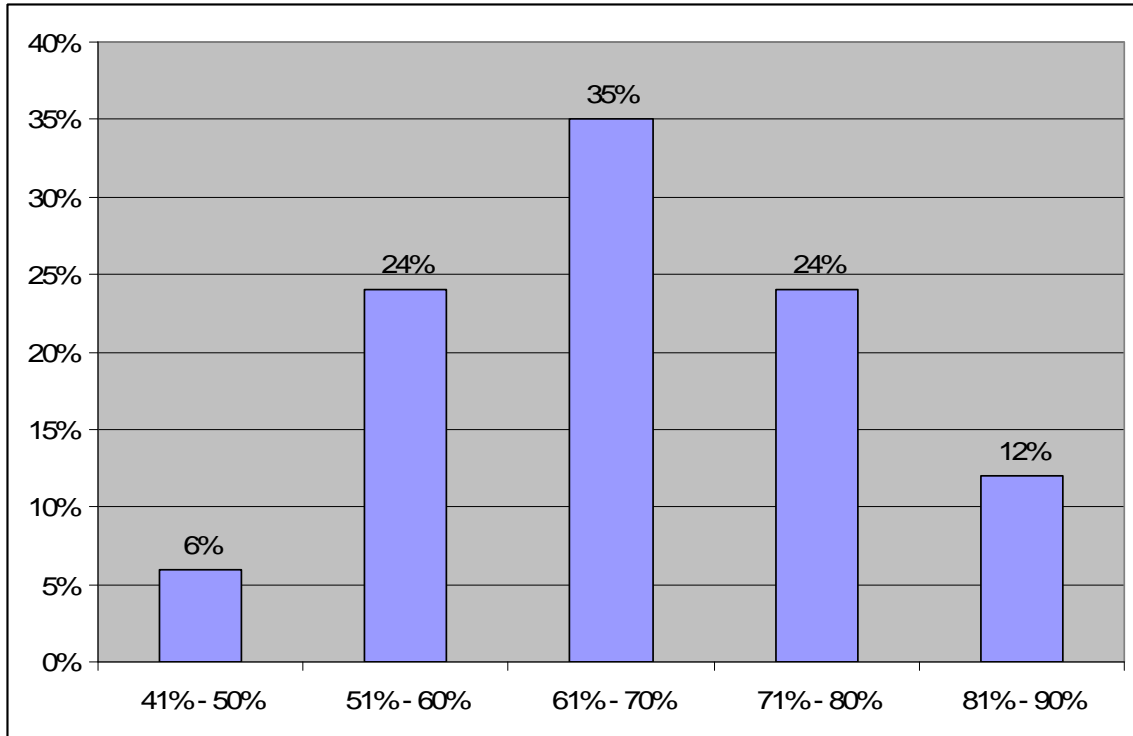
CASE STUDY 3

There were twenty four themes identified as relevant to case study 3.

	Percentage	Reliability	
Person participation	100%	High	**
Person awareness	100%	High	**
Decision-making facilities	94%	High	**
Sensory functioning	59%	Low	NS
Arthritis	94%	High	**
Mobility issues	94%	High	**
Mental health issues	100%	High	**
Isolation	88%	High	**
Risks	94%	High	**
Carers intervention	71%	Moderate	NS
Quality of relationship	88%	High	**
Short-term help	88%	High	**
Cancer treatment	94%	High	**
Concern for mother	77%	Moderate	**
Accommodation issues	59%	Low	NS
Carers assessment	100%	High	**
Accommodation issues	88%	High	**
Social network	59%	Low	NS
Carers Services	71%	Moderate	NS
Residential Care	94%	High	**
Vulnerable adult	88%	High	**
Legal Arrangements	89%	High	**
Benefits Review	65%	Moderate	NS
Financial contributions	94%	High	**

Table 3. Case Study 3 Reliability Scores

Assessors were able to identify an average of 85% of the themes. Over 70% (n=17) of the themes were rated as having high reliability with a further 17% (n=4) having moderate reliability. This accounted for 88% of the themes, all scored as being reliable. Three quarters (75%) of the themes were scored as statistically significant. Three themes were not significant and require further amendment.



