

# **Evaluation Report**

## **NICAN Brief Holistic Assessment Tool Pilot Project**

**May 2010**

### **Authors**

**Dr Sonja McIlfatrick**

**Reader, University of Ulster/ AD (Nursing  
Research & Development, NHST**

**Ms Felicity Hasson**

**Senior Lecturer, Institute of Nursing Research,  
University of Ulster**

**Dr Marie Truesdale-Kennedy**

**Research Fellow, Institute of Nursing  
Research, University of Ulster**

## **ACKNOWLEDGEMENTS**

The authors would like to thank the Health and Social Care Board, the Modernisation and Reform of Palliative Care Steering Group and the NICaN Supportive and Palliative Care Network Project Team led by Ms Sue Curry, Hospice Manager Marie Curie and Mrs. Heather Weir, Regional Lead for Service Improvement in Palliative Care for their support of this study. For their active participation to enable the study, the authors would like to thank each Trust and the individual Trust champions and assessors who took part in the audit.

Thank you.

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## EXECUTIVE SUMMARY

Following widespread consultation the NICaN Brief Holistic Assessment Tool was developed by the Northern Ireland Cancer Network (NICaN) Supportive and Palliative Care Guidelines subgroup, under the joint project leadership of Sue Curry, Marie Curie Hospice and Heather Weir, Northern Ireland Hospice over a period of 2 years from 2007. The tool has been adapted from the NHS National Cancer Action Team 'Holistic Common Assessment of Supportive and Palliative Care needs for Adults with Cancer (2007)' and mapped with the Northern Ireland Single Assessment Tool (NISAT). The tool was developed to ensure patients' will be assessed holistically by a competent health care professional throughout their disease trajectory, therefore ensuring that their physical, social, psychological and spiritual needs are identified and onward referral made to the most appropriate member of the multi disciplinary team and/or the specialist palliative care team.

In September 2009 a regional pilot project of the NICaN Brief Holistic Assessment Tool was undertaken with consent from all Trusts, this was completed in November 2009. The University of Ulster were commissioned to audit and evaluate the tool against the Generic Palliative Care Standard 1 using a multi-phased approach including a overview of the theoretical literature, analysis of piloted holistic assessment tool (n=132) discussion groups (n=10) and assessor feedback questionnaire (n=24).

### Findings:

The findings obtained indicate the following:

1. The tool did appear to enable health professionals to identify and gain an understanding of the needs of the patients, specifically in relation to the patients' physical health care needs. Patients social and occupational wellbeing needs were under recorded, which could be attributed to the fact that the majority of assessors were nurses and were perhaps not practising holistically but focusing on physical aspects.
2. A number of discrepancies appeared to exist within the documented responses for the piloted NICAN Brief Holistic Assessment tool. For example despite *Mental Health and Emotional Wellbeing* being identified only 15 responses considered an onward referral to psychology. Such findings however must be read with caution as they may be related to the perceived gaps within the tool in terms of documenting actions taken or reflect a lack of knowledge among participants relating to onward referral systems.

Whilst analysis of the tool documentation revealed that 59 (68.8%) responses had discussed preferred priorities of care with the patient, focus groups comments revealed participants had concerns around discussing sensitive issues with patients and that the experience of the assessor had a significant impact on the overall assessment. Therefore, questions exist around the extent to which preferred priorities of care and future planning are happening in practice and the availability of training to implement holistic assessment tools into practice.

3. The use of clinical prognostic indicators was ambiguous. The findings from the first phase of the evaluation indicated that over half of responses (n=50 57.5%) had considered a prognostic clinical indicator for the patient as an action. However, both the focus groups and the assessor evaluation questionnaire indicated that there are questions around health care professional's knowledge about clinical prognostic indicators and perceived usefulness in practice.

4. In terms of evaluation of the tool both positive and negative aspects were noted.
  - a. *Positive aspects:* it was easy to understand; not considered time consuming; the use of prompts triggered further assessment when required, it captured the needs of individuals, it was comprehensive and encouraged more teamwork.
  - b. *Negative aspects:* it was considered to be repetitive in that some assessors considered that information gathered had already been documented through the use of other tools and measures; the layout was not always clear and some areas required further explanation; the experience of assessors and training were issues that required consideration.
5. It was recommended that the implementation of the tool be linked with the current assessment tool NISAT rather than a standalone assessment tool.

### **Discussion**

Holistic assessment is a complex, integrated-ongoing process; challenges therefore persist in delivering holistic assessment in practice. Assessment tools are merely an aid in the assessment process, not as a panacea for all assessment problems. Thus whatever methodology is used for assessing needs, staff need to be appropriately trained in their use to be able to complete such assessments competently and with sensitivity. The findings of this evaluation, however, raised questions around whether practitioners are practising holistically, not only for the health care professional but also for patients and families. Moreover whilst the inclusion of clinical prognostic indicators are recommended (Maltoni et al 2005) results highlight that implementing and facilitating this aspect in practice remain.

A recurrent message from all stages of the evaluation was a view that holistic assessment was being carried out already and that the completion of this tool was duplication and repetition of existing assessment procedures. Similar barriers to holistic assessment have been noted within other areas in the UK (Morris, 2009). It is therefore important to consider how this tool could link with other pre-existing tools to help allay this sense of duplication and provide more effective integrated care. A possible mechanism for this could be the inclusion of the NICAN Brief Holistic Assessment tool within the existing comprehensive Northern Ireland Single Assessment Tool (NISAT).

Evaluation of the tool revealed that it was viewed as transferable across disease groups and was not too onerous in terms of time required to complete it, however the need to improve its structure and layout were identified. A specific aspect was the lack of focus on action required prompting participants to recommend a section within the tool detailing confirmation on actions undertaken and for the tool to be signed and dated in line with correct documentation procedures. This would assist the holistic assessment to form the basis of an individualized patient-centred care plan; agreed with the patient and aimed at planning and delivering care that best meets their circumstances and requirements.

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## 1.0 Background

The NICaN Brief Holistic Assessment Tool was developed by the Northern Ireland Cancer Network (NICaN) Supportive and Palliative Care Guidelines subgroup, under the joint project leadership of Sue Curry, Marie Curie Hospice and Heather Weir, Northern Ireland Hospice over a period of 2 years from 2007.

The tool has been adapted from the NHS National Cancer Action Team 'Holistic Common Assessment of Supportive and Palliative Care needs for Adults with Cancer (2007)' and mapped with the Northern Ireland Single Assessment Tool (NISAT). During its development it was modified following two consultation processes which captured feedback from each discipline in the multi disciplinary team, working in both generalist and specialist areas, caring for people with cancer, and other chronic conditions requiring palliative and end of life care.

The overall purpose of the project was that:

**Patients' will be assessed holistically by a competent health care professional throughout their disease trajectory, therefore ensuring that their physical, social, psychological and spiritual needs are identified and onward referral made to the most appropriate member of the multi disciplinary team and/or the specialist palliative care team.**

### Specific Objectives

1. To improve person centred holistic assessment in practice.
2. To promote holistic assessment within multidisciplinary teams at key stages in the patient journey
3. To design, test and validate a meaningful tool which can be utilised across a range of health care settings.
4. To enable health care professionals to acknowledge successful or challenging management of an individual patients current care plan and enable appropriate onward referral to the multidisciplinary team and/or to specialist palliative care team, if required.
5. To apply the holistic assessment across a range of advanced non curative conditions.

In September 2009 a regional pilot project of the NICaN Brief Holistic Assessment Tool was undertaken with consent from all Trusts, this was completed in November 2009. Pilot sites were chosen from across the region which reflected both primary and secondary care teams caring for people with a life limiting condition. In December 2009 the University of Ulster was commissioned to undertake an external evaluation of the tool.

## 1.1 Summary of the evaluation methodology

The University of Ulster external evaluation team consulted and agreed with the NICaN project leads that this project was considered as fitting the criteria for audit and was measured against the Generic Palliative Care Standard 1:

*Health and social care professionals, in consultation with the patient, will identify, assess and communicate the unique supportive, palliative and end of life care needs of that person, their caregiver/s and family.*

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## **Methodology**

A mixed method research design was employed to address the research objectives, and comprised of four stages, including:

- Stage 1: An overview of the theoretical literature with regard to holistic assessment and tools for palliative care to place the study in current context and facilitate comparison of findings.
- Stage 2: Analysis of piloted holistic assessment tool (n=132) and assessors appraisal of instrument
- Stage 3: Discussion groups with pilot leads and assessors (n=10) to explore usability, applicability and potential service barriers and facilitators towards implementation.
- Stage 4: Assessor questionnaire (n=24) evaluating the structure, format and presentation of the holistic tool.

