

THE MANUAL FOR CANCER SERVICES CONSULTATION PROFORMA DRAFT MEASURES FOR PSYCHOLOGICAL SUPPORT SERVICES

1 Gateway Reference 12552 Draft Measures for Psychological Support Services October 09

Measure Number / Section	Is the measure explicit? If 'no' suggest modifications.	What other types of information are required to demonstrate compliance?
ALL	<p>As a multi-disciplinary organisation for professionals working with adults, young people, children and their families [1] in health, social care, education and Third Sector services, AFT [2] has been asked by its members to respond to the Manual for Cancer Services: Draft Measures for Psychological Support Services.</p> <p>AFT welcomes the document's invitation to comment on its clarity, important gaps and necessary supplementary guidance.</p> <p>AFT wishes to express its serious concern at the document's inadequate recognition of and response to the impact of cancer on family members and relationships, the impact of this on the person with cancer, and the importance of skilled and effective supports for all caregivers (within and beyond the family, including professionals).</p> <p>The impact of cancer on family and couple</p>	<p>Supporting the psychological needs of patients and family members/carers requires staff trained to recognise and respond effectively to those needs.</p> <p>Workforce trainings in systemic family practice skills should be provided alongside other useful approaches (see http://www.aft.org.uk/docs/FAMILYFRIENDLYUKAFTSeptember2009.doc)</p> <p>Highly skilled, fully qualified Family Therapists (known as Family and Systemic Psychotherapists) are needed in specialist psychological support services and multidisciplinary teams to support families with more complex and serious problems and to support staff supervision, training and service development.</p>

relationships, on sexual relationships, on people's mental health and on relationships across generations is generally acknowledged. That relational issues are often an area of clinical concern is demonstrated in the document's own case studies. Yet the document makes no reference to the need for interventions that consider, work with and support couple and family relationships, apart from psychosexual therapy and an ill-defined reference to 'couple therapy'. The only clearly defined therapies recommended are individual-focused therapies that do not generally involve the family.

There is no reference to Family and Systemic Psychotherapy or to the importance of systemic skills workforce trainings to better equip staff to recognise and respond to the needs of all family members. This is a curious and concerning omission, given that Family and Systemic Psychotherapy (commonly called Family Therapy) is an evidence-based psychological therapy available within the NHS for adults, children, couples and families (see

<http://www.aft.org.uk/docs/Reportontheevidencebaseofsystemicfamilytherapy2005.doc>

and

<http://www.aft.org.uk/media/documents/V9Feb09.doc>

Family and Systemic Psychotherapists provide effective interventions for families experiencing serious and complex difficulties. Systemic trainings support other professionals in recognizing and responding to the

	<p>needs of the person with cancer <i>and</i> the important people in their lives, including children, developing family members' and carers' strengths and understandings and helping those in close relationships help each other.</p> <p>Competence for working with families from diverse ethnic and cultural backgrounds requires specific training and support. These competences are considered in the draft measures. They are a fundamental component of systemic and family therapy but these therapies have been excluded from the recommendations.</p> <p>[1] The 'family' takes many shapes in our culturally diverse society. AFT takes 'family' to mean any group of people who define themselves as such, who care about and care for each other. We believe this underlines the importance of expanding training for those working with children and families, to better enable them to support and work with families and relationships in all their many forms and contexts.</p> <p>[2] Further information about AFT is available via www.aft.org.uk</p>	
<p>ALL</p>	<p>Levels and competencies</p> <p>AFT is concerned that the levels described in this draft document do not reflect common NHS practice or frameworks, Agenda for Change processes, or recent</p>	<p>The bias towards certain professions within the draft document could be judged as discriminatory and thus open to challenge. If not amended to reflect existing and planned competency frameworks, it will certainly diminish the breadth of clinical expertise and</p>

