

Supportive Care Intervention Program - Frequently Asked Questions 2009

	Questions	Answers
1.	What are the Supportive Care Intervention Program objectives?	<ul style="list-style-type: none"> • Build the evidence base in cancer outpatient supportive care and quality of life through a robust patient centred system intervention and its evaluation, using screening for distress as a major component; • To increase staff skills, develop referral options and reduce patient burden of unmet needs and support timely and appropriate referral to best evidence based interventions; • To identify if the Supportive Care Intervention Program is effective and for which patients (e.g. patients with different levels of distress, at different stages) and understand the full impact of the Intervention including its impact on the cancer service; • Provide cancer outpatients with timely, credible and evidence based information, tailored to their needs; • Encourage distress screening programs to use standardised tools with strong psychometrics; • Improve cancer outpatients' quality of life; • Identify economic efficiencies and effectiveness related to the intervention program.
2.	How is distress defined in the context of the Supportive Care Intervention Program?	<ul style="list-style-type: none"> • Distress is considered a multifactorial unpleasant experience related to psychological, social, physical or spiritual aspects of cancer, the cancer journey or its treatment.
3.	What is supportive care in the context of the Supportive Care Intervention Program?	<ul style="list-style-type: none"> • Care provided to cancer outpatients that addresses physical (pain and other symptom management), psychological (anxiety and depression), social, and practical needs (including information needs). • The Program is not designed to evaluate "other supportive care interventions or treatments" such as drug treatments (e.g. antibiotics, antiemetics, colony stimulating factors) or blood product support or nutritional support.
4.	Why is the Supportive Care Intervention Program required if cancer services are already screening for distress?	<ul style="list-style-type: none"> • Not all services are screening for distress and ad hoc approaches are being used in some cancer services. • Implementation designs rarely include control data, limiting the strength of evidence. • Lack of standards and guidelines related to supportive care has led to large variation in clinical practice and the use of tools that do not have good psychometrics. Evidence is required, linked to a robust intervention and evaluation. • Program involvement of cancer services currently undertaking routine distress screening will depend on the final Supportive Care Intervention Program design and consideration of confounder. If not included, cancer

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		services are encouraged to continue with routine screening and associated referral to supportive care.
5.	What has influenced the focus of the Supportive Care Intervention Program?	<ul style="list-style-type: none"> • Many different sources of evidence and stakeholder consultations influenced the focus of the Program including reviews of clinical practice and the identification of clinical variation related to screening for distress, workshops on screening for distress, consumer requests, and patient unmet needs related to support, information requirements and symptom management.
6.	Does the distress screening component of the Cancer Supportive Care Intervention Program have to be touch screen computer based?	<ul style="list-style-type: none"> • Yes. Evidence indicates that computers will reduce data entry requirements, improve data quality and that there is high patient acceptability of touch screen technology as part of distress screening. • Program funds will go towards establishing the touch screen system (e.g. purchase of kiosks, tablets, servers, software and helpdesk support during the program).
7.	How will different language groups be included in the Cancer Supportive Care Intervention Program?	<ul style="list-style-type: none"> • Strategies to include a variety of language groups should be considered by investigators. • The Cancer Institute NSW is mandating that the HADS tool be used as an outcome measure of anxiety depression and distress, due to its excellent psychometric properties. This tool is available in English, Arabic, Cantonese, Italian and Greek. The Cancer Institute NSW is mandating that that the FACT-G is used which is available in English, Cantonese, Italian, Greek and Vietnamese. The CES-D is available in Arabic, Cantonese, Italian, Greek and English and should be used if a depression related outcome measured is to be included.
8.	Are adult and child patients eligible for inclusion in the intervention?	<ul style="list-style-type: none"> • No. The target patient population is ADULT cancer non-admitted patients (outpatients). Children (under 17 years) are NOT eligible for inclusion as there is insufficient evidence to assist with the design of an appropriate intervention.
9.	What population groups can be included in the intervention?	<ul style="list-style-type: none"> • Potentially all population groups could be included in the study including urban, rural, aboriginal, and CALD patients. It is anticipated that multiple NSW Area Health Services would be included as well as private cancer services. Justification for inclusion / exclusion of groups should be included in designs/ submissions.
10.	Who should be screened for distress?	<ul style="list-style-type: none"> • All patients regardless of cancer type or stage (excluding haematology patients as they may have non malignant disease).

