Implementing outcomes through 'Integrated Palliative Care Outcomes Scale' at St Ann's Hospice

Overview:
Following a review of potential patient reported palliative outcome measures, there is a plan in Stockport to phase an implementation of a validated tool, Integrated Palliative Care Outcome Scale (IPOS) that can be used within clinical care, but can also provide patient reported outcome information.

IPOS is part of a suite of measures within the OACC (Outcome Assessment and Complexity Collaborative), originally developed by Guys and St Thomas, Kings College London.

The measurement of outcomes will help understand the difference and benefits that interventions make for palliative care patients regarding holistic outcomes, including global physical and psycho-social symptoms burdens and quality of life. This will ensure people are receiving the right support to meet their needs and help inform future service development and requirements.

IPOS questionnaire:
The validated IPOS tool has been extensively tested with patients and is a measure that is brief, but captures key spectrum of patient concerns – each measure scored with higher scores requiring more clinical attention. The tool will be used in conjunction with collecting both the patient's Phase of Illness, and the patient's current Australian-modified Karnofsky Performance Score (measured as a percentage in relation to performance) – **See Appendix**.

IPOS is a measure of global symptom burden, it is a means of assessing all key domains of palliative care: Physical, Psychosocial, Social and Spiritual. There is a patient questionnaire which asks key questions of the patient around pain, shortness of breath, weakness or lack of energy, constipation, poor mobility, feelings of being depressed or anxious, and feelings of being at peace. A second version of the questionnaire for staff to complete on behalf of patients who are unable to complete one themselves is also used.

Delivery Case Study:
St Ann's Hospice has been working with the IPOS measures since September 2017, and Stockport CCG/Stockport Together has been working collaboratively with them to understand how to collect, present and report the outcomes, as well as receiving support with local implementation and training. Dr David Waterman, Consultant in Palliative Medicine, has facilitated this collaboration as the clinical lead for Stockport's Expert Reference Group for End of Life Care Outcome Measures and also a Consultant at St Ann's Hospice.

The hospice is an organisation which provides specialist palliative and end of life care from its three sites in Heald Green in Stockport, Little Hulton in Salford, and The Neil Cliffe Centre in Wythenshawe Hospital, as well as via a range of community and outreach services. Staff at the hospice care for people with cancer and non-cancer life-limiting illnesses, right from the point of diagnosis, through treatment, and beyond, including via inpatient services, day therapy, outpatient support services, and help in the place patients call home.

St Ann's work with the IPOS measures developed as part of their work on OACC (Outcome Assessment and Complexity Collaborative). Within the hospice, IPOS was initially implemented within the Inpatient Units, and is now also being used in Outpatients and Day Care settings.
It is the aim also to use IPOS, Phase of Illness and the Australian-modified Karnofsky Performance Score as an approach across Greater Manchester and Eastern Cheshire to collate patient reported outcomes.

Results:
The outcome scores can be used in two ways – to provide overall score understanding overall concerns at a particular time, as well as individual item scores to track particular dimensions of need and interventions. This will aid evaluation of services, and ultimately hopefully link to incentives for outcome and service improvement.

The work with St Ann's Hospice is helping us to understand how to collect, present, and report the outcomes for our own local implementation in Stockport.

Data captured during the first six months of the work (October 2017 to March 2018 has indicated that overall there was a 76.9% improvement on average across all domains measured (pain, energy levels, nausea, appetite, mouth soreness, mobility, constipation etc.) This was for 40 patients. Of significant note, 69.7% of discharged patients, and 57.9% of deceased patients, had reported an improvement in pain management which was a really encouraging positive impact.

The use of the IPOS questions has also led to other benefits, including the facilitation of the conversation with patients, and helping to direct support needed on to what really matters to patients at that time.

AKPS and phase provides a shared language, by describing patients in terms of their AKPS, phase and IPOS scores practitioners very instantly get a picture of what the patient is like. This has proved useful in dialogues with local commissioners and provided evidence of the complexity of the patients who are referred to us. It has also allowed us to provide an explanation of what we do and the impact we have on the community in which we sit.

The MDT has been made more efficient as it has allowed us to review the way in which we work and the way in which we assess our patients.

Looking ahead:
Stockport is planning to implement the recording of Australian-modified Karnofsky Performance Score, Phase of Illness and Integrated Palliative Care Outcomes Scales (IPOS), initially for patients known to the Specialist Palliative Care Service. Further implementation for other services is planned for the future.

The IPOS work at St Ann's Hospice will continue and develop further, to help better understand key themes and trends within groups of patients. It is hoped that these themes will help inform future service development and allow proactivity in addressing patient needs.

Medical and clinical staff at the hospice will also be encouraged to review the IPOS data to further aid in working with individual patients, and understanding their own specific needs at a given time. The use of common language around phases of illnesses is also beneficial, not only for patients in the hospice or hospital environment, but also when patients move to other services or departments.

There are also future plans to use a validated survey of the bereaved (VOICES) to understand their views of care in the last few weeks of life.

Key contacts for further information:

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- Jude Holt, Head of Practice Development, St Ann's Hospice jholt@sah.org.uk

Appendix

Phase of Illness Category:

Phase	This is the current phase if…	This phase ends when…
Stable	Patient's problems and symptoms are adequately controlled by established plan of care* **and** further interventions to maintain symptom control and quality of life have been planned **and** family/carer situation is relatively stable and no new issues are apparent.	The needs of the patient and or family/carer increase, requiring changes to the existing plan of care.
Unstable	An urgent change in the plan of care or emergency treatment is required **because** the patient experiences a new problem that was not anticipated in the existing plan of care **and/or** the patient experiences a rapid increase in the severity of a current problem **and/or** family's/carer's circumstances change suddenly impacting on patient care.	The new plan of care is in place, it has been reviewed and no further changes to the care plan are required. This does not necessarily mean that the symptom/crisis has fully resolved but there is a clear diagnosis and plan of care (i.e. patient is stable or deteriorating) **and/or** death is likely within days (i.e. patient is now dying).
Deteriorat-ing	The care plan is addressing anticipated needs, but requires periodic review, **because** the patient's overall functional status is declining **and** the patient experiences a gradual worsening of existing problem(s) **and/or** the patient experiences a new, but anticipated, problem **and/or** the family/carer experience gradual worsening distress that impacts on the patient care.	Patient condition plateaus (i.e. patient is now stable) **or** an urgent change in the care plan or emergency treatment **and/or** family/ carers experience a sudden change in their situation that impacts on patient care, and urgent intervention is required (i.e. patient is now unstable) **or** death is likely within days (i.e. patient is now dying).
Dying	Dying: death is likely within days.	Patient dies **or** patient condition changes and death is no longer likely within days (i.e. patient is now stable or deteriorating).
Deceased	The patient has died; bereavement support provided to family/carers is documented in the deceased patient's clinical record.	Case is closed.

Australian-modified Karnofsky Performance Score:

Australian-modified Karnofsky Performance Scale	
100	Normal with no complaints or evidence of disease
90	Able to carry on normal activity but with minor signs of illness present
80	Normal activity but requiring effort. Signs and symptoms of disease more prominent
70	Able to care for self, but unable to work or carry on other normal activities
60	Able to care for most needs, but requires occasional assistance
50	Considerable assistance and frequent medical care required
40	In bed more than 50% of the time
30	Almost completely bedfast
20	Totally bedfast and requiring extensive nursing care by professionals and/or family
10	Comatose or barely rousable
0	Death