	<p>and 'in-progress' consultations including The Health Professions Council's Standards of proficiency (SOPs) and Standards of education and training (SETs), National Occupational Standards developed by Skills for Health and Professional Occupational Standards drawn together by the UKCP.</p> <p>The document should make clear when practitioners may practice techniques and skills rooted in particular therapeutic approaches, and when they can be considered sufficiently trained and skilled to practice a psychological therapy. Creating measures that could be used to allow or encourage staff to work beyond their competencies is short sighted and potentially dangerous.</p> <p>The levels as described are biased towards certain professions. This contradicts the framework developed through Agenda for Change, which scores job descriptions and person specifications for given posts and embraces a variety of core professions enriched by additional therapeutic qualifications.</p> <p>AFT wishes to stress the importance of systemic skills in working with families for all professionals working with patients with cancer and the important people in their lives*. Such skills enrich core trainings but do not equip practitioners to support patients and families experiencing complex, serious and multiple difficulties.</p>	<p>experience available in psychological services for people with cancer and their families and carers.</p> <p>A competency framework is needed to measure practitioners' clinical skills in working not only with the person with or recovering from cancer, but also with their family members, carers and other important people in their lives. Any competency framework that fits the declared aims of the document (re services for patients and families/carers) must therefore include reference to systemic skills and trainings.</p> <p>AFT develops and accredits professional systemic trainings in the UK at all levels, from basic skills to full clinical, doctorate and supervisory qualifications. AFT would be happy to collaborate with the National Cancer Peer Review team to support the development of systemic competencies for inclusion in the framework</p>
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Working with people with cancer and their families and carers is complex, demanding and requires a range of additional skills and understandings to working solely with individuals.

These skills include supporting all family members to listen and be heard; managing distress, grief, loss, conflict, and differences in belief, perspective and experience; building on family strengths; recognising safety and risk factors; helping children and others with less power express their wishes and needs; challenging and intervening to halt harm; managing confidentiality; supporting families in choosing if, when and how to address 'unspoken' issues; recognising when individual or family group meetings are more appropriate; talking with families about painful or difficult experiences; supporting those in close relationship to support each other, and to find ways to make useful changes in their lives and in their relationships.

Most cancer services staff are not adequately trained to recognise the impact of parental physical and mental health problems on children. Some workers receive training to recognise 'children at risk' but not 'lower level' problems which may develop in to more embedded, chronic difficulties. There is clear and urgent need for family sensitive provision and trainings, inclusive of and sensitive to the needs of family members of all ages.

	<p>As the SCIE draft guidance on working with parents with mental health problems and their children states: "Parental mental health problems can adversely affect the development and in some cases the safety of children... children, particularly those with emotional, behavioural or chronic physical difficulties, can precipitate or exacerbate mental ill health in their parents/carers"</p> <p>http://www.scie.org.uk/pmhcwg/files/consultationdraft080409.pdf</p> <p>Staff tell us that they do not feel sufficiently confident or skilled to work with vulnerable adults, children and their families without specialist trainings and support. Children, parents and other family members tell us what a positive difference working with staff skilled in family-inclusive, systemic approaches can make in their lives. (see http://www.aft.org.uk/docs/FAMILYFRIENDLYUKAFTSeptember2009.doc)</p>	
<p>All</p>	<p>Access to specialist supports for patients, families and staff.</p> <p>Families affected by cancer who experience serious and/or complex relational and mental health difficulties require skilled and specialist therapeutic intervention. The importance of qualified Family and Systemic Psychotherapists within multi-disciplinary teams is</p>	<p>Levels and competency frameworks need to stress the importance of access to highly trained specialist professionals with skills sufficient to support patients and family members of all ages experiencing serious and complex difficulties, and the staff working with them</p>

inadequately addressed in this document. Such specialist supports are essential if families who support patients are themselves to be adequately supported through the impact of diagnosis, treatment, recovery and/or palliative care and bereavement.

Access to specialist consultation and supervision from fully qualified Family Therapists is essential [1] if staff working with families in cancer services at all levels are to

- intervene effectively with 'lower-level' problems
- recognise when families need referrals to more specialist supports
- work safely, ethically and effectively within their competencies. Without robust structures of training, supervision and consultation with highly qualified clinicians, staff can find themselves in roles they are neither trained nor qualified to perform.
- consolidate and develop their skills in family sensitive practice. Research [2] demonstrates how important and cost-effective it is for staff skills to consolidate and embed in practice through effective use, supported by clinical supervision by fully qualified staff. Without this, skills and learning are lost.