## **2.0: Literature Review**

A review of the literature was undertaken focusing around three themes.

1. Holistic Assessment
2. Palliative Care Holistic Assessment Tools
3. Barriers to use of tools

### **Introduction**

Palliative and end-of-life care is facing a period of unprecedented change influenced by policy frameworks, changing patterns of care and disease (NISRA, 2009), ageing population projections (DHSSPS, 2009) and new knowledge (National Institute of Clinical Excellence (NICE). An increasing emphasis on quality end-of-life care has evolved regionally and nationally following government reports showing that patients and carers want choice over care at the end of life (Department of Health (DH), 2003; NICE, 2004; DH, 2006) and the need to promote such choice and quality of care has been reiterated in the Living Matters: Dying Matter A Strategy for Palliative and End of Life Care in Northern Ireland (DHSSPS, 2010).

Delivering a person-centred approach to palliative care requires a holistic approach to planning, co-ordinating and delivering high quality reliable care. Therefore a careful assessment of patients' needs is central to the process of providing care. All palliative and end of life care is planned around the assessed needs of the patient, their family and carers and is responsive to their expressed preferences. Although evidence suggests that patients want health care professionals to ask about their physical and emotional needs, it can be argued that current assessment is not always systematic and professionals frequently do not capture accurately what patients are trying to tell them (Brown et al., 2001). The need for more effective and structured assessment of patients' needs and multidisciplinary involvement or ownership of care plans has been identified as necessary (DH, 2000; National Council for Palliative Care (NCPC), 2000, NICE, 2004). The Living Matters: Dying Matters Strategy for Palliative & End of Life Care describes that, a holistic assessment of need goes beyond the physical needs of the individual and includes the social, mental health, emotional and spiritual well-being of the patient, their family and carers, as well as recognising other issues that might impinge on wellbeing, such as financial and legal concerns (DHSSPS, 2010). The English National End of Life Programme in its guidance for Holistic Common Assessment (Richardson, 2010) suggests that people at the end of life frequently have highly complex and wide ranging needs, therefore managers and practitioners are required to adopt a unified

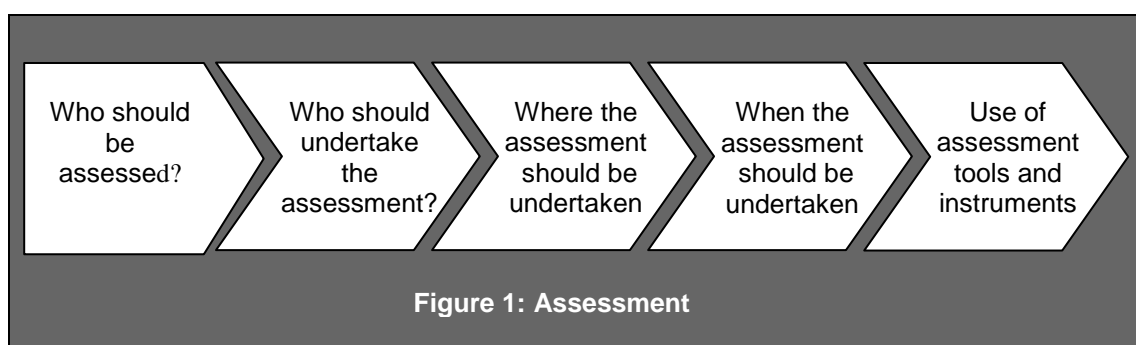
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approach to assessment and ensure effective processes for holistic assessment exist in order to minimize repeated unnecessary assessment in the final phase of life.

### **Holistic assessment process**

Assessment is about collecting information on a person's needs and circumstances and making sense of that information to identify and decide what support or treatment to offer (Slater & McCormack, 2005; Richardson et al., 2007). It is a complex, integrated process comprised of many elements, with the person and family/carer at the centre of the process. Therefore, the assessment process is seen as a basic principle of person-centredness (DH, 2001). The use of an assessment tool is an important strand of the assessment process but the holistic nature of the assessment process is based on multi-sourcing of information (Slater & McCormick, 2005). Central to this is the individual's viewpoint which is paramount, followed by their carers, health professionals, social services and other relevant organisations. An assessment tool should enable health care professionals to understand the specific needs patients would like met through professional care, at clearly defined points in the patient pathway (Richardson et al., 2007).

Individual patient needs assessment is seen as a continual iterative process. It begins with the first consultation at the beginning of an episode of care between an individual and a health or social care professional. It continues through a series of any number of consultations until care needs are met and no longer required. It encompasses all forms of assessment from any professional or patient perspective in any care setting. The assessment process needs to take into account the individuals circumstances, identifying cultural, religious and race differences (DH, 2001). The key areas for consideration during the assessment process are summarised in Figure 1. These areas include:



*(Source: Adapted from King's College 2007)*

#### ***Who should be assessed?***

All patients who have been recognised to be approaching the end of their life should be offered a holistic common assessment of their supportive and palliative care needs.

#### ***When the assessment should be undertaken***

All individuals should have a full assessment of their personal needs and the needs of their carer's during key stages of their disease trajectory (NICE, 2004; DHSSPS, 2010). Therefore continuous holistic assessment of palliative and end of life care need is crucial and should be viewed as an integral part of the care. As recommended in the National End of Life Care Programme (DH, 2010a) structured assessments should be undertaken at each of the key points or triggers in the patient pathway (see Figure 2).

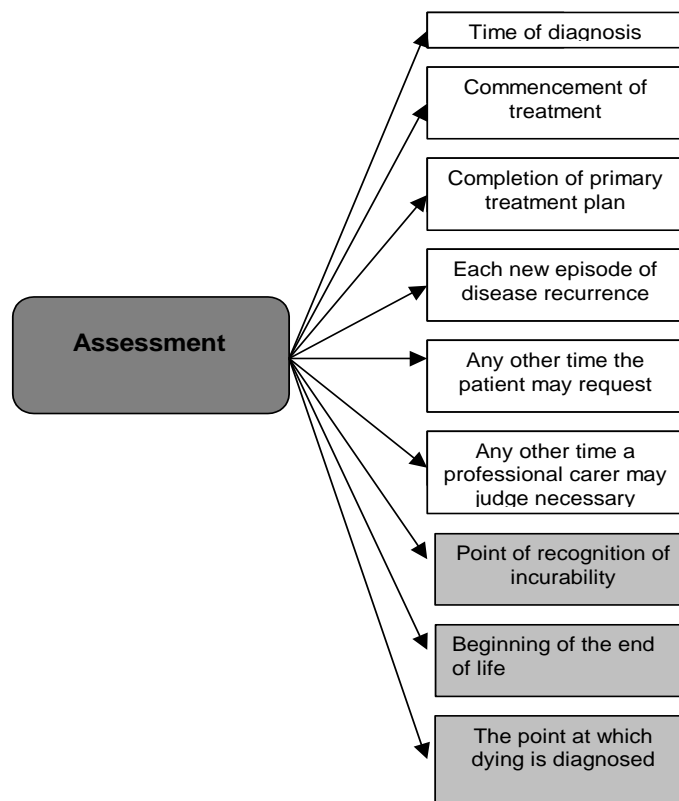
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### ***Who should undertake the assessment?***

It is recommended that patients be assigned a key worker at each stage of their care pathway to undertake the assessment. The selection of the 'assessor' should be subject to the following criteria in terms of an agreed level of competence; taking cognisance of patient preferences for communicating with particular professionals and have access to up to date information about local service providers, referral criteria and support service. The assessor role in coordinating care is a key role within the National End of Life Care Programme (DH, 2010a).

### ***Where the assessment should be undertaken?***

The place of assessment will be determined by the person's care setting and where the key point for triggering an assessment occurs i.e. in a hospital, in the community, in a voluntary or independent sector provider or in any other place.



**Fig 2: Key stages of assessment**

### **Use of assessment tools and instruments**

The holistic assessment of a patient's need can be supported through the use of assessment tools. Regular review and consistent recording of needs are essential, especially when the patient's or their family or carers' wishes or circumstances change (King's College, 2007).

Key principles of carrying out a holistic assessment should be patient 'concerns-led', (National End of Life Care Programme, DH, 2010a).