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11.	When should distress screening be undertaken?	<ul style="list-style-type: none"> • Screening needs to be done on a routine basis, including upon entry to the cancer service and at critical points in the cancer journey e.g. initial diagnosis, treatment commencement, end of treatment, recurrence, progression, surveillance.
12.	What if patients have pre-existing depression?	<ul style="list-style-type: none"> • Patients with pre-existing depression are eligible for inclusion. • Many patients with pre-existing mental illness are not recognised and the intervention can identify, assess, appropriately refer and treat these patients.
13.	Does the biopsychosocial focus to the Program include more than pain?	<ul style="list-style-type: none"> • Yes. Other symptom distress and management should be included, such as nausea.
14.	What mandatory patient-reported <u>outcome measures</u> (PROMS) need to be included in Program design?	<ul style="list-style-type: none"> • A systematic review commissioned by the Cancer Institute NSW in 2009, to identify optimal measures of anxiety, depression, distress and health related quality of life (HRQoL) identified three tools with adequate psychometric properties. • The following tools are mandated for inclusion as outcome measures at a minimum: <ul style="list-style-type: none"> ○ The Hospital Anxiety and Depression Scale (HADS) ○ The Functional Assessment of Cancer Therapy General (FACT-G) ○ The CES-D (if depression is a specific outcome of interest).
15.	What <u>screening</u> tools should be included in Program design?	<ul style="list-style-type: none"> • A consultancy assignment was recently undertaken for the Cancer Institute NSW to determine suitable tools for screening physical symptoms in a generic cancer population. This literature review focused on the ideal characteristics of an instrument for screening. • Currently there is no consensus about the “ideal” screening instrument for physical symptoms. However, an instrument (or package of instruments) with good psychometric properties for screening of symptoms would have the following characteristics: <ul style="list-style-type: none"> - Detect symptoms that occur most frequently, and of note pain must always be included; - Detect symptoms that are the most distressing; - Be brief, completed in under 5 minutes; - Be easy to understand and complete through patient self report; - Be easy to process;

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		<ul style="list-style-type: none"> - Provide enough information for triage and decision making; - Can be administered via computers. • Examples of rigorously validated instruments that may be appropriate for screening of physical symptoms in a generic cancer population include the Edmonton Symptom Assessment System (ESAS), the M.D. Anderson Symptom Inventory (MDASI), the Memorial Symptom Assessment Symptom Assessment Scale (MSAS) and the Symptom Distress Scale. Details about these tools and others will be available to applicants when the call for applications is made on 1 March 2010, including opinion of selected worldwide experts in the field. • In regard to screening for emotional distress (ie anxiety and depression) a recent publication by Vodermaier et al (2009) identified two short measures with adequate psychometric properties, including HADS , a mandated outcome measure for the Supportive Care Intervention Program (see point 14). To minimise patient burden related to tool completion, it is strongly recommended that HADS be consider both a screening and outcome measure. • While the National Comprehensive Cancer Network Distress Thermometer (DT) is widely used internationally in relation to distress screening programs, it has poor specificity. However, the DT includes a problem list which is perceived to be of high value and several modifications and extensions of the DT demonstrate better psychometric properties. Inclusion of a problem check list is desirable as part of distress screening as there is indication that a problem list supports identification of broad supportive care needs that other tools don't identify (e.g. financial needs). • A combination of screening tools is, therefore, recommended.
16.	Health services use different supportive care assessment approaches and different psycho-social interventions. How prescriptive is the Program in regard to assessment and intervention referral?	<ul style="list-style-type: none"> • No psycho-social or supportive care assessment or intervention has been prescribed in the Program Guidelines. However, it is anticipated that researchers identify and promote the use of best evidence assessment and interventions.
17.	What interventions could be	<ul style="list-style-type: none"> • Referral and interventions by disciplines such as physiotherapy, occupational therapy, pharmacy, dietetics are not included In the Supportive Care Program Intervention but may need to be considered as a

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	considered as confounders?	<p>confounder if patients are referred to such services as part of usual care.</p> <ul style="list-style-type: none"> While specific referral interventions could be considered a confounder the Program evaluation focuses on the impact of the Program Intervention package which includes timely and appropriate referral, not specific interventions such as Mindfulness Therapy.
18.	Will the Picker patient survey tool be used again to evaluate the intervention?	<ul style="list-style-type: none"> No. Investigators need to design the intervention to include measures that will determine the impact of the intervention. Baseline data will be required to measure change through time. The Cancer Institute NSW and/or NSW Health may decide to utilise other survey methods to continue to monitor the cancer experience, separate to the Supportive Care Intervention Program.
19.	Can submissions only focus on one aspect of the Supportive Care Intervention Program or the evaluation?	<ul style="list-style-type: none"> No. The Intervention is comprised of multiple components but is considered one intervention that will improve distress and quality of life. Funding submissions should include partners with skills to implement and evaluate the full Program. Involvement of a biostatistician and health economist is encouraged.
20.	What is the focus of the evaluation - the Cancer Supportive Care Intervention Program or its components?	<ul style="list-style-type: none"> The Program is focused on system change and supports person centred care. Routine screening for distress is one part of a programmatic approach. The evaluation should focus on the impact of the whole Intervention (i.e. routine electronic screening, use of referral pathways (based on the Clinical Practice Guidelines for the Psychosocial Care of Adults with Cancer), appropriate referral, tailored patient information, staff training, and use of question prompt lists).
21.	How relevant is quality of life as a program outcome?	<ul style="list-style-type: none"> The evaluation should focus on improvements in distress derived from having skilled staff providing timely and relevant referral and interventions, following routine screening and monitoring for distress. The Cancer Institute NSW is also interested in improved quality of life of cancer patients, as this is one of its core goals. A recent study examining quality of life and supportive care needs indicated that while different tools may be used, the underlying constructs are the same. The domains within quality of life are therefore considered relevant in the context of the Cancer Supportive Care Intervention Program and quality of life should be examined as part of the study.
22.	Is the Cancer Supportive Care Intervention Program open to	<ul style="list-style-type: none"> Yes. Innovation can be included if it is related to the Program's objectives. However, all submissions will need to describe interventions that include routine distress screening using computer touch screens, staff training, tailored information for patients and question prompt lists. The inclusion of optional funding to