	<p>AFT suggests that Arthur Frank's comments on palliative care apply to the care of those with cancer and their families at all stages of treatment and care:</p> <p style="padding-left: 40px;">"Palliative care is distinguished not by its expertise in pain control, crucially important as this skill is, or by caring for patients whose death is anticipated to be imminent. What truly distinguishes it is that it resists the impulse to unify and finalise what can be said about patients within the single voice of scientific knowledge and technical control. Instead palliative care is dialogical; it seeks to expand not only what a patients they say about themselves but also the capacity of caregivers (<i>family members and professionals</i>) to hear what their patients say"</p> <p style="text-align: center;">–</p> <p>Frank, A. W, (2004) The Renewal of Generosity (Illness, Medicine and How to Live) University of Chicago Press.</p> <p>[1] NHS Executive (2000) Psychological Therapies Working In Partnership: Guidance for the Implementation of the NHS Executive Review of Psychotherapies. NHS Executive, London. April 2000.</p> <p>[2] Burbach, F. and Stanbridge, R., (2006) Somerset's family interventions in psychosis service: an update, <i>Journal of Family Therapy</i>, 28: 39-57; Brennan, G. and Gamble, C. (1997) Schizophrenia, family work and clinical practice, <i>Mental Health Nursing</i>, 7: 12-15</p>	
1.3	<p>AFT wishes to register serious concern at the assumptions implicit in the following extract:</p>	

'To date, the measures have been confined to adult cancer services, except where they relate incidentally to children, for example, a radiotherapy department would normally treat adults and children. However, measures are currently being developed that specifically address the provision of services for children and young adults with cancer'

This extract seems to suggest that adult cancer services in general 'relate incidentally to children' – a worryingly myopic view of psychological support services for patients and their families. Clearly, a significant percentage of adults with cancer will be parents and/or grandparents of children and young people who may experience distress which may in turn impact on the patient.

There is evident need for services and staff to be equipped to recognise and respond to the needs of all family members to ensure

- No more 'invisible' children, whose needs are too often overlooked by adult services caring for their parents
- No more 'invisible' mothers, fathers and grandparents, whose understandings, resources and needs are too often ignored
- Appropriate interventions tailored to individual and family needs, to prevent difficulties

escalating into crises

- Effective skilled supports when crises arise and/or serious problems cascade through generations
- Increased sensitivity to diverse family forms, experiences and beliefs
- Active and constructive collaboration between professionals, so families are not overwhelmed or pulled in different directions by multiple interventions from different professionals and disciplines.

Given the gaps in these draft measures, AFT wishes to take this opportunity to emphasise in the strongest terms the importance of family sensitive and family inclusive forms of psychological supports for children and young people with cancer when these measures are developed.

Family and Systemic Psychotherapists offer a range of knowledge and skills in working with children, young people and families affected by cancer.

Department of Health (DOH) [1] and Social Exclusion Unit reports emphasise the importance of seamless access, reliable consistent support and information for families of critically sick or injured children [2] children with a disability [3], children who are palliative or with life threatening diseases [4] and issues involving the transfer of care [5, 6]

Children and young people with acute and chronic illness are often from vulnerable families. Systemic practitioners in hospital paediatric services engage with families at admission in ways that can help de-stigmatise supportive interventions.

Systemic and family psychotherapists also offer consultation and supervision to a wide range of medical and non medical professionals involved in patient care, aiming to improve working relationship between individuals and systems, facilitating open dialogue between staff and a greater coherence of bio/psycho/social approaches to patient and family care.

The clinical benefits of such systemic approaches, supported by staff sufficiently trained and supervised to deliver them effectively, have been stressed repeatedly in services reviews and consultations over recent years [a brief selection of extracts is copied, below. Our emphases].

Adequate revisions of these and future measures could be important steps in the journey from clear and good intent to delivery.

'Palliative care for children and young people with life-limiting conditions is an active and total approach to care, embracing physical, emotional, social and spiritual elements. It focuses *on enhancement of quality*

of life for the child and support for the family and includes the management of distressing symptoms, provision of respite and care through death and bereavement.

Commissioning Children and Young People's Palliative Care Services: A Practical Guide for NHS Commissioners

DH, November 2005

Psychological distress is common among people affected by cancer and is an understandable response to a traumatic and threatening experience. Patients draw on their own inner resources to help them to cope and many derive emotional support from family and friends

... The goal of palliative care is achievement of the best quality of life for patients and their families...