- Helping patients to self assess their own needs should be central to the process
- The patient remains at the heart of the process therefore the assessment process should promote control and choice whilst remaining flexible enough to respond to the individual's changing circumstances.

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- Patient consent is necessary to the assessment process and for sharing the assessment summary with the multi disciplinary team and other specialist services, if required.
  - Professionals undertaking the assessment should have reached an agreed level of competence in key aspects of assessment.
  - Patient preferences for communicating with particular professionals, their family and friends, should be taken into account.

### **Palliative and End of Life Care Holistic Assessment Tools**

Central to the assessment process is the assessment tool. In a review of assessment tools currently available for patient assessment in cancer care Richardson et al., (2007) identified 15 tools for the systematic assessment of individual patients' needs for help, care or support, to be used for clinical purposes. Table 1 summarises these assessment tools and their properties used within the UK as identified by Richardson et al. (2007), in addition to some recently developed Northern Irish specific tools. The majority of tools developed to date focus on cancer patients, however it is widely acknowledged that end of life and palliative care relates to both malignant and non-malignant conditions.

The tools outlined in Table 1 focus on the health status of patients, which provide information on particular symptoms or problems, personal resources, and sources of support, care preferences and satisfaction with care. The SPARC and Concerns Checklist, developed to address the needs of specific groups of patients such as those with advanced cancer, help guide referral to palliative care and are considered as aids for clinicians to enable them to recognise and document supportive care needs as an adjunct to consultation.

Most of these tools were developed for use in an outpatient clinic with the exception of the SPARC and Symptoms and Concerns checklist both of which can be used in a primary care setting (Richardson et al., 2007). The most comprehensive instruments with respect to health status (covering some degree of the full range of needs related to health status) include Symptoms and Concerns checklist, SPARC and the most recently developed tools devised for use in Northern Ireland NISAT and NICaN Holistic Palliative Care Assessment Tool. The NICE Guidelines (2004) and the National End of Life Care Programme Guidance (DH, 2010b) identified holistic assessment as one of the ten key priority areas and includes considerations for administering assessment tools.

Tool	Purpose (Population)	Domains
Concerns checklist (Harrison et al., 1994; Heaven & Maguire, 1996;1997;1998)	To elicit and register main concerns of patient (various groups and hospice patients)	<ul style="list-style-type: none"> <li>▪ Illness</li> <li>▪ Practical</li> <li>▪ Psychological</li> </ul>
Problems checklist (Cull et al., 1995; Wright et al., 2001)	To assess the prevalence and severity of psychosocial problems experienced by the cancer patients	<ul style="list-style-type: none"> <li>▪ Daily living</li> <li>▪ Relationships</li> <li>▪ Economics</li> <li>▪ Emotions</li> </ul>
Sheffield profile for assessment and referral to care (SPARC) (Ahmedzai et al., 2004; Ahmed et al., 2004; Bestall et al., 2004)	To assess the distress caused by advanced illness and to screen symptoms and problems to guide referrals to specialist and palliative care (for patients with advanced illness)	<ul style="list-style-type: none"> <li>▪ Communication and information</li> <li>▪ Physical symptoms</li> <li>▪ Psychological issues</li> <li>▪ Religious and spiritual issues</li> <li>▪ Independence and activity</li> <li>▪ Family and social issues</li> <li>▪ Treatment issues</li> </ul>
Symptoms and concerns checklist (Butters et al., 2005; Lidstone et al., 2003)	To determine prevalence and severity of symptoms and concerns in routine practice as adjuvant to clinical assessment (of patients with advanced cancer)	<ul style="list-style-type: none"> <li>▪ Physical symptoms</li> <li>▪ Cognitive/psychological</li> <li>▪ Other concerns</li> <li>▪ Patient defined</li> </ul>
GSF PEPSI COLA Aide Memoir Holistic Checklist (DH, 2005)	Intended to complement the Medical Discharge Summary to document aspects of care unique to the needs of palliative patients	<ul style="list-style-type: none"> <li>▪ Physical symptoms</li> <li>▪ Emotional</li> <li>▪ Personal, social support &amp; information/ communication</li> <li>▪ Control</li> <li>▪ Out of hours</li> <li>▪ Late and after death</li> </ul>
Northern Ireland Single Assessment Tool (NISAT)	To assess the health needs of older people in Northern Ireland	<ul style="list-style-type: none"> <li>▪ All aspects of a persons life</li> <li>▪ Abilities</li> </ul>
NICaN Holistic Palliative Care Assessment Tool (currently piloted)	To holistically assess the needs of patients throughout their disease trajectory and ensure onward referral is made to the most appropriate multidisciplinary team.	<ul style="list-style-type: none"> <li>▪ Physical health</li> <li>▪ Social and occupational well-being</li> <li>▪ Mental health and emotional well-being</li> <li>▪ Family and close relationships</li> <li>▪ Spiritual well-being</li> <li>▪ Awareness and decision making</li> <li>▪ Prognostic clinical indicators</li> </ul>

**Table 1: Summary of Palliative and End of Life Care Tools in the UK**

### **Northern Ireland Context of Person Centered Holistic Assessment Tool**

In 2007 the Department of Health commissioned the development of the Northern Ireland Single Assessment Tool (NISAT) to improve the assessment experience for older people and staff. This assessment tool was designed to capture the information required for holistic, person-centred assessment of the health and social care needs of the older person in Northern Ireland. NISAT aims to focus on a person's abilities and strengths rather than their disabilities. While other regions across the UK have developed Single Assessment Processes, they have chosen to use "off the shelf" tools, with different regions using different tools.

In comparison with other assessment tools this single assessment tool helps to overcome some of the problems noted in using other tools such as the time and paperwork required for assessment; variations in depth and content of assessment across the province and the need to be person-focused rather than service-focused.

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In addition it also helps to respond to inadequate information received between professions and settings and difficulties sharing information with others.

Key features of NISAT:

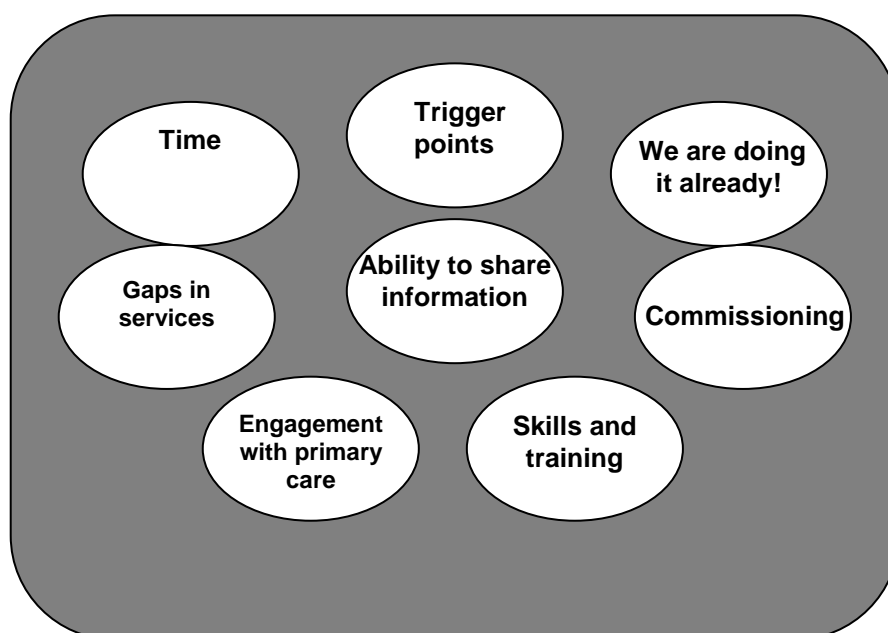
- Its multidisciplinary
- It covers all aspects of a persons life
- Levels help keep assessment appropriate to need
- Information gathered at each level does not need to be gathered again
- Each level informs the next
- It does not replace specialist assessment
- Concentrates on ability, not disability
- It will capture everyone's perspective and views, including the older person
- It structures assessment
- It is designed around domains and uses prompts to clarify questions
- Replaces care management documentation
- It is well researched

The use of NISAT will build on existing good practice.

### **Barriers to implementation of tools**

McCormack et al (2006) noted that for an assessment tool to succeed it must be facilitated by receptive procedures and processes and embedded in an organisational culture. Therefore the development of the instrument must pay cognisance to the organisational culture within which it is to be used. Glover (2005) suggested that the development of an assessment tool is seen as easier than challenging the values underpinning the assessment process itself.