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	intervention innovation?	support postdoctoral salaries and/or PhD scholarships also supports innovation.
23.	Is the \$3M to cover the Cancer Supportive Care Intervention Program and State roll out led by the Cancer Institute NSW?	<ul style="list-style-type: none"> No. The \$3M on offer is to support Program implementation and evaluation in a cross section of NSW cancer services, including public and private hospitals. Sample size and unit of analysis considerations will in part determine number of cancer services involved. If the program evaluation provides strong evidence to support program expansion to other cancer services in NSW, the Cancer Institute NSW would identify additional resources. It is envisaged that sustainability, transferability and scalability are considered by investigators when developing and implementing the Intervention Program. It is also envisaged that investigators would provide advice to the Cancer Institute NSW based on the intervention experience that would support State roll out by the Cancer Institute NSW and sustainability by services.
24.	Is the economic Program evaluation meant to identify cost savings?	<ul style="list-style-type: none"> No. A number of approaches are available to understand the economic costs and impact on health interventions and outcomes. The Cancer Institute NSW is interested in the efficiencies and effectiveness of the Intervention Program and the cost model. Inclusion of a health/clinical economist in the partnership would be advantageous.
25.	Is it assumed that Program results will be transferable to all settings in NSW?	<ul style="list-style-type: none"> Yes. It is envisaged that a range of service settings are included in the study (e.g. rural and urban; public and private) with learnings that can be taken forward to support implementation in non-participating cancer services.
26.	How will cancer services cope with potential increased demand for supportive care?	<ul style="list-style-type: none"> Evidence suggests that distress screening programs, incorporating standardised validated screening tools, can reliably identify patients with pronounced clinical symptoms, thus ensuring that patients who are referred to supportive care are those who will benefit the most. Programs therefore do not necessarily result in an increase in referrals to cancer service staff and can in fact control and support appropriate and timely referral. It is envisaged that patients with distress are identified early rather than late. The number of patients requiring intervention may not rise dramatically as patients may be seen earlier in their cancer journey, rather than later. It is also possible that early referral will allow interventions to work better than trying to manage more difficult late crisis. Use of a referral pathway will assist in the identification of internal and external referral options including referral to primary health care allied health professionals who provide services for patients with chronic and

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		<p>complex conditions including cancer. Under the Medicare Plus initiative patients can access services provided “for and on behalf of” a GP by an allied health professional including psychologists, social workers, dieticians, speech pathologists, physiotherapists and occupational therapists. The Medicare item covers as many as five allied health professional consultations per calendar year, per patient, delivered under a Multidisciplinary Care Plan. Intensive training for staff who have not traditionally worked with cancer patients (including staff within and external to NSW health services), on ‘cancer’ and ‘distress screening’ should be considered as it may support referral.</p>
27.	Can Program funding be used to purchase clinical services?	<ul style="list-style-type: none"> No. Purchasing clinical services is not sustainable. Funding can be used to support infrastructure, training, program staff but NOT frontline services. Use of a range of referral options should be considered as described under point 26.
28.	Are there likely to be confounders that need to be considered in intervention design?	<ul style="list-style-type: none"> Yes. All research and intervention programs should consider potential confounders. Other interventions may be occurring in cancer services that could potentially be a confounder. For example NSW Health is rolling out the Essentials of Care Program which focuses on nurses working with hospital in-patients. This program may be offered in cancer in-patient settings. At this stage the program is not targeting nurses who work in cancer outpatient settings. The Cancer Supportive Care Intervention Program is targeting clinicians who work with outpatients.
29.	Is one consortium only likely to be funded?	<ul style="list-style-type: none"> Yes.
30.	How long is the funding period?	<ul style="list-style-type: none"> \$3 million is being offered across 3 – 4 years.

References

Vodermaier A, Linden W, Siu C (2009) *Screening for Emotional Distress in Cancer Patients: a systematic review of assessment instruments*. Journal of the National Cancer Institute. 101(21):1464-1488.