... assessments should be undertaken by designated professionals (such as nurse specialists, social workers and GPs), appropriately trained in screening for psychological distress. They should include the impact of cancer on people's daily lives, mood, family relationships (including sexual relationships) and work.

Improving Supportive and Palliative Care for Adults with Cancer, NICE, 2004

The working definition of supportive care suggested by NCHSPCS is care that:

'...helps the patient and their family to cope with

cancer and treatment of it – from pre-diagnosis, through the process of diagnosis and treatment, to cure, continuing illness or death and into bereavement. It helps the patient to maximise the benefits of treatment and to live as well as possible with the effects of the disease. It is given equal priority alongside diagnosis and treatment.'

National Council for Hospice and Specialist Palliative Care

Services. Definitions of Supportive and Palliative Care. Briefing paper 11. London: NCHSPCS. September 2002.

Tailored, flexible and holistic services that work with the whole family can turn lives around dramatically' – **Reaching Out, Think Family, Cabinet Office**, June 2007

[1] Department of Health (2004) *National Service Framework for Children, Young People and Maternity Services*. Standard 7: Hospital Services, Chapter 3: Hospital Standard Part One Child-Centred Services 3.2, p 13

[2] Department of Health, (October 2006) The critically sick or injured child in the District Hospital Setting. Department of Health, (October 2006) The critically sick or injured child in the District Hospital Setting.

[3] Department of Health, (May 2007), Aiming high for disabled children; better support for families.

[4] Department of Health, (June 2008) Better Care;

	<p>Better Lives: Improving outcomes and experiences for children and young people with life threatening illness [5] Department of Health (2008) Transitions: moving on well: A good practice guide for health professionals and their partners on transition planning for young people with complex health needs or a disability</p>	
<p>1.4</p>	<p>The section 'Reviewing the Measures' states clearly that the National Cancer Peer Review Programme aims to improve care for people with cancer and their families. Concerning, therefore, to find so little in the draft document about supporting families, family members and wider relationships affected by cancer.</p> <p>A systemic approach encourages psychological services to look beyond traditional policy notions of patient and carer. Recent evidence [1] indicates that the impact of cancer is felt across wide reaching networks and relationships. The dyadic model of patient and carer ignores these much wider ramifications throughout family systems. Acknowledging and working with those affected in wider systems and contexts of care also better supports the patient and involved professionals.</p> <p>[1] Forbat et al (2009) Better cancer care: A systemic approach to practice. Dunedin, Edinburgh.</p>	<p>Service design, staff trainings and posts to equip psychological support services to recognise and respond to the needs of people with cancer and their carers and family members, including children.</p>

<p>Intro</p> <p>P12</p>	<p>These measures, we are told, ‘do not attempt a definition of what constitutes psychological support, but for the purpose of Peer Review this has become, by default, the activities of the Professional groups specified in the measures and of those staff specified by the types of training required in the measures.’</p> <p>Can we pause for a moment and look at the argument here? It seems to be suggesting that</p> <ul style="list-style-type: none"> • The measures don’t attempt to define psychological support • But ‘by default’ do define it • By considering the activities of those professions that ‘by default’ it has found itself considering <p>The review team may wish to review this.</p> <p>AFT wishes to challenge the view that the review has included ‘those staff specified by the types of training required in the measures’. The measures pay lip service to the importance of supporting families in psychological services, yet those professionals specifically trained to do this, and to support others in doing so, have been excluded from its vision and recommendations.</p>	<p>Include in the documents’ recommendations those specialist professionals skilled in supporting families and other networks of care: Family and Systemic Psychotherapists</p> <p>Include in the documents’ recommendations specialist workforce trainings in systemic practice to better equip staff at all levels to recognise and respond to family members’ needs</p>
<p>09-1A-301X</p>	<p>This item states that: ‘The network board should agree a single named lead for psychological support, for the network, who should be a consultant liaison psychiatrist or a clinical psychologist with a clinical postgraduate degree in psychology. In either case, they should, in</p>	<p>High level systemic trainings for the named lead professional</p>