A number of barriers have been identified in the use of assessment tools (see Figure 3 for summary). Specific barriers include organisational and instrument related aspects. Organisational Factors include: time to undertake assessments; lack of integration; ability to share information; concerns about gaps in services and commissioning. Instrument related factors include: perceptions of assessment, comprehensiveness of instrument; instrument content and training issues for assessors (National Cancer Action Team, 2009).



**Figure 3: Barriers to using assessment tools**

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In summary, with people now living longer than ever before and the increased likelihood of chronic conditions affecting our health and general well-being good quality palliative and end of life care is imperative. Assessment of patients' needs is fundamental to understanding their experiences and developing an effective care response. The activity serves to direct professionals to whom and how they might focus their care efforts. The development of holistic assessment tools and guidance for their use in identifying the patients' physical, social, mental health, emotional and spiritual well-being is one of the main contributing factors to planning and delivering such care.

### 3.0: Analytic review of the piloted NiCaN Brief Holistic Assessment Tool

#### Introduction

This section is comprised of two elements: the presentation of quantitative data gathered from completed patient holistic assessments and health professionals' evaluation of the use of the tool at that time. It needs to be acknowledged that the information presented is based on what was documented on the completed assessments and no other inferences can be made from this information. Assessors were asked to identify risk factors, record interventions and outlined what action to be considered in light of assessment responses (see appendix 1 for tool). A description of the sample is given including frequencies, percentages, means and standard deviations (SD's) on various descriptive variables.

#### Part 1: Piloted Holistic Assessment Data

An overall total of 132 patients were assessed holistically by a qualified health care professional. Of these the majority of patients (n=45; 34%) were from the Belfast Trust, with 38 (29%) patients from the Western Trust, 23 (17%) from the Northern Trust, 13 (10%) from the South Eastern Trust, and 13 (10%) patients from the Southern Trust area. Figure 4 below diagrammatically presents the percentages of all the patients in each of the five trust areas.

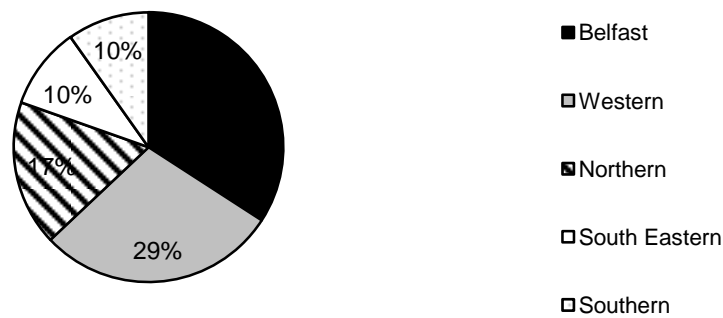


Figure 4: Percentage of patients within each Trust area

### Health care section

Overall there were 12 documented area sections in which patients were assessed within. These are presented in Table 2.

Area section	Frequency	Percentage
Primary care	39	29.5
Cancer services	16	12.1
Respiratory specialist services	12	9.1
Community	12	9.1
Medical ward	12	9.1
Radiotherapy	10	7.6
Lung specialists	8	6.1
Specialist Palliative Care Team	8	6.1
Chronic disease management team	5	3.8
Outpatients Haematology	4	3.0
Renal	3	2.3
Palliative Care Ward	3	2.3
Total	132	100

Table 2: Area sections

As detailed in Table 2 nearly two fifths of patients assessed (n=51; 38.6%) were from primary care and community settings followed by cancer services (n=16; 12.1%) with the remaining area sections listed comprising less than 10% of the overall patients assessed.

### Identification of patients needs

In order to help understand the needs of the patients a number of domains were assessed including: physical health, social and occupational well-being, mental health and emotional well-being and adjusting to the illness, family and close relationships, spiritual well-being, awareness and decision making and prognostic clinical indicators. Descriptive summaries of each of these domains are subsequently presented.

### Physical health

The majority of patients assessed were identified as having a diagnosis of cancer (n=67; 50.8%), as illustrated in Figure 5.

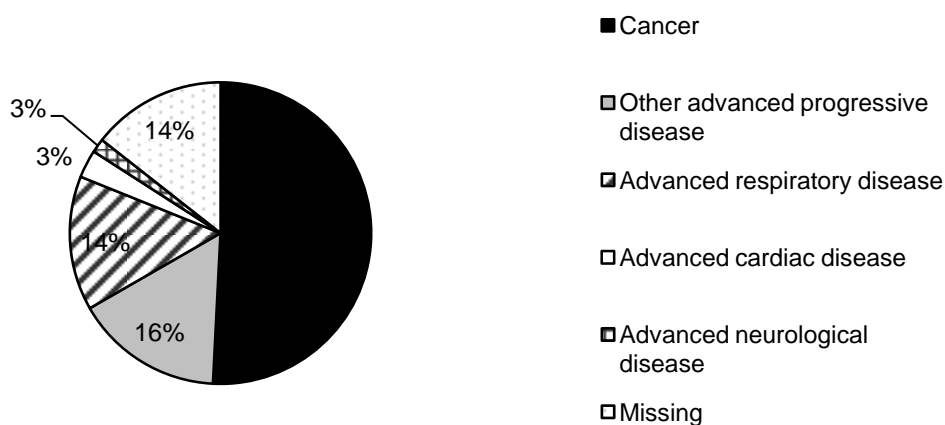


Figure 5: Diagnosis of patients assessed

The patients were assessed on various physical health issues, such as pain or other symptoms associated with the patient's illness, see table 3. In terms of successful management of patients' physical health 60 (45.5%) responses reported 'yes' that a comprehensive pain assessment or other appropriate assessment had been completed. Eighty-seven (66%) responses reported that 'yes' the health professional had considered seeking advice and/or formal referral to other specialist professional.

Other symptoms	Frequency	Percentage
Physically weak	53	40.2
Feeling tired more than usual	47	35.6
Breathing problems	43	32.6
Mobility issues	42	31.8
Easily exhausted	36	27.3
Eating and drinking/nutrition	29	22
Sleep disturbance	27	20.5
Urinary or bowel problems	25	18.9
Pain	25	18.9
Loss of function	19	14.4
Balance problems	17	12.9
Nausea or vomiting	17	12.9
Swollen limbs	16	12.1
Skin integrity compromised	14	10.6
Coughing or choking	13	9.8
Confusion or disorientation	13	9.8
Oral discomfort	8	6.1
Swallowing	8	6.1
Hearing or communication	6	4.5

**Table 3: Number of patients with other symptoms of physical health**

### **Social and occupational well-being**

In terms of the social and occupational well-being of patients, health professionals were asked to assess whether or not a patient had issues with work and finance which were causing distress and/or are unresolved despite interventions. It was found that less than 20% (n=26; 19.7%) of responses reported 'yes' that the patient had work issues. Specific work and planning for the future are outlined in Table 4.

Work issues	Frequency	Percentage
Managing at home/community re personal care	26	19.7
Long term financial concerns for family	20	15.2
Mental capacity	14	10.6
Immediate financial concerns	8	6.1
Advance directive/ living will	5	3.8
Making a will	4	3.0
Inability to work	4	3.0
Power of attorney	4	3.0
Concerning employer	3	2.3
Workplace relations/ workmates	3	2.3

**Table 4: Social and occupational well-being issues**

Health professionals were asked to assess whether or not the patients required onward referral namely 'Is there a social worker involved?' and 'Have you considered seeking advice from and/or formal referral to other specialist professional?' Of those who completed these questions it was reported 'yes' there was a social worker involved for more than half of the patients assessed (n=74, 58.7%) and 'yes' they had considered seeking advice from and/or formal referral to another specialist professional (n=50; 48.1%).

### **Mental health and emotional well-being**

Information was obtained in relation to the patient's psychological needs. Health professionals recorded 'yes' or 'no' to whether or not patients presented with a variety of mental health issues to determine if there is a pre-existing psychological condition or history of mental health issues requiring professional support. Table 5 presents the frequencies and percentages of a range of mental health issues of patients.

<b>Mental health issues</b>	<b>Frequency</b>	<b>Percentage</b>
Anxiety	36	27.3
Feeling down	31	23.5
Panicky	22	16.7
Fear	20	15.2
Depressed	17	12.9
Restlessness	13	9.8
Hopelessness	9	6.8
Body image difficulties	6	4.5
Sexual difficulties	2	1.5

**Table 5: Frequency and percentage of mental health risk factors**

### **Adjusting to the illness**

In order to identify patient's psychological needs an assessment was made on the patient's adjustment to their illness. It was reported 'yes' that twenty-one (15.9%) patients had knowledge and understanding of the disease and prognosis, 8 (6.1%) were reported to have experienced sleep disturbances, 7 (5.3%) were adjusting to losses, 5 (3.8%) were reported as having unresolved concerns, and 5 (3.8%) had suffered from exhaustion.