Graph 3. Percentage of identified themes for case study 3

The themes contained in case study 3 were assessed by 17 assessors. The number of correctly identified themes was calculated for each assessor. The percentage of successfully identified themes by assessors is displayed in graph 3. Averages of 69% of the themes were identified by the assessors. There was considerable variability in the scoring of the themes. The majority of the assessors identified between 61% - 70% of the themes in case study 3. A third of the sample identified more than 70% of the themes whilst the remaining two thirds were below 70%. This represents a considerable variability in scoring.

Qualitative Analysis

Each assessor participated in a short interview to discuss the usability of the complex NISAT. Overall the assessors felt the trained actors accurately portrayed real-life situations that assessors would often encounter as part of their day to day work schedule. The accuracy of the portrayal meant that the assessors could engage in the role play “as if it was the real thing”. This view was confirmed in a debriefing session with the actors

after the study was completed. The actors felt that the assessors were able to view each case study as “a real assessment”.

Each participant was asked three questions: what worked; what didn't work and how it could be improved. The latter two questions naturally lead on to each other and therefore the responses to both are merged together. The comments were transcribed and themed using content analysis. The themes helped inform the development of the assessment instrument.

Question 1. What worked in the NISAT?

Generally comments were positive regarding the Complex NISAT. The assessors felt that the information was useful and very comprehensive in capturing the ‘holistic’ person. The assessors felt the majority of the information regarding the person was captured in the Contact and Core NISAT and the Complex NISAT allowed the assessor the opportunity to use the interview to talk about a potential action plan (and discussions) with the person. One assessor felt “driven towards exploring her (the actor) choices”.

Questions 2 and 3. What didn't work and how could it be improved?

Assessors suggested minor modifications to the complex NISAT. The modifications were on two themes: the structure of the Complex NISAT, and the training of assessors.

The Structure of the Complex NISAT

- Assessors felt there was repetition in the Complex NISAT of information contained in the Core NISAT. This repetition was particularly evident in the initial sections of the instrument.
- The assessors felt that they would be better guided through the instrument with the inclusion of prompts within the separate sections. The prompts would help remind the assessors of the relevant issues to be explored in each section and would reduce the amount of information repetitively captured as a result of misinterpretation of the questions, for example, in triggering different types of

accommodation such as residential home, nursing home, or sheltered accommodation.

The views expressed were used to inform the further development of the complex NISAT.

Training Issues

- Assessors felt that there was a need for extensive training in the use of the tool. There was an expressed need for assessors to have an opportunity to discuss and ask questions regarding the terms and conditions used in the instrument (for example autonomy and choice).
- Assessors felt that their professional background strongly influenced the decision-making process regardless of their service specialty. This was also evident within the services specialty within each profession, such as mental health.

Conclusions

The findings confirm the view that case studies were effective in the development (Devitt et al 1997) and testing the reliability of an assessment instrument (Skre et al 1991, Marder et al 2003, Lilford et al 2007). The trained actors successfully portrayed the roles outlined in the case studies and the assessors engaged with them on a professional level. The assessors believed the use of standardized scenarios were accurate and representative of a typical assessment. The key findings were:

- The findings support the reliability of the complex NISAT. Overall there was a high level of reliability in identifying the main themes in each case study between assessors.
- There was variability in the assessors' ability to identify the themes/measures. Assessors were able to identify the correct response as determined by the tool designers but not all assessors were able to do so. The more complex the case study the more variability in the themes/measures reported.

- The qualitative findings highlight key areas for potential modification: the reduction of repetition, increase clarity of the Complex NISAT and add structure to the provision of evidence for complex support.
- Assessors expressed a desire for comprehensive training and clear guidance on the correct way to complete the Complex NISAT. This was reinforced by the variability between the scores in the findings. A standardized training program would ensure consistency across assessors in the completion of the tool. The assessment tool can assist the standardization of the assessment of older people, but only if imbedded in a standardized process of assessment.