	<p>addition, have at least 2 years' experience of practice involving cancer / physical health patients. (This includes palliative care services). The lead should be the chair of the network psychological support group. The network board should agree a list of responsibilities and specified time in their timetable or job plan, for the role of network psychological support lead.'</p> <p>Given the emphasis on the importance of skilled and effective supports for patients and their families/carers, AFT wishes to highlight the importance of high level systemic trainings for the named lead professional.</p>	
<p>09-1A-302x</p>	<p>The draft document states: ' the network psychological support group ... should be recognised as the network's primary source of opinion on issues relating to patients' and carers' psychological support and for co-ordination and consistency across the network on such issues'</p> <p>Clearly, if the group is to be the network's primary source of opinion on issues relating to patients' and carers' psychological support, it is essential that this group includes professionals trained and skilled in working with patients and their families and carers ie family and systemic psychotherapists and other professionals with high level systemic trainings.</p>	<p>The network psychological support group to include professionals trained and skilled in working with patients and their families and carers ie family and systemic psychotherapists and other professionals with high level systemic trainings.</p>
<p>09-1E-103x</p>	<p>The draft document states: 'There should be at least one core member of each of the network MDTs currently being included in the annual network self-assessment who is able to practice at, at least Level 2</p>	<p>Each MDT to include a professional with sufficient training to recognise, respond to and if necessary refer on vulnerable children, adults and families who may require more skilled psychological and psycho-</p>

	<p>for psychological support for patients and carers'</p> <p>Given the lack of detail of competencies at each level. or how these fit with current or planned frameworks, it is difficult to respond with useful precision, but it seems important to highlight the importance of each team including a professional with sufficient training to recognise, respond to and if necessary refer on vulnerable children, adults and families who may require more skilled psychological and psychotherapeutic supports.</p>	<p>therapeutic supports.</p>
<p>09-1E-104X-09-1E-106X</p>	<p>The network must have ready access to named practitioners sufficiently trained and skilled to provide advice, consultation and supervision in supporting families and family members and who can take referrals of those cases beyond the competencies of the 'lower level' practitioners.</p> <p>Workforce training and access to specialist consultation and supervision in family-sensitive, family-inclusive working are essential if staff are:</p> <ul style="list-style-type: none"> • to intervene effectively with 'low-level' problems • to recognise when individuals and families may need more specialist support • to support families in getting the specialist support they need, when they need it • to work safely, ethically and effectively within their 	<p>Network to have ready access to named practitioners sufficiently trained in working therapeutically with families and other networks of care.</p>

	<p>competencies</p> <p>Without robust structures of training, supervision and consultation, staff can find themselves in roles they are neither trained nor qualified to perform</p>	
09-1E-107X	<p>'For the purpose of this measure, the term 'screening' is taken to mean an evaluation of the need for psychological intervention, of each of the individuals in the population group in question'</p> <p>The implicit bias of the draft measures towards individual psychological approaches is evident here. If, as the document states, the intention is to screen 'cancer patients and/or their carers' to assess need for psychological supports, it is clearly necessary to have professionals trained in assessing family needs and resources.</p>	Staff trained to assess family needs and resources
09-1E-113x	To meet the stated aims of the draft measures, workforce trainings must also include systemic trainings in working with patients and important people in their lives affected by the cancer who may have important roles to play in supporting the patient in recovery and/or enhancing their quality of life	Workforce trainings to include systemic trainings in working with patients and the important people in their lives (see http://www.aft.org.uk/docs/FAMILYFRIENDLYUKAFTSeptember2009.doc)
Appendix 1	<p>AFT's concerns about the levels as currently described have already been outlined.</p> <p>To reflect the aims and objectives of the document, the list of professionals eligible for current 'level four' status needs to include a Family and Systemic Psychotherapist with at least 2 years experience of practice involving</p>	<p>See 'Levels and competencies' section, above.</p> <p>The list of professionals eligible for current 'level four' status needs to include Family and Systemic Psychotherapists</p>

	cancer/physical health patients (inc palliative care services)	
Appendix 2	<p>These case examples illustrate the commonly acknowledged link between anxiety and pain management and people's important relationships, and the crucial role of these relationships in patients' recovery and/or management of their illness, and in enriching their quality of life.</p> <p>They serve to highlight the importance of workforce trainings in systemic practice with couples and with families, and the importance of access to specialist Family and Systemic Psychotherapists for those patients and their families experiencing serious and/or complex difficulties.</p>	<p>Workforce trainings in systemic practice with couples and families.</p> <p>Ready access to specialist Family and Systemic Psychotherapists for those patients and their families experiencing serious and/or complex difficulties.</p>