Onward referral for psychology had been made for 13.8% (n=15) of those patients of whom this question was completed for. It was reported that 43 (32.6%) responses considered seeking advice from and/or formal referral to other specialist professional. Data was missing for 34 (n=25.8%).

### **Family and close relationships**

Health professionals were asked to assess whether or not patients had any issues or concerns in relation to their family and close relationships about their illness. Issues and concerns that health professionals identified are presented in Table 6. Health professionals were asked to report on whether or not a carer assessment was required. Only one fifth (n=28) of those who responded reported 'yes'.

Issues and concerns	Frequency	Percentage
Needs related to partner	16	12.1
Family dynamics	12	9.1
Unable to discuss issues of concern with partner/spouse	9	6.8
Conflict present	8	6.1
Needs related to patients children	5	3.8
Intimacy/sexual difficulties	2	1.5

**Table 6: Family and close relationship issues and concerns**

### **Spiritual well-being**

Patient spiritual well-being needs were identified by health professionals responding 'yes' or 'no' to specific issues relating to spiritual well-being which are causing distress to the patient. Risk factors of spiritual well-being experienced by patients are highlighted in Table 7 below.

Issues relating to spiritual well-being	Frequency	Percentage
Anxiety	12	9.1
Fear	12	9.1
Impact of illness on faith/belief	9	6.8
Hopelessness	9	6.8
Life goals	9	6.8
Important occasions	8	6.1
Ethical issues including treatment and end of life care	6	4.5
Issues related to culture or ethnic background e.g. diet, medicines, treatment product	3	2.3

**Table 7: Frequency and percentage of issues relating to spiritual well-being**

It can be noted that over 50% of the completed assessments identified issues relating to spiritual wellbeing (n=68; 51.5%). This finding needs to be considered in light of the actions to be considered where it was noted, that where data was available, only sixteen (17.2%) responses revealed 'yes' there was immediate cultural/religious requirements.

### **Awareness and decision-making**

Health professionals were prompted to assess preferences and priorities for future care. Responses revealed that 15 (11.4%) discussed family/carer support; 12 (9.15%) were prompted to talk about place of care; 11 (8.3%) raised the issue of setting realistic goals; 7 (5.3%) reviewed resources available and only 2 (3%) discussed things important to the patient.

However when asked about appropriate advice or onward referral being given responses reveal that two-thirds (n=62 66.7%) recorded this action. In total 59 (68.8%) of the responses revealed that preferred priorities of care had indeed been discussed as an action.

### **Prognostic clinical indicators**

Responses revealed that only 2 (1.5%) of responses reported that they used the prompt to apply clinical prognostic indicators to estimate the disease status for patients. However over half of responses (n=50 57.5%) had considered a prognostic clinical indicator for the patient as an action to be considered.

## Part 2: Health Professionals Reported Evaluation of Tool

### Ease of Use, Comprehensive and Reliability of Tool

To assist in the evaluation of the brief holistic assessment, health professionals were asked to complete information on the ease of use, comprehension, reliability of tool, whether or not it prompted referral/s to other professionals and overall completion time. In addition they were given the opportunity to add additional comments if they chose too. Eighty-four percent (n=100) out of an overall total of 119 assessments reported 'yes' the assessment was practical and easy to use in their clinical setting. .

With regards to the comprehensiveness and reliability of the tool in identifying the patients concerns/area of need, the majority of responses (n=103; 91.2%) reported 'yes' the assessment was comprehensive and reliable in identifying the patient's concerns/area of need.

### Referrals to Other Professionals

Over half of responses 58 (51.8%) reported 'yes' the assessment prompted referral/s to other professionals. Health professionals were asked to list referrals to other professionals. The referrals made to specific health care professionals and comments noted were grouped within a number of categories and quantified and listed in Table 8.

Reasons given for 'yes' response	Frequency
Social worker	12
Citizens Advice Bureau	5
Occupational therapist	5
Macmillan team	5
Palliative care team	5
Psychology	5
Physiotherapist	4
GP	3
Nurse specialist	3
Specialist	3
Increased personal awareness	3
Marie-curie	2
Dietician	2
Community Psychiatric Nurse	2
Nursing team	2
Oncology	2
Other	2
Hospice team	1
Speech and Language Therapy	1
Community Palliative Care Team	1
Counselling	1
Solicitor	1
No	
Reasons given for 'no' response	Frequency
No	
Not required	22
Would have referred via other assessments	21
Tool not practical to complete	1

**Table 8: List of professional referred to and reasons for non-referrals**

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### Length of Time to Complete Assessment Tool

With reference to the completion time of the tool it was found that the mean number of minutes it took to complete the assessment was 27 minutes (SD=17.42) with the shortest completion time reported to be 5 minutes and the longest completion time 95 minutes.

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## 4.0: Focus group interviews

### Introduction

This section details findings from two focus group interviews that were undertaken with 10 pilot leads and assessors. The overall aims of the focus groups were to determine the following in relation to the Brief Holistic Assessment Tool:

- General opinions of the tool in terms of its usability, ease of use and the various domains of the instrument
- Issues/strategies for the possible implementation of the instrument

### Findings

In total 10 participants were interviewed in two geographical locations and included representatives from all 5 Health Care Trusts. The participants included both specialist and generalist palliative care nurses, and the average length of time working in current post ranged from 8 months to 32 years. The interviews were digitally recorded, with participant's agreement, using a Dictaphone and written notes were taken. A process of content analysis was used to analyse the focus group data and the themes that emerged across the two focus groups are presented below.

### **General opinions of the Brief Holistic Assessment Tool**

Focus group participants were asked to discuss both their opinions and the opinions of their colleagues about the usability of the instrument including the overall positive and negative aspects.

#### **Positive aspects**

A number of positive aspects of the tool were identified in relation to the practical application, design and content of the instrument. A number of participants across focus groups stated that the tool was 'quick to use', 'nicely laid out', 'it is clear' and that 'the prompts were good'.

#### Comprehensive

In terms of the content of the tool one participant described how it was very comprehensive:

*"It covers everything from the nutrition to social aspects, financial aspects. All various aspects that you would use in other assessment tools – adjusting to the illness. You get an opportunity to discuss those things."* (FG1)

Another participant stated:

*"Well I was quite impressed with tool; I felt it was a good tool to identify the issues."* (FG2)

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### Prompted action

Participants in focus group two reported that they felt the tool highlighted areas which would not necessarily be considered:

*"I thought that a positive aspect was that it had good indicators that wouldn't normally be asked, so it could be considered as good highlighting as a sign post for other things."* (FG2)

*"I think it does help you to consider new areas that are not usually considered....the psychological care bit, it would help you to consider this and especially preferred place of care which is not normally or routinely discussed or considered, this is very much from my own experience."* (FG2)

In relation to the time required to undertake the assessment there were mixed reports. In contrast to a comment made by a participant in focus group one that it was 'quick to use', a participant in focus group two stated that they felt the tool was "time consuming".

Other positive aspects of the tool which were identified by focus group two were that the tool allowed specific areas e.g. social problems, to be assessed deeper, it cut down on inappropriate referrals, and it allowed the opportunity to consider the carers needs.

### **Negative aspects**

A number of negative aspects of the tool were reported across the two groups. These were grouped within 3 themes, which were repetitiveness, experience of assessors' and the need for training.

### Repetitiveness

There was a general consensus across the two focus groups that in relation to those health care professionals with a nursing background in particular, that the specific areas within the assessment were already being collected using other methods and tools:

*"..it was a wee bit repetitive coming from a nursing background. I think district nurses would be covering these areas in their own assessments really....."* (FG1)

*"Well I'm not sure how good it really was as I feel we are already asking these questions ....for me I think we are doing it anyway."* (FG2)

### Experience of assessors'

In general there was a consensus that the experience of the assessor would have an impact on the completion of the assessment tool which highlighted the need for training. A number of subthemes are identified in relation to the assessors experience, the usefulness of prompts and the timing of their use in addition to the profession of the assessors and the discomfort that some health care staff may experience in addressing sensitive issues.