The study confirmed the reliability of the Complex NISAT and the use of case studies in the development and testing of assessment tools, particularly in the healthcare setting. Issues to arise from the study were the variability in the ability of assessors to identify presenting patient problems; minor modifications to the Complex NISAT were required; a standardized approach to training and guidance in the use of the instrument is required.

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APPENDIX I

INTER-RATER RELIABILITY SCORES

Two researchers independently scored each of the Complex NISAT forms. The scoring matrix was generated for each assessor by both researchers. A cross tabulation was calculated for the classifications of the presence or absence of themes according to each researchers. The percentage of responses correctly replicated by both assessors was calculated and the significance of the relationship was calculated using kappa scores. Significance levels are indicated with a ** for probability 0.01 and * for probability 0.05.

CASE STUDY I

THEME	%	Statistical Significance
Client participation	100	**
Client Awareness	100	**
Decision making Facilities	100	**
Change in physical health	100	**
Mobility – getting upstairs	100	**
Mobility – get to toilet	94	**
Mobility – O2 therapy	94	**
Ability to conduct daily tasks	100	**
Changes in mental health	100	**
Isolation	100	**
Risks	69	NS
Carers Assessment	100	**
Accommodation issues	94	*
Assistance required with ADL's	88	**
Independence	88	**
Lack of family assistance	88	**
Friendships	81	*
Vulnerable Adult	92	*
Legal Financial Arrangements	100	**
Control over finance	88	**
Payments advice	75	NS
OVERALL PERCENTAGE	93%	

Table 4. Inter-rater reliability scores (percentage and kappa scores) for case study 1
All but two of the twenty one themes were accurately identified by both researchers at a statistically significant level.

CASE STUDY II

	%	Statistical Significance
Person participation	100	**
Person awareness	85	NS
Decision-making facilities	100	**
Personal Care	100	**
Incontinence	100	**
Risk of choking	100	**
Walking	100	**
Wandering	100	**
Changes in Mental health	88	NS
Fear and agitation with strangers	100	**
Reduced involvement	100	**
Aggression with others	100	**
Risks	100	**
Changes in physical health	87	*
Respite care	88	*
Caring issues	100	**
Quality of care	100	**
Assistive technologies	88	*
Carers Assessment	86	*
Living arrangements	87	*
Living changes	88	*
Support network	69	NS
Family connections	75	NS
Vulnerable adult	85	*
Legal Financial arrangements	100	**
Power of attorney	100	**
Benefits and payments	88	**
OVERALL PERCENTAGE	93%	

Table 5. Inter-rater reliability scores (percentage and kappa scores) for case study 2

Twenty seven themes were identified relating to case study 2. Twenty three of the twenty-seven themes were reliably identified by both researchers at a statistically significant level. Fifteen of the twenty-seven themes were reliably scored at 100% agreement between researchers. Four of the themes required clarification.

CASE STUDY III

	%	Statistical Significance
Person participation	100	**
Person awareness	100	**
Decision-making facilities	100	**
Sensory functioning	100	**
Arthritis	94	**
Mobility issues	100	**
Mental health issues	100	**
Isolation	94	*
Risks	100	**
Carers intervention	76	NS
Quality of relationship	100	**
Short-term help	100	**
Cancer treatment	100	**
Concern for mother	94	**
Accommodation issues	77	*
Carers assessment	100	**
Accommodation issues	88	*
Social network	94	**
Carers Services	82	*
Residential Care	88	*
Vulnerable adult	100	*
Legal Arrangements	89	**
Benefits Review	94	**
Financial contributions	94	**
OVERALL PERCENTAGE	94	

Table 6. Inter-rater reliability scores (percentage and kappa scores) for case study 3

Twenty three of the twenty-four themes had inter-rater reliability at a statistically significant level. Only 1 theme required further clarification and reassessment by the raters.

APPENDIX II

CASE STUDY 1 – MRS MARY BEATTIE

Mary has lived in the Belfast area throughout her life. Her mother was a seamstress and her father worked in Harland and Wolfe shipyard. She had a sister and a brother who have died. Mary was the only member of her family to go to university, where she qualified as a primary school teacher and taught until she retired at sixty. She is also an accomplished musician both on piano and clarinet and gave private lessons until symptoms of dementia prevented her from playing.

Mary and her husband, John have one son who lives in America. Up to three years ago they were able to visit him, but as Mary's dementia progressed this was no longer possible and John did not want to leave her.

Mary is 78 and has an advanced stage of dementia caused by Alzheimer's disease. Her husband first noticed that Mary was finding it difficult to remember day to day appointments and arrangements about six years ago. At around the same time Mary was finding it difficult to concentrate on her music and gave up teaching privately. Over the past year John has noticed a marked deterioration in her condition to the stage where she is now fully dependent on him in all aspects of her life

Mary had been admitted to hospital via her GP when she developed a urinary tract Infection. When her medical condition stabilized she was admitted to the Oakfield Centre to assess her health and social care needs to support her ability to return home.

She lives with John who is 72 years old and has arthritis and well-controlled heart disease. Mary was present during her assessment, but lost concentration easily, appeared to have difficulty finding the right words to express herself and became upset on several occasions throughout the assessment. When this happened the assessment was stopped and a more suitable time arranged when Mary appeared to be more lucid. Information

was also gathered from previous case notes, staff and from John who felt able to represent Mary's views as far as possible.

John reported that Mary can speak, but it has not been possible to have a normal conversation as she often cannot find the correct words, uses inappropriate words in the context of the conversation then becomes frustrated or will not engage in conversation at all. John is not sure how much she understands, but she has periods during the day when she is more lucid and at this time she can follow instructions and expresses emotion. He also thinks she recognizes him as when strangers speak to her she becomes agitated, but when he is beside her she calms down.

John reports that Mary had had no history of mental illness until her diagnosis of dementia. Following this her mood changed dramatically and she often told him that she felt life was not worth living. She had mood swings, alternating between appearing to be happy and then sad and can now often be aggressive. She had been treated with anti-depressants, but these were stopped when she could no longer express how she was feeling. John knows that she can be frustrated and appears to be sad or upset during lucid moments, but is not sure whether this is due to her dementia or depression.

Mary becomes disorientated in new surroundings and Mr. Beattie has noticed an increase in her confusion and agitation since her admission to hospital and he is keen that she will return home as quickly as possible. John feels that Mary no longer can make decisions or choices for herself, but he tries to make these relating to her views and wishes prior to her present condition. They had discussed her future wishes when she was diagnosed initially and had made a will and advance directive.

John describes their relationship as "very close" but became visibly upset when describing how it had changed to total dependence and her inability to talk to and recognize him. He is with her constantly although friends visit, but Mary no longer recognizes them. Crossroads provide him with 2 hours respite per week so that he can shop, but as Mary becomes so agitated when he leaves, he does not enjoy these breaks.

John and Mary live in a bungalow they have owned for 15 years.

Apart from dementia, Mary had had good health and had only had one previous admission for a hysterectomy in 1982. In the past 12 months she has had numerous kidney infections, but prior to this admission they had been treated by her GP. She has a disturbed sleep pattern and often attempts to get out of bed at night. She has been prescribed night sedation but this appears to make her more confused during the day.

She was incontinent of urine before admission, but is now occasionally doubly incontinent. She wears incontinence pads at all times.

She cannot chew as she has difficulty swallowing and will not keep her dentures in, therefore she needs to have a soft diet and have drinks thickened. During lucid periods she can be encouraged to feed herself, but in general John feeds her. John has not noticed any recent weight loss.

John orders, collects and administers Mary's tablets.

Mary can walk slowly with a Zimmer frame but needs constant supervision. John is worried she will try to get up and walk without help. She uses a wheelchair when outside and John is still able to drive although he has not taken her out in the car for over 6 months. John states he needs help to get her out and into bed and from the bed to the chair. A care worker helps him with this morning and night. Recently he has found this very difficult as his arthritis has become worse and Mary can sometimes be aggressive and will hit out at him when she is being moved. In between visits from the care worker he is finding it hard to lift her when she is incontinent or stand her up to help her walk. In hospital her ability to walk has deteriorated and she now requires two people to help her move from chair to chair or into bed. It is hoped that a period of rehabilitation will help her return to the level of mobility she had prior to admission. Adaptations have been made to the bungalow such as handrails in the bathroom and outside.

John attends to all Mary's personal care, assisted by a care worker in the morning and at night. He finds it too difficult to bath her, so has planned to install a walk-in shower. During the day he attends to all her toileting needs and prepares all food. John has bought adapted kitchen equipment and cutlery, but over the past 12 months Mary has not always been able to feed herself. John employs a cleaner once weekly, but does laundry himself

John feels he can manage financially and receives Attendance Allowance and Carer's Allowance in addition to his occupational and state pension. He would like information on Direct Payments as he feels he needs more help so that Mary can stay at home.

John is adamant that Mary should return home as soon as possible after her rehabilitation. He is worried that as her condition is deteriorating he will not be able to manage to give her the care she needs. He would also like to have 2 weeks respite care so that he can visit his son in America.

John has been offered and accepted a separate Carer's Assessment

CASE STUDY 2 – MRS EDITH SMYTH

Mrs. Edith Smyth is an eighty-six year old woman. She grew up on a Farm outside Ballymena and had 2 sisters and 3 brothers. One sister has dementia and is currently in a local nursing home. She has not been able to visit her sister for 6 months.

She married when she was 23 and was happily married until her husband's death 15 years ago. Her husband was a Methodist minister and she was involved in all church activities which she said was her part of the job. They traveled as missionaries to Africa before they had 2 daughters and settled in a parish in Belfast where they stayed until her husband retired. One of Edith's daughters lives in England and the other lives three miles away with her husband.

Edith was referred for assessment by her care worker and her daughter as recently two events had seriously threatened her ability to remain at home independently. A month ago Edith had been the victim of a burglary where two youths had locked her under the stairs while they stole a small amount of cash and personal belongings. Edith was not found until her care worker came to make her tea in the evening. Edith did not have any physical injuries, but following the incident her emotional health has rapidly deteriorated to the extent she feels that she can no longer stay at home as she feels vulnerable and lonely.

The following week her daughter, Mrs. Joan Love, was diagnosed with cancer and had been advised to start treatment immediately. Joan is her main care-giver. She works full-time as a Civil Servant, but is hoping to reduce her hours as she is finding it difficult to work and help her mother as her health deteriorates. On week days she helps her mother to get up, wash and dress and prepares her breakfast. She returns in the evening to prepare her supper and help her get ready for bed. A care worker visits Edith at lunch and tea-time to prepare a meal and help her to the toilet. At weekends Joan attends to all her needs. Both Edith and Joan are very worried about how Edith will manage during Joan's treatment, but Edith now wants to make long term plans for the future. Joan is keen for

Edith to move in with her and her husband, but Edith wants to make her own plans and does not want to “be a burden” to her daughter. She does not want Joan to have to worry about her care when she is having surgery and treatment.

Edith is a very articulate lady who has no problems speaking to or understanding others. She wears a hearing aid, glasses and uses a magnifying glass to read small print. She used to enjoy writing to friends abroad, but has painful hands due to arthritis and cannot hold a pen properly. This also means she relies on her daughter to complete any forms or other correspondence required and feels this has “taken away her privacy”. Joan reports that her mother’s hearing has become a lot worse and feels this may have contributed to the burglary as she would not have heard the youths breaking in.

Edith reports that her mood has changed recently. She used to feel optimistic about her future and enjoyed socializing as much as possible. Now she has lost her trust in strangers and feels anxious, worried all the time and gets upset very easily. A combination of deterioration in physical health and affects on her emotional health has caused Edith to become isolated and withdrawn from her friends and she seldom goes out.

Edith does not have any problems with memory or decision-making, however she will consult with her daughter when taking major life decisions.

Edith states she has a “really good” relationship with her daughters and is especially close to Joan, but is upset that she needs to rely on her so much for personal care. Her daughter in England visits at least yearly and she has two sons who also visit their grandmother.

Edith feels lonely and isolated in her home and thinks that if she moved to a new area or into alternative accommodation she may have more company of people her own age. She has two good friends she knows through her church who visit her weekly.

Edith currently lives in a two-storey council house. Her bedroom and bathroom are upstairs. Handrails have been placed in the bathroom, at the stairs and at the front and

back door. She feels that if she lived “on one level” she would be able to be more independent.

She is also scared in her home following the burglary, but this is only one factor as she feels that her physical health will not improve and a house with stairs is no longer suitable. She wants to discuss her housing options.

Her physical condition has deteriorated, with increased severe arthritic pain in her hands, back and hips, mild congestive heart failure and urinary incontinence. Pain keeps Edith awake at night and is especially bad in the morning. She takes her pain relief as prescribed, but feels it is no longer working. She feels she has become incontinent as she can't get to the toilet in time but does not want to have a commode put in her living room. She wears an incontinence pad at all times “just in case”.

Edith does not smoke, enjoys a “sherry now and again”, but cannot take exercise due to her arthritis. She relies on her daughter to collect and dispense her medication as she finds containers difficult to open.

Edith's ability to walk and move is severely affected by arthritis. She walks indoors very slowly with a stick and is worried she will fall if not supervised, so does not tend to walk when on her own. She had used a Zimmer frame when walking outside until her pain increased and now uses a wheelchair. Joan finds it difficult to help her in and out of a car. Edith needs someone to help her in and out of bed and to stand from a sitting position. She needs support to get up and down stairs or steps.

Joan helps her mother carry out all aspects of her personal care although Joan reports she will try to do as much as she can, but finds it difficult to use her hands and would not be able to reach her feet, tie laces or fasten buttons. Joan has arranged for a mobile hairdresser to come weekly to wash and set her mother's hair. Joan ensures she has any aids or equipment she needs to remain as independent as possible with personal care.

Edith can no longer prepare a meal or carry plates or cups. Joan prepares breakfast in the

morning, a care worker heats a cooked-chilled meal or one prepared by Joan at lunch-time and a light snack at tea-time. Joan prepares supper and a flask for drinks at night-time. Edith relies on her daughter to collect her pension from the post office and shop. Joan pays a cleaner privately to clean her mother's house weekly and do the laundry.

Edith enjoys playing cards and can still do this when her friends visit. She also has a daily paper delivered. She has requested a benefits review as she finds it difficult to manage financially on her husband's pension and Attendance Allowance and information on any costs associated with moving to residential or nursing care.

CASE STUDY 3 – MR MICHEAL MURPHY

Mr Michael Murphy is 68 years of age, has never married and was an only child. He worked in a cigarette- making factory from the age of 15 until medical retirement at the age of 50. He had always regretted having no formal qualifications and following retirement he took adult literacy classes. Since then has completed several courses through the Open University and hopes to finish his degree in the next year. His goal is to write about his life as a factory worker through the troubles as he says he “has met some characters in his time”.

Michael has had Emphysema for five years, but his symptoms have got worse over the past 6 months following a serious chest infection. This affects all aspects of his daily life. He finds it continually difficult to breathe, wheezes and coughs up sputum after exercise. He finds it difficult to sleep and needs pillows to sleep in an upright position. Recently his doctor has prescribed oxygen therapy for use at home after exercise and he can manage this himself. He also has inhalers and uses these as necessary and monitors his condition with a pulse oximeter. Michael also has high blood pressure which is well controlled by medication and was diagnosed with heart disease following an angina attack 12 months ago. A friend picks up his medication which is on a repeat prescription.

Michael smoked up to 40 cigarettes per day until 2 years ago, but has found them very hard to give up completely. He would now have “one or two” when he is at the social club, has had a drink or when he “is feeling low”. He explains that he smoked from an early age as cigarettes were given to workers as part of their wages before the harmful effects were known. Now he feels the company is partly to blame for his condition. Michael is currently attending the Pulmonary Assessment Clinic where he has a breathing retraining programme and a physiotherapist is working with him to improve his exercise tolerance. A Continuing Care Nurse visits every 2 weeks to take blood samples and monitor his condition. Michael is able to chew and swallow foods and is continent. Due to his Emphysema he needs annual influenza jabs but cannot take regular exercise. Michael is able to manage all aspects of his medication and self-administers his oxygen.

His only problem is collection of medication, but at present a friend is doing this for him. His prescription has not been changed for some time and he takes them as prescribed.

On assessment you find that Michael wheezes continually and relies heavily on his oxygen when talking or moving around for any length of time. He also appears quite cyanosed around his lips. He agreed to a dietetic assessment regarding his diet as he is not happy with the quality of food he eats at present.

Michael reports he has no problems with communication or sensory functioning, although he has lost some sense of taste and smell due to long-term smoking habits.

He thinks his mood has changed recently and he is becoming more easily annoyed and “grumpy”. His friends have also noticed these changes and this upsets Michael as he wants to maintain the good relationships. He has and has been told that mood changes can be due to a lack of oxygen which will get worse as his physical condition deteriorates. He says he does feel depressed about his deterioration in health but doesn't want to visit his GP as he can cope with this. He has not had any previous history of mental health problems or treatment. He also sometimes finds it hard to concentrate on his coursework and is worried he will not be able to continue to study until he finishes his degree.

Michael has no immediate family but has a close network of friends who he met every Friday night in the social club linked to the cigarette factory. He is finding it harder to get to this now as he can only walk short distances and needs oxygen after exercise, but takes a taxi to the club once a month. He has always lived in the area and so enjoyed walking to the shops as he would often meet people he knew well, but now relies on the internet to buy food and clothes which are then delivered. He feels he is becoming very isolated and lonely. He uses his computer to speak to others on chat lines and enjoys reading and watching television.

Michael lives alone in an upstairs, housing executive flat and is happy with the arrangement but finds the stairs to the flat more difficult to climb. He feels the layout of his flat suits him as he does not have far to go for everything he needs. He has applied for a ground floor flat, but as he wants to remain in the same area he may be waiting for some time for a vacancy.

Michael is able to walk and move independently but his condition is deteriorating and he often struggles as he becomes short of breath. He finds climbing stairs the most difficult and as a result avoids going out very often, both because of the stairs and he does not want to be away from his oxygen supply. He can use public transport, but does not drive a car.

Michael was advised to contact social services by his GP as he is finding it very difficult to dress and undress and get in and out of a bath without extreme shortness of breath. He feels that although he is upset and embarrassed to be asking for help for such personal tasks, he is starting to neglect his hygiene as it is too much effort. He can manage to shave and brush his teeth independently but struggles with other tasks. He is able to choose and adjust clothing and use buttons and zips. He tires very easily and this also affects how he makes meals as he cannot stand for long periods of time and is often dizzy and weak. He is currently eating ready meals or cold snacks as they take less time to prepare. He also orders “carry outs” when he can afford them but feels he is putting on weight as a result. He can carry plates and cups and use cutlery. He finds it too difficult to clean the house or do his laundry and this is very upsetting to him. He has to rely on a friend to take his washing to the launderette. He is able to shop and bank on the internet as he can’t walk to the shops. He is currently on the Community Occupational Health waiting list for home assessment and hopes he will be given equipment to make kitchen tasks possible.

Michael does not work in paid employment at present, but is studying for an Open University degree. He watches television and listens to music as well as using a chat-room for company.

Michael has recently had a benefit review and currently receives Attendance Allowance, a medical retirement pension and state pension. He would be interested in details about Direct Payments and has complete control over his financial affairs.