### Usefulness of prompts

There was an agreement amongst participants in focus group one that although the prompts were good, their usefulness was dependent on the experience of the assessor:

*"It depends on your experience whether you would use these prompts or not, really. If you were quite well experienced, I don't think you would need them."* (FG1)

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### Profession of assessors

During the focus group interviews there was a consensus in relation to putting some health care professionals, namely allied health professionals in vulnerable positions by getting them to explore areas that they would have not necessarily done in the past:

*“From an allied health professional perspective, you know, I don’t think they would have had the same deeper enquiry that we have would undertake.” (FG1)*

*“I also wonder about considering multi-disciplinary team training and the need to consider how roles and aspects might overlap.” (FG2)*

In analysis of the piloted tool it was found that the physical domains were completed well compared to other domains. Focus group participants were asked what they thought were the reasons for this. The reasons given were attributed to the majority of assessors being nurses:

*“It’s a nursing profession thing, we can fix physical problems...that’s where we are comfortable.” (FG2)*

*“We think we are holistic but maybe they are not practising holistically, this can be caused by many things, it could be inexperience, time as in they know they have four other calls that they need to do, also feeling, under pressure covering sickness (FG2)*

### Timing

There was agreement amongst the focus group participants that the timing of the use of certain prompts could be an issue and guidance on when to ask certain questions would be useful:

*“I felt about the social and wellbeing section – the prompts – some of them, I wouldn’t go just as far as that on the first assessment and the initial assessment, because I feel some of those questions might put a patient off building an open relationship. To talk about making a will on my first meeting, I think is just a bit too heavy.” (FG1)*

### Discomfort in addressing sensitive issues

Linked with timing, it was also identified that there was a need to develop a rapport with patients and to ‘build a relationship’ in order to address ‘very very personal questions’. It was evident in discussions that some health care professionals had concerns about discussing sensitive areas with patient, namely making a will:

*“Talking about futures, and have you made your will and your power of attorney and stuff like that – personally I wouldn’t go there on a first visit.” (FG1)*

Other concerns highlighted during discussions were regarding where the assessment takes place and who holds the notes. One participant stated that:

*“it was probably much easier to do it in the community than it was to do it in the acute, because of the turnover of patients within the acute.....whereas in the community, there seemed to be a longer time frame, because obviously that patient stays on your caseload.” (FG1)*

It was thought that if the patients had ownership of their notes then this could pose problems and the prompts could have an impact on their responses:

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*“Where is this [assessment] going to be kept, because in effect this is the patient [referring to the assessment]...this is all about them. There is a question about whether the sensitivity of this information would be good for patients to have access to this.” (FG2)*

#### The need for training

It was evident that training was a key factor in the successful implementation of the assessment tool:

*“But I think that fact is, that the tool was not actually built for the specialist. This was built for generalists, so that in itself leaves a big cloud over it. I also think, apart from the boundary issues, there are mass training implications...Because we are asking them to dig deeper within themselves, and ask more open questions as a lot of generalists often have problems sort of trying to disseminate information and provide answers at a level in which both the patient is comfortable with, and that is currently correct.” (FG1)*

It was clear across both focus groups that there were issues relating to some health care professionals understanding of clinical prognostic indicators. There was an agreement amongst both focus groups that these indicators were not routinely recorded or looked at and depended on *‘the assessor’s own judgement and knowledge of clinical prognostic indicators’*.

Focus group two reported the lack of knowledge of these indicators among some health care professionals:

*“You might think that staff in the acute side might know about prognostic indicators...you know within specialist multidisciplinary meetings they might be discussed but they are not really embedded in practice, and it’s not happening across generalist teams/nurses.” (FG2)*

#### **Suggestions on how the tool can be improved**

A number of suggestions were made by participants on how the assessment tool could be improved. The suggestions put forward included those related to the documentation space e.g. if there are multiple referrals, additional tick boxes in the intervention section as well as the need for clarity of what is meant by clinical prognostic indicators.

#### **Issues/strategies for the possible implementation of the instrument**

Participants were asked to describe how the tool can be implemented. A common thought across both focus groups was linking it with the current NISAT:

*“...if it was mapped in some way to do special assessment section of NISAT – everything that is in this assessment would be the questions that would need to be asked whenever they’re actually doing the part of the NISAT assessment, but maybe not lengthy like this.” (FG1)*

*“I wonder if this tool could be incorporated into NISAT.....I’m not really sure how this could be done but thinking about how they could be linked would be good.” (FG2)*

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## 5.0: Assessors Evaluation Questionnaire

The third stage of the evaluation sought further information from the assessors who had used the Holistic Assessment tool. A quantitative survey was designed and assessors were asked to rate each item on a four point Likert Scale ranging from Strongly Agree to Strongly Disagree. Assessors were invited to provide additional qualitative information to two open-ended questions at the end of the survey. The feedback sheet was designed to cover issues regarding usability of the tool, practical challenges encountered, process issues and training and development issues. Completed forms were either emailed or posted to the researcher. The completion of the survey forms was anonymous. Frequency scores were generated for each of the items contained in the feedback sheets. A total of twenty four respondents completed this questionnaire.

### Demographics

The majority of respondents were female (66.7%. n=16), nurses (n=21; 87.5%); aged between 40-49 years (n=14; 58.4%); qualified 10-20 years (n=13; 54.1%). See Table 9 for current job title; note one person did not disclose this information.

Title	Frequency	Percent
Respiratory nurse	6	25%
Staff nurse	6	20.8
District Nurse	4	16.7
Ward/Case Manager	3	12/6
Primary care nurse team leader	2	8.3
Nurse specialist	2	8.3
Radiographer	1	4.2
Total	23	100

**Table 9 Assessors job title**

The respondents were asked to identify what parts of the tool worked well and why and conversely what parts did not work so well and why (see Table 10). The main aspects that worked well were the prompts because it helped them to think more holistically, prompt onward referral and consider other aspects that they may have overlooked previously. The negative aspects related to the use of clinical prognostic indicators and lack of information and prompts for this section. Other negative aspects were related to practical aspects such as layout and lack of space to document interventions

The general consensus among the assessors indicated a favourable view of the Holistic Assessment tool. The assessors responses to a third of the statements contained in the questionnaire were entirely positive. The findings may be summarised as: the Brief Holistic Assessment tool was

- easy to understand and use yet the layout was not always clear and there were areas that required further explanation
- not considered particularly time-consuming to complete;
- comprehensive, triggering further assessment when required and promoting a clear understanding of the individuals needs;
- not always considered helpful in assisting health professionals to identify patients entering end of life care phase as there was ambiguity and uncertainty in the use of the clinical prognostic indication section

Overall the findings revealed that the majority of respondents would like to use HAT in their Trust.

<b>Statements.</b>	<b>Strongly Agree</b>	<b>Agree</b>	<b>Disagree</b>	<b>Strongly disagree</b>
The HAT easy to understand	20.8%	70.8%	4.2%	4.2%
HAT easy to use	20.8%	70.8%	4.2%	4.2%
HAT is time consuming	4.5%	31.8%	63.6%	
HAT captures the needs of individual	12.5%	83.3%		4.2%
HAT promotes professional judgement	12.5%	75%	8.3%	4.2%
The layout of HAT tool is clear and easy to follow	21.7%	47.8%	26.1%	4.3%
The terminology used is consistent and familiar	16.7%	66.7%	12.5%	4.2%
HAT encourages more teamwork	18.2%	50%	27.3%	4.5%
HAT changes the way I would care for palliative care patient		33.3%	50%	16.7%
The domains are comprehensive	13%	82.6%		4.3%
Each domain triggers further assessment where appropriate	12.5%	75%	8.3%	4.2%
I would like to use HAT in my Trust	10.5%	68.4%	10.5%	10.5%
There are areas that require further explanation	17.4%	47.8%	34.8%	
The inclusion of outcome section at end is helpful	12.5%	79.2%	4.2%	4.2%
Actions to be included is useful	10%	85%		5%
The guidance explained all the main prompts in each domain adequately	8.3%	87.5%	4.2%	
I found the Clinical Prognostic Indicator Section helpful in assisting me to identify patients entering the end of life phase of care.	13.6%	36.4%	45.5%	4.5%
The structure of the tool flowed easily	4.2%	75%	16.7%	4.2%
At the end of the assessment I have a clear understanding of the individuals needs	12.5%	70.8%	12.5%	4.2%

**Table 10: Assessor feedback statements**

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## 6.0: Final Conclusions

The findings obtained from the three phases of the evaluation of the tool would indicate the following:

1. The tool did appear to enable health professionals to identify and gain an understanding of the needs of the patients. Specifically this was related to the patient needs in terms of physical health care needs. Lower numbers of needs were recorded for social & occupational wellbeing. Therefore questions exist as to whether these other domains were not issues for this sample of patients or were these issues not being identified or documented by staff? This question was posed to the focus groups participants and some possible explanations included: the majority of assessors were nurses and therefore would be responding to identified 'nursing needs' and were perhaps not practising holistically but focusing on physical aspects.
2. It was noted that some discrepancies appeared to exist within the documented responses for the piloted NICAN Brief Holistic Assessment tool.

For example:

- (a) Within the domain *Mental Health and Emotional Wellbeing* a positive aspect was that a lot of mental health issues were identified yet only 15 responses considered onward referral to psychology and 43 (32.6%) considered seeking advice from and/or formal referral to specialist professional.
- (b) Within the domain *Family & Close Relationships*; 52 problems/needs identified and yet only 28 health care professionals reported that a carer assessment was required.
- (c) Within the domain *Spiritual Wellbeing*: 68 needs were identified, yet in terms of actions, only 16 (less than 20%) responses reported that 'yes' there was immediate cultural/religious requirements.

Therefore it would appear that questions exist around the identification of needs and discrepancies in terms of actions undertaken. However, caution needs to be exercised in interpreting this finding as this may also be related to perceived gaps within the tool in terms of documenting actions undertaken. In addition, findings may also reflect participants' lack of knowledge of onward referral services as well as perceived availability of services. This issue will be discussed further in the discussion section.

3. Whilst it is interesting to note that the analytic review of the piloted NICAN Brief Holistic Assessment Tool found that 59 (68.8%) responses indicated that preferred priorities of care had been discussed as an action for this group of patients, questions around the reality of the situation in practice emanated from the focus group discussion with assessors and pilot leads. From these discussions it was found that participants had concerns around discussing sensitive issues with patients, such as talking about the future and that the experience of the assessor had a significant impact on the overall assessment. Therefore, questions exist around the extent to which preferred priorities of care and future planning are happening in practice and the availability of training to implement holistic assessment tools into practice.

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4. The use of clinical prognostic indicators was ambiguous. The findings from the first phase of the evaluation indicated that over half of responses (n=50 57.5%) had considered a prognostic clinical indicator for the patient as an action. However, both the focus groups and the assessor evaluation questionnaire indicated that there are questions around health care professional's knowledge about clinical prognostic indicators and perceived usefulness in practice. Within the focus groups there was general agreement that these indicators were not routinely recorded or looked at and were dependent on the assessor level of knowledge. In addition, the assessor feedback questionnaire highlighted that 43.3% assessors disagreed that the clinical prognostic indicator section in the tool was helpful in assisting them to identify patients entering EOL phase.
  5. In terms of evaluation of the tool both positive and negative aspects were noted.
    - a. *Positive aspects*: it was easy to understand; not considered time consuming; the use of prompts triggered further assessment when required, it captured the needs of individuals, it was comprehensive and encouraged more teamwork.
    - b. *Negative aspects*: it was considered to be repetitive in that some assessors considered that information gathered had already been documented through the use of other tools and measures; the layout was not always clear and some areas required further explanation; the experience of assessors and training were issues that required consideration.
  6. In relation to strategies on how the tool could be implemented, through the focus group discussion it was suggested that the tool should be linked with the current assessment tool NISAT rather than a standalone assessment tool.

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## 7.0 Discussion

In seeking to undertake an evaluation of an assessment tool it is important to acknowledge that holistic assessment is a complex, integrated process comprised of many elements. These can include the person and family/carer at the centre of the process as well as assessment 'tool', and the health care professional. It is important therefore to ensure that the 'tool' is clearly seen for what it is –merely a tool to aid in the assessment process, not as a panacea for all assessment problems.

The recent strategy for palliative and end of life care in NI (DHSSPS, 2010) recognised this, noting the importance of undertaking a holistic assessment to go beyond the physical needs of the individual to include the social, mental health, emotional and spiritual well-being of the patient, their family and carers. Nevertheless, challenges persist in delivering holistic assessment in practice. These can include: the health care professional's understanding of holistic assessment; preparation and training; timing for holistic assessment; moving beyond cancer, clinical prognostic indicators and considerations of duplication and repetition.

### **Holistic Assessment: Rhetoric or Reality?**

The term holistic assessment is used frequently and can be argued is synonymous with the principles of palliative and end of life care (NAPC, 2000; NICE, 2004; NICaN, 2008). The findings of this evaluation, however, raised questions around practitioners' understanding of this term and the reality of the practice situation. Whilst there is clear rhetoric around the term, noted within the various domains contained in holistic assessment tools (Richardson et al, 2007), questions exist around whether practitioners are practising holistically and what this concept means in practice (Castledine, 2001), not only for the health care professional but also for patients and families. It is vital that the individual and their carer remain at the heart of the assessment process and that the process flexible enough to respond to the individual and carer's changing circumstances (Richardson, 2010). Furthermore, it is acknowledged that whilst holistic assessment tools tend to focus on an assessment of the individual patient needs, carers' needs are often highlighted throughout the process. Specifically for NI, this can provide a link to the legislative requirement to inform individual carers of their right to an assessment (Carers and Direct Payments Act, NI, 2002 (DHSSPS 2004), enabled through the NISAT Carers Support and Needs Assessment Tool (DHSSPS, 2009).

### **Timing and Efficiency of Holistic Assessment**

The question of when to undertake a holistic assessment is an important point to consider. Key trigger points have been previously identified within the guidance documents for holistic assessment (Richardson et al, 2005; 2010). These include key points in the individual's care pathway, such as the identification of the end of life phase; the point at which dying is diagnosed and any other time that the individual may request or a professional carer may judge necessary. Other issues relating to the timing of a holistic assessment include the need for the assessor to develop a sense of trust and understanding between themselves and the individual. This is particularly relevant for sensitive conversations within particular domains such as psychological well-being, spiritual well-being and life goals.

Therapeutic relationships are developed over time and link with the identified need for a key worker role for coordination of care as recommended in the Living Matters: Dying Matters, a Strategy for Palliative and End of Life Care in Northern Ireland (DHSSPS, 2010). It is vital to recognise that such discussions, particularly in relation to spiritual well-being and life goals, may lead into conversations about preferred place of care and potentially advance care planning. Assessors need to feel prepared and equipped for this possibility. Thus whatever methodology is used for assessing

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needs, staff need to be appropriately trained in their use to be able to complete such assessments competently and with sensitivity. Alongside considering when to undertake an assessment, efficiency is another important factor that was clearly identified by health professionals.

It was found that practitioners considered that this tool was not too onerous in terms of time required to complete it. This is in line with the view that the average time required for undertaking assessments should normally be around 30 minutes (Richardson, 2010). It is important to note, however, that assessment is not a once off activity but that continuous holistic assessment of palliative and end of life care need is crucial and should be viewed as an integral part of care.

### **Transferability: Beyond Cancer**

Although the concept of holistic assessment originated in the cancer field, the core principles of assessing an individual's needs remain the same whatever their condition or care setting. Therefore a positive aspect of this holistic assessment tool is the transferability across disease groups. This is reflective of movement of the concept of palliative care to include care given to patients with advanced irreversible disease and not just those with a cancer diagnosis (Thomas, 2006). Possible criticisms of existing published assessment tools, such as the Pepsicola aide memoire and distress thermometer, are that they assess either a more limited range of end of life related needs or assess in-depth a specific area of need (Richardson et al, 2005). These criticisms can limit their usefulness in practice.

### **Clinical Prognostic Indicators**

It is recognized that one of the greatest obstacles to the improvement of palliative and end of life care is the difficulty in identifying dying patients early enough (Burt et al, 2010). One way of trying to overcome this difficulty is the development of clinical prognostic indicators. A Prognostic Indicator Guidance document has been developed by Gold Standards Framework Centre to assist generalist clinicians with early identification of people approaching the end stage of their disease process. This guidance has brought together a number of aspects, with the 'surprise question' at the core, and includes specific clinical indicators plus factors such as repeat admissions and level of functioning. According to Maltoni et al (2005) using and communicating prognostic information should be part of a multidisciplinary palliative care approach. However, it was found in this project that the use of clinical prognostic indicators in practice was ambiguous. Questions around practitioners' knowledge of these aspects exist. Recognition that the end of life is approaching can be challenging, and the use of the 'surprise question', ('would I be surprised if this patient died within the next 12 months?') is recommended to provide an indication of need for care (Transdrum et al, 2000; GSF, 2009). Questions around implementing and facilitating this aspect in practice remain.

### **Barriers to Implementation: Duplication and replication**

It has been noted that in order for an assessment tool to be implemented into practice, cognisance is required both of the organisational culture and the values underpinning assessment processes (Glover, 2005; McCormack et al, 2006). A recurrent message from all stages of the evaluation was a view that holistic assessment was being carried out already and that the completion of this tool was duplication and repetition of existing assessment procedures. Similar barriers to holistic assessment have been noted within other areas in the UK (Morris, 2009). This indicates the need to constantly challenge the perception that holistic assessment is being undertaken routinely and challenge practitioners to provide evidence to demonstrate holistic assessments, resulting in appropriate action. It is also important to consider how this tool could link with other pre-existing tools to help allay this sense of duplication and provide more effective integrated care. A possible

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mechanism for this could be the inclusion of the NICAN Brief Holistic Assessment tool within the existing comprehensive Northern Ireland Single Assessment Tool (NISAT).

**Action orientated documentation**

Feedback from all the stages of the evaluation noted that the negative aspects of the tool were related to its structure and layout. A specific aspect was the lack of focus on action required. It was noted that the outcomes section in the tool documented a list of actions that could be 'considered' for practice. However, questions exist as to what 'considered' might mean and how this can be interpreted by practitioners. Thus there was consensus that there needed to be a section within the tool detailing confirmation on actions undertaken and for the tool to be signed and dated in line with correct documentation procedures. This would assist the holistic assessment to form the basis of an individualized patient-centred care plan; agreed with the patient and aimed at planning and delivering care that best meets their circumstances and requirements.

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## Appendix 1: Brief Holistic Assessment and Referral Screening Tool



### BRIEF HOLISTIC ASSESSMENT AND REFERRAL SCREENING TOOL PILOT PROJECT

The process of assessment can help to produce a common understanding of needs. Please read the accompanying guidance before completing the assessment below.

The assessor should be an experienced health or social care professional, who normally undertakes assessments as part of their role; and has an appropriate knowledge of the patient, disease process, symptoms, treatment and likely prognosis.

**Diagnosis:** (Please circle as appropriate or state for **Other**)

Cancer /Advanced Respiratory Disease /Advanced Cardiac Disease /Advanced Neurological Disease/Other Advanced Progressive Disease\_\_\_\_\_

Domains	Risk factor <i>PROMPTS (Please circle as appropriate)</i>	What interventions have been tried to date? <i>(Including other professionals involved and treatment plans)</i>	Actions to be considered	Outcome
<b>PHYSICAL HEALTH</b> Are there issues with pain or other symptoms associated with the illness which are causing distress or disability and remain unsolved despite intervention (for more than 48 hours)?	<b>Pain</b> <i>Altered sensation, numbness, and/or loss of function?</i> <b>Other symptoms</b> <i>Loss of function, feeling tired more than usual, easily exhausted, physically weak, balance problems, mobility issues, sleep disturbance, swollen limbs, breathing problems, oral discomfort, eating and drinking/nutrition, swallowing, coughing or choking, nausea or vomiting, urinary or bowel problems, confusion or disorientation, hearing or communication, skin integrity compromised?</i>		<ul style="list-style-type: none"> <li>Has a comprehensive pain assessment or other appropriate assessment been completed?</li> <li>Have you considered seeking advice and/or formal referral to other specialist professional?</li> </ul>	<input type="checkbox"/> Yes <input type="checkbox"/> No Which assessment?  <input type="checkbox"/> Yes <input type="checkbox"/> No Consider contact to clarify or seek advice.
<b>SOCIAL AND OCCUPATIONAL WELLBEING</b>	<b>Work issues:</b> <i>issues concerning employer, workplace relations and workmates, change in work patterns,</i>		<ul style="list-style-type: none"> <li>Is there a Social Worker involved?</li> </ul>	<input type="checkbox"/> Yes <input type="checkbox"/> No If No, consider a referral.

Are there issues with work and finance which are causing distress and/or are unresolved despite intervention/s?	<i>inability to work immediate financial concerns. Managing at home and in the community, meeting day to day needs e.g. personal care. <b>Planning for the future</b>, long term financial concerns for family, mental capacity, power of attorney, making a will, advance directive/living will.</i>		<ul style="list-style-type: none"> <li>Have you considered seeking advice from and/or formal referral to other specialist professional?</li> </ul>	<input type="checkbox"/> Yes <input type="checkbox"/> No If No, consider a referral.
<b>Domains</b>	<b>Risk factor</b>	<b>What interventions have been tried to date?</b>	<b>Actions to be considered</b>	<b>Outcome</b>
	<i>PROMPTS (Please circle as appropriate)</i>	<i>(Including other professionals involved and treatment plans)</i>		
<b>MENTAL HEALTH AND EMOTIONAL WELLBEING</b> Is there a pre existing psychological condition or history of mental health issues requiring professional support?	<i>Feeling down, depressed, hopelessness, anxiety, panicky, fear, restlessness. Sexual difficulties, body image difficulties</i>		<ul style="list-style-type: none"> <li>Has onward referral for psychology been made?</li> <li>Have you considered seeking advice and/or formal referral to other specialist professional?</li> </ul>	<input type="checkbox"/> Yes <input type="checkbox"/> No If No, consider a referral.  <input type="checkbox"/> Yes <input type="checkbox"/> No If No, consider a referral.
<b>ADJUSTING TO THE ILLNESS</b> Are there issues of concern?	<i>Knowledge and understanding of the disease and prognosis, unresolved concerns, exhaustion, sleep disturbances, adjusting to losses.</i>		<ul style="list-style-type: none"> <li>Carer's Assessment?</li> </ul>	<input type="checkbox"/> Yes <input type="checkbox"/> No
<b>FAMILY &amp; CLOSE RELATIONSHIPS</b> Are there issues of concern?	<i>Needs related to partner, family dynamics. Needs related to patient's children. Intimacy/sexual difficulties, unable to discuss issues of concern with partner/spouse. Conflict present.</i>		<ul style="list-style-type: none"> <li>Are there any immediate</li> </ul>	<input type="checkbox"/> Yes <input type="checkbox"/> No If No, consider a referral
<b>SPIRITUAL WELLBEING</b>	<i>Impact of illness on faith/belief, be it</i>			

Are there issues relating to spiritual wellbeing which are causing distress?	<i>religious or non-religious. Issues related to culture or ethnic background e.g. diet, medicines, treatment product. Life goals, important occasions. Ethical issues including treatment and end of life care. Hopelessness, anxiety, fear.</i>		cultural/religious requirements?	to a Chaplain or appropriate faith leader/community cultural agency.
<b>AWARENESS AND DECISION MAKING</b> Preferences and priorities for future care?	<i>Things important explored, setting realistic goals, resources available, family/carer support, place of care discussed.</i>		<ul style="list-style-type: none"> <li>• Has appropriate advice been given or onward referral?</li> <li>• Have preferred priorities of care been discussed?</li> </ul>	<input type="checkbox"/> Yes <input type="checkbox"/> No If No, consider a referral.  <input type="checkbox"/> Yes <input type="checkbox"/> No Where has it been recorded?
<b>PROGNOSTIC CLINICAL INDICATORS</b>	<i>Clinical Prognostic Indicators are used to estimate the disease status for patients with cancer and organ failure e.g. heart disease, COPD, renal disease and neurological disease.</i>		<ul style="list-style-type: none"> <li>• Has a Prognostic Clinical Indicator been considered for this patient?</li> </ul>	<input type="checkbox"/> Yes <input type="checkbox"/> No
<b>OUTCOME</b>	<b>ACTION</b>	<b>BY WHOM</b>	<b>BY WHEN</b>	<b>ASSESSMENT COMPLETED BY:</b>
Current situation is stable	Continue routine management and review	By those providing the day to day care to the patient and family either at home or in hospital	Date of review _____	Name:
Some risk factors identified	Consider interventions/advice or consultation/referral with other professional/s	Medical/Nurse Specialists Dietitian/Speech & Language Therapist/Occupational Therapist/Physiotherapist Social Worker/Counsellor/Psychologist Chaplain	Date of referral _____	Designation:  Department:
Complex/multiple risk factors identified	Make referral to appropriate specialist team	Hospital/Community Specialist Palliative Care Team.	Date of referral: _____	